



"Turning *Commitment* Into

*Action*"

...in the First Four Years

An Evaluation of The Delaware Cancer Consortium's Process and Progress

Prepared for the Delaware Cancer Consortium and The Division of Public Health  
by Concept Systems, Inc.

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DELAWARE  
CANCER  
CONSORTIUM



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## I. Executive Summary

This process evaluation reflects the progress of the Delaware Cancer Consortium through the period of its establishment and first three complete years of its work, and constitutes one element of Delaware's Comprehensive Cancer Control Program's multi-faceted evaluation plan. The following report illustrates how the Consortium has achieved the significant progress noted in its annual reports, and provides feedback regarding key process concepts and structures that were used during the period covered.

Focusing on the functioning of the Consortium as an organization, this report describes the conceptual framework for process evaluation of the Consortium and outlines the methods used in the conduct of the process evaluation. Findings are reported across Committees using the process models developed for this initiative. Recognizing that each Committee has its own unique recommendations, charges and challenges, a section following the cross-Committee findings is devoted to a Committee-by-Committee discussion of the findings. The report concludes with a discussion of overall observations and recommendations for the Consortium as a whole. Figures, tables, and appendices provide supporting information.

The Delaware Advisory Council on Cancer Incidence and Mortality was appointed by Governor Ruth Minner in 2001, with a charge to develop a clear and usable cancer control plan based on the input of professionals in cancer control, citizens affected by cancer, advocates and policy leaders. The Council agreed to create a shared awareness and agreement on the range of cancer control issues to be addressed now and in the future, create a structure and agenda for addressing those needs, and enable Delaware to move forward with meaningful action. (Evaluation Plan Proposal for Delaware's Comprehensive Cancer Control Program, June 28, 2006)

Following a state-wide engagement and inquiry process using concept mapping, individual testimony and research, the Consortium was made a permanent entity in 2003 and adopted the structure suggested by the inquiry process. The Consortium formed seven committees, chaired by members of the Advisory Council. The Consortium Committees are Insurance, Knowledge and Information, Tobacco, Quality, Colorectal Cancer, Environment and Disparities.

This evaluation focuses on the processes, organizational elements and activities in evidence in the first four years of the Consortium's operations. The evaluation surfaces and tracks the Consortium as an entity and the Committees individually, in relation to committee structure and management, leadership, program and intervention planning, data development and use, partnerships development, and communications and reporting. Process models for the Consortium at large and for each committee were developed to indicate the charges, the processes and the sources or types of documentation queried to assess whether the processes took place as relevant to each committee.

Documents issued by the Consortium as a whole and its Committees individually, documents or reports used by the Consortium or Committees, public relations material, and a range of other items were reviewed using the process model as the guiding structure. These documents covered the time period 2003-2006, and included the report *Turning Commitment into Action: Accomplishments of the*

*Delaware Cancer Consortium*, for the first three years of work. To ensure additional currency of information, interviews were conducted with key leadership and contributors to the Consortium. Meeting observations and review provided context for the evaluation, as did individual guidance and discussion with Division of Public Health senior staff.

The Consortium has reported its progress in interventions and innovations to address the burden of cancer, through its annual report, *Turning Commitment into Action...*, known by the Consortium and Staff as “The Green Book.” This evaluation reviews how that progress was achieved; what the leadership expected would take place, the processes used by each committee to arrive at milestones in their progress toward fulfilling their charges; the manner in which leadership was demonstrated; the involvement and use of partners to accelerate the work of the Consortium; the degree to which Committees used data to inform decisions, and the organizational elements that supported or hindered the progress of the Committees.

Basic engagement elements such as meeting attendance are shown with ranges and averages across committees. Interview data and document reviews identify the level of formal and informal leadership. Partnership, an important concept for an organization like the Consortium, is reflected in data both from the Committee documents themselves (membership rosters, attendance, recruitment initiatives) and the interviews (queries regarding the overall effectiveness of the Consortium and the Committees regarding involvement of partners). We include a sector-by-sector report of Consortium membership, to illustrate partnership representation.

By and large, all Committees and the Advisory Council are successful in achieving and maintaining at least an acceptable level of volunteer (member) involvement in the work of their Committees. The high level of Member retention on the Advisory Council, most of whom are Committee Chairs, provides a strong level of stability to the group. Members not on the Council reported more difficulty in maintaining connection to the Consortium, and described the challenges of the bi-monthly committee schedule.

The Consortium is at an early maturity point in its organizational life. The work accomplished thus far, with steady and committed staffing and guidance by the Division of Public Health, will now benefit from deliberate attention to the workings of the enterprise, and some process standardization. This will enable greater communication, impact, and effective use of the many valuable resources that current members and as-yet-untapped partners may bring to the endeavor. Recommendations include the development of a retention, succession and recruitment plan; as well as Consortium focus on documentation standardization for ease of common access across Committees and with the Council.

In addition, the results should enable the Consortium to identify their own priorities for improvement, and ways to evaluate how well those priorities are being met.

## **II. Introduction**

This report presents the findings of a process evaluation of the Delaware Cancer Consortium, concentrating on the Consortium's structure, processes and activities. The methodology developed for this purpose is outlined in this report and described in further detail in a separate Process Evaluation Guide.

The evaluation findings provided here reflect and support the progress made in the establishment and first three complete years of its work; and illustrate how the Consortium has achieved the significant progress noted in its annual reports. In addition, the results should enable the Consortium to identify priorities for improvement, and ways to evaluate how well those priorities are being met. This process evaluation constitutes one element of Delaware's Comprehensive Cancer Control Program's multi-faceted evaluation plan.

This report begins with background on the Delaware Cancer Consortium, its evaluation plan and the intent of this process evaluation. It describes the conceptual framework for evaluation and outlines the methods used in the conduct of the process evaluation. Findings are then reported across Committees using the conceptual framework of the process model developed for this initiative. Recognizing that each Committee has its own unique recommendations, charges and challenges, a section following the cross-Committee findings is devoted to a Committee-by-Committee discussion of the findings. The report concludes with a discussion of overall observations and recommendations for the Consortium as a whole. Appendices provide supporting information.



### III. Background

Cancer is the second leading cause of death in Delaware and in the nation. In 2001, in response to Delaware's high cancer incidence and mortality rates, Delaware Governor Ruth Ann Minner appointed a fifteen-person Advisory Council. The Delaware Advisory Council on Cancer Incidence and Mortality was charged with advising the Governor and the Delaware Legislature on the causes of cancer incidence and mortality and potential methods for reducing both. (Evaluation Plan Proposal for Delaware's Comprehensive Cancer Control Program, June 28, 2006)

The Advisory Council began meeting in 2001 with a charge to develop a clear and usable cancer control plan based on the input of professionals in cancer control, citizens affected by cancer, advocates and policy leaders. With these priorities in mind, the Advisory Council agreed to develop a system to create a shared awareness and agreement on the range of cancer control issues to be addressed now and in the future, create a structure and agenda for addressing those needs, and enable Delaware to move forward with meaningful action. (Evaluation Plan Proposal for Delaware's Comprehensive Cancer Control Program, June 28, 2006)

The Advisory Council initiated a deliberately comprehensive process of concept mapping to get input on cancer issues from citizens, medical and public health professionals; and to help establish priorities for the Advisory Council's scope of work. The Advisory Council also heard from outside experts, cancer survivors, and family members who had lost a loved one to cancer. By blending statistics and data with the stories of people whose lives have been touched by cancer, the Council drew attention to the "faces of cancer". The results of the planning initiative yielded a draft structure for the organization of the planning Committees, which is included as Appendix 1.

In June 2001, The Advisory Council approved the conceptual structure for the group's work. Between this date and October 2001, subcommittees concentrated on each topic area, and developed a draft agenda for each focus. The results of the groups' deliberations were presented and approved by the Council at their Fall 2001 meeting. The data associated with this meeting is included in the document review for this report.

Once the plan was established, the Advisory Council was reauthorized in early 2003, as a permanent Consortium, and Committees were seated. Chaired by a Council member, each Committee developed and finalized the list of priorities in its focus area, based upon the initial concept mapping and subcommittee recommendations. The Committees then made decisions regarding priorities to accomplish those goals. (Evaluation Plan Proposal for Delaware's Comprehensive Cancer Control Program, June 28, 2006)

Many of those who have served on the Council Committees also served in the formative stages of the Council. Appendix 2 provides a list of current and past Advisory Council members.

In May 2006, the Division of Public Health conducted a survey of membership, to assess the operational needs of the Consortium as well as to inquire about perceptions of priorities. The following were identified by the respondents as the top five priorities for the DCC:

- Evaluation of the impact of DCC activities
- Enhancing data-driven decision making
- Focusing efforts on reducing health disparities
- Developing a new 4-year plan
- Advocating for new cancer dollars.

In this report, we provide feedback to support the first, the second and the fourth items.

#### **IV. Delaware's Cancer Program Evaluation**

The Division of Public Health (DPH) has developed a comprehensive, multi-stage evaluation plan that encompasses the programs of the Division's cancer program in its entirety. This includes the programs and initiatives that have emerged as a direct result of the Consortium's work, as well as other Division initiatives. The evaluation plan was submitted to the CDC on June 30, 2006 and approved July 31, 2006.

This evaluation report will support the Division's comprehensive evaluation initiative. It provides feedback about the processes employed and progress made to date to fulfill the Council's responsibilities. The results will provide valuable data to augment the interpretation of findings from other parts of the comprehensive evaluation.

The Division of Public Health is also interested in constructing, through this process, an evaluation model and approach that the Division will document, refine and disseminate for use in other contexts, either within the State or for the benefit of other Comprehensive Cancer Control Programs in the country. A separate Process Evaluation Guide details the methods developed for this effort.

## **V. Focus of this Report: Process Evaluation of the Consortium's Functioning**

Focusing on the Consortium's process and implementation progress, the evaluation presented here concentrates on the planning processes, actions taken and progress made by the Committees and the Consortium on stated priorities. Data and input gathered from all relevant Committees and other relevant sources produce a description of expectations as reported and observations at this time in the life of the Consortium.

The evaluation contains two primary units of inquiry: the Committees of the Consortium, and the Advisory Council as an operating or management entity. We also discuss the Consortium as the encompassing structure.. The evaluation conforms to the CDC Prevention Evaluation Framework Model's standards of good evaluation: utility, feasibility, accuracy and propriety. (Centers for Disease Control and Prevention. (1999) Morbidity and Mortality Weekly Review, 48(RR11), 21.)

In addition to the focus on process, actions and progress, a significant focus of this evaluation is on partnerships and the leadership required to facilitate this sort of collaborative functioning. Strategically developed partnerships across multiple organizations, each of which brings important resources and relationships to bear on an issue, are needed to take on complex, persistent challenges such as cancer prevention and control. We consider the functions of leadership and partnership in relation to the Consortium at large, and the Committees individually.

Another key feature of the work of the Consortium is its intention to use and add to the evidence base for cancer control. According to the CDC evaluation logic model, programs are expected to "effectively use pre-existing evidence-based programs". They are also expected to "make data-driven decisions by analyzing existing sources of population-based local, state and federal data", use state registries and compile data into reports, and analyze lessons learned and best practices. We consider the role of data access and use in the committees' functioning in this review.

## VI. Conceptual Framework for Evaluation

The planning and implementation of the Cancer Consortium began with a structured theoretical model (the concept map, provided in Appendix 1). This concept map provided a framework for the content and structure of the Cancer Consortium's work. Priorities were established, drawing heavily on the broad input provided through the concept mapping process and subsequent task group deliberations. At that time, the conceptual framework was refined to recognize the priorities in Medical Community Action, which became the Committees for Colorectal Cancer and Quality. The priorities described in Public Awareness and Education and Research and Data analysis were combined to form the Provide Knowledge and Information Committee. The Provide Knowledge and Information Committee in the rest of this document is referred to as the Knowledge and Information Committee. In addition, the disparities focus, which was pervasive throughout the conceptual framework, was defined as a Committee level priority.

The Committees of the Cancer Consortium established an ambitious plan to make significant progress within four years to reduce the burden of cancer in the State. Progress is reported annually in the *Turning Commitment into Action: Accomplishments of the Delaware Cancer Consortium* series, known colloquially as the "Green Book." These annual reports are organized by Committee and summarize the accomplishments for each the recommendations tasked to that Committee. Table 1 provides a summary of the Committees and the recommendations with which they are charged. For each recommendation, Committees have identified a set of tasks or initiatives that will lead to progress on that charge. The Green Book contains not only the recommendations listed below, but also details tasks under each recommendation.

Table 1: Committees and their Charges

Committee	Charges (Recommendations)
Consortium	<ol style="list-style-type: none"><li>1) Create and maintain a permanent council, managed by a neutral party that reports directly to the governor to oversee implementation of the recommendations and comprehensive cancer control planning. The council should have medical, environment, research policy and education Committees that continually evaluate and work to improve cancer care and cancer-related issues in Delaware.</li><li>2) Develop and implement a state cancer control and prevention plan. The plan should be based on CDC guidelines and involve multiple stakeholders with assigned responsibilities.</li></ol>
Insurance	<ol style="list-style-type: none"><li>1) Reimburse the cost of cancer treatment for every uninsured Delawarean diagnosed with cancer up until one year after diagnosis.</li></ol>
Colorectal Cancer	<ol style="list-style-type: none"><li>1) Create a comprehensive statewide colorectal cancer screening and advocacy program.</li><li>2) Reimburse for colorectal cancer screening of uninsured Delawareans age 50 and older.</li></ol>

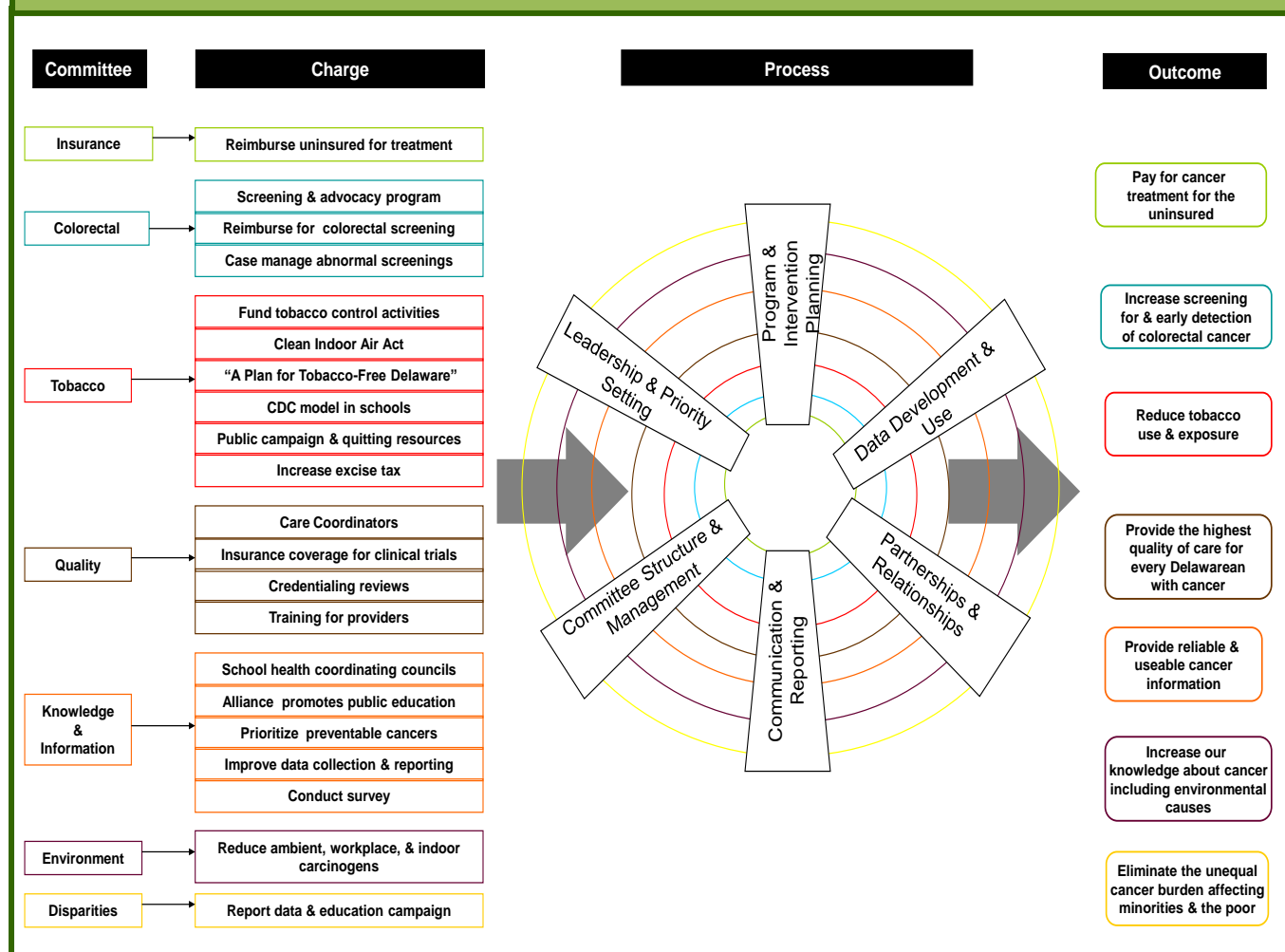
	3) Case manage every Delawarean with an abnormal colorectal cancer screening test.
Tobacco	<ol style="list-style-type: none"> <li>1) At a minimum, fund comprehensive statewide tobacco control activities at \$8.6 million (CDC recommended minimum).</li> <li>2) Strengthen, expand, and enforce Delaware's Clean Indoor Air Act to include public places and workspace environments.</li> <li>3) Strongly endorse, coordinate, and implement the action plan recommendations presented in "A Plan for Tobacco-Free Delaware."</li> <li>4) Formally adopt, implement, and enforce the CDC model policy for tobacco control in all Delaware schools.</li> <li>5) Expand and sustain a comprehensive public awareness campaign on the health risks of tobacco use and support resources available to help quit smoking.</li> <li>6) Increase the Delaware excise tax on tobacco products to \$0.74 and seek to identify other potential funding sources to support tobacco and cancer control efforts.</li> </ol>
Quality	<ol style="list-style-type: none"> <li>1) Provide a care coordinator who is part of a statewide-integrated system to every person diagnosed with cancer in Delaware. Care coordinates will be culturally competent to overcome the language, ethnicity and gender barriers</li> <li>2) Ensure insurance coverage for state-of-the-art cancer clinical trials.</li> <li>3) Institute centralized credentialing reviews of medical practices by third-party payors that include cancer screening, prevention, early detection, and treatment practices as well as ongoing provider education.</li> <li>4) Support training for physicians and other health care providers in symptom management and end-of-life care approaches.</li> </ol>
Knowledge and Information	<ol style="list-style-type: none"> <li>1) Initiate and support statewide and district-level school health coordinating councils. The statewide council will serve as a model, resource, and funding vehicle for the district councils.</li> <li>2) Form a statewide, permanent alliance to coordinate and promote public education on cancer.</li> <li>3) Estimate the number of cancers that can be prevented and the number of deaths that can be avoided by primary prevention and early detection. Prioritize our common and preventable cancers.</li> <li>4) Improve the collection and reporting of cancer incidence and mortality data.</li> <li>5) Conduct a survey to examine the importance of past exposure to today's cancer rates.</li> </ol>
Environment	<ol style="list-style-type: none"> <li>1) Reduce exposure to carcinogenic substances in the ambient environment.</li> <li>2) Coordinate with OSHA to reduce workplace carcinogenic risk and exposure.</li> <li>3) Reduce exposure to carcinogens in the indoor environment.</li> </ol>
Disparities	<ol style="list-style-type: none"> <li>1) Compile and analyze existing data on health disparities and cancer into a report, and inform through a public education campaign.</li> </ol>

#### A. *The Process Model for the Cancer Consortium*

This evaluation links both the *process* undertaken by the Consortium and the *content* of each Committee's initiatives. It focuses on the inputs and activities section of the overall logic model of the Delaware Cancer Consortium, while helping the Consortium visualize the "through-lines" from current state to desired outcomes. As such, a key task in planning this evaluation was to develop a "working" Process Model framework to guide data collection, reporting and interpretation. The process model, shown in Figure 1, was used by the evaluation team to describe the key elements of Consortium processes that would be included in the evaluation.

The Consortium process model provides an overall framework for the evaluation, and links common processes to the program specific goals of each of the Committees, as articulated in the Green Book. All of the Committees are listed on the left side of the figure. The charges represent a condensed version of the recommendations assigned to each Committee, as articulated in full in Figure 1 above and in the Green Book. All Committees use the same set of processes, as illustrated in the third column. These common processes are the major constructs that are evaluated. Effectively addressing each of these six processes is assumed to lead to the desired outcomes on the right side of the figure. Thus, the process model brings together the content of the Committees and their recommendations with Consortium processes, creating an integrated conceptual framework for the process evaluation.

**Figure 1: Delaware Cancer Consortium Process Model**

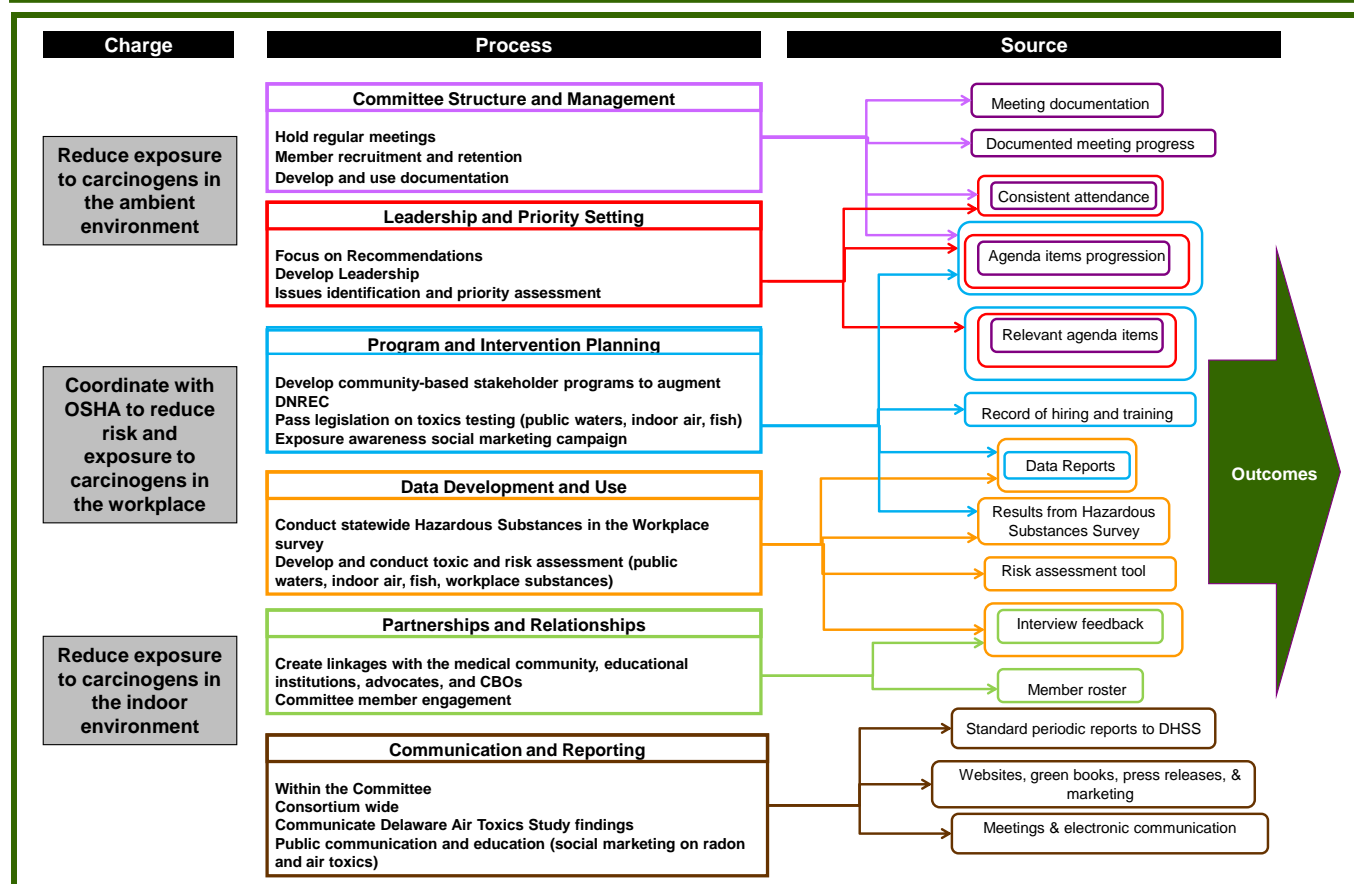


This overall Process Model was adapted for each of the Committees, resulting in a set of seven process models to guide our individual review of the Committees. These Committee-specific working models were refined during data collection and analysis to achieve more meaningful levels of detail. The updated process model for each Committee is provided in Section X of this report, which discusses the findings by Committee. Here, Figure 2, the Delaware Cancer Consortium Process Model: Environment Committee provides an example of how the process model is applied to a specific Committee. The Committee's charge appears on the left side. The processes, illustrated as a wheel in Figure 1, appear in the second column, with further definition of each of the major processes of relevance to the committee in question. These detailed definitions serve as the criteria for assessment of the construct. For instance, "Committee structure and management" is defined as holding regular Committee meetings, recruiting and retaining members and developing and using documentation (such as meeting minutes, role assignments and planning documents, and so forth). Definitions of each of these indicator areas follow, in Section VII D. The "Sources" column indicates the sources to be used to make determinations about those constructs. Section VII below (Findings by Committee) shows the process models for each Committee.



Each Committee was reviewed to assess its use of, or engagement in, the processes described in the Process column, below. By and large, the process to investigate each committee was similar for the areas of Committee Structure and Management, leadership and Priority Setting, partnerships and Relationships, and Communications and Reporting. Differences are noted from Committee to Committee in the Process Models specifically in the areas of Program and Intervention Planning, and Data Development and Use. These are the areas where differences in process would be expected if not encouraged, since each Committee was to address a range of charges, with differing levels of maturity, ease of fulfillment, availability of data and so on.

**Figure 2: Process Model Example: Environment Committee**



The overall Consortium process model and the Committee-specific process models provide an overview of expected processes, and sources for assessing progress as they relate to desired outcomes. The process model enables the Division to identify contexts and assumptions that have framed the Cancer Consortium's work; and to define inputs and activities as well as describe outputs and desired outcomes. We indicate in the process model that "Outcomes" would follow in the overall evaluation logic model.

## VII. Methods

This evaluation uses a mixed methods approach. To ensure an appropriate level of inquiry and triangulation of findings, structured interviews with short quantitative and qualitative surveys, observations of meetings, and a comprehensive document review were conducted. This section describes each of these major methods. Table 2: Measures for Process Model categories by Data Source summarizes the measures developed for each of the categories of the process model by the source of that information. A separate Draft Process Guide provides further details of each of these methods, offering a template that will assist others who wish to use these methods for evaluating similar collaborative initiatives.

**Table 2: Measures by Data Source across Committees for each Process Model Category**

<b>Process Model Category</b>	<b>Measures based on Document Review</b>	<b>Measures based on Interviews</b>
Committee Structure and Management	<ul style="list-style-type: none"> <li>▪ Number of meetings held by Committee</li> <li>▪ Average number of attendees per meeting by Committee</li> </ul>	<ul style="list-style-type: none"> <li>▪ Interviewee ratings of Committee administration and management</li> </ul>
Leadership and Priority Setting	<ul style="list-style-type: none"> <li>▪ Number of initiatives to address stated charges</li> </ul>	<ul style="list-style-type: none"> <li>▪ Interviewee ratings of leadership by Committee</li> <li>▪ Interviewee comments about leadership</li> </ul>
Program and Intervention Planning	<ul style="list-style-type: none"> <li>▪ Average number of activities per Committee initiative</li> <li>▪ Number of activities per Committee initiative</li> </ul>	<ul style="list-style-type: none"> <li>▪ Interviewee ratings of progress toward goals</li> </ul>
Data Development and Use	<ul style="list-style-type: none"> <li>▪ Percent of Committee discussions focused on data development and use</li> </ul>	<ul style="list-style-type: none"> <li>▪ Interview ratings of use of evidence in decision-making</li> </ul>
Partnerships and Relationships	<ul style="list-style-type: none"> <li>▪ Consortium members by sector</li> <li>▪ Committee membership by sector</li> </ul>	<ul style="list-style-type: none"> <li>▪ Interviewee ratings of partnership</li> <li>▪ Interviewee comments on partnerships</li> </ul>

## A. Interviews

Interviews with each Committee Chairperson and other identified leaders were a major element of the evaluation. Eighteen leaders were interviewed in May, June, and July 2007. These positions interviewed represented:

- ❑ Political leadership
- ❑ Division leadership
- ❑ Founding members of the Consortium (now either Chairs or Committee members)
- ❑ Chairs of Committees
- ❑ Committee members

A list of the interviewees and their roles is provided in Appendix 3.

The Division guided the selection of key themes from the process model above in constructing the interview protocols. Interviews consisted of five major sections that correspond with the process model:

- ❑ Section A: Introduction and background to the purposes of the Interview and Inquiry on Expectations.
- ❑ Section B: Inquiry on Leadership
- ❑ Section C: Inquiry on Administration and Management
- ❑ Section D: Inquiry on Participation and Partnerships
- ❑ Section E: Request for information on Committee documentation as needed and appropriate to the interviewee.

See Appendix 4 for examples of these sections.

The partnership portion of the interview protocol was adapted from Lasker and Weiss' Partnership Self-Assessment Tool. (<http://www.cacsh.org/psat.html>); and supported by the evaluation consultants' independent work in public health partnerships.

A "360-degree"-like approach was taken with the interviews to enable leaders not only to contribute feedback on the work of their own group or area of interest, but also to comment on the work of other Committees or the Consortium as a whole. This approach enables us to aggregate findings and gain a variety of viewpoints on each of the Committees. For sections B, C and D, most interviewees gave input on the Consortium, detailed feedback on the Committee with which they were primarily affiliated, and condensed assessments of other Committees in the Consortium. Respondents rated each question on a 1 (low) to 5 (high) scale. Interviewees had the opportunity to comment on each question.

Referring to the process model, the interviews are the primary source of data regarding the constructs of Leadership and of Partnerships and Relationships. Interview ratings and comments supplement the assessments provided by the document review for the other process model categories.

## B. Document Review

A second major element of the evaluation was an intensive review of available documents related to the Committees. The document review included the following materials provided by DPH:

**Table 3: Sources in Document Review**

*Turning Commitment into Action: Accomplishments of the Delaware Cancer Consortium* Annual Report series ("Green book") March 2002, September 2004, November 2005

Available Advisory Council notes for the subcommittee recommendation report meeting of October 2001

Available meeting minutes for all Committees and the Advisory Council for September 2003 through July 2006

Reports issued by the Committees or the Council

Reports and presentations given at Committee and Advisory Council retreats and major workshops

Data reports, such as those from the Behavioral Risk Factor Surveillance System (BRFSS), Institute of Medicine and the Consortium-commissioned Disparities in Cancer Incidence and Mortality Among Delaware Residents, 1998-2002 Report

Reports on studies conducted by the Division of Public Health (DPH), the Department of Natural Resources and Environment Control (DNREC) or contractors as staff

Reports on studies conducted by Committees themselves

Marketing materials, such as brochures and media advertised produced by AB&C, the contractor for marketing collateral

Press releases

Memos

The evaluation team reviewed and coded 1,376 documents during this process. Questions of missing data or information were clarified during interviews with Committee Chairs, via Section E of the interview protocol, as described above.

An intensive content analysis of the documents was conducted so that each action or discussion item was briefly summarized and then coded by:

- Major categories and subcategories of the process model
- Date
- Initiative
- Source (document citation)

The evaluation team set the following guidelines regarding the document review content analysis:

- When *Advisory Council* minutes referenced a specific *Committee's* charge or activities, that documentation item was coded as relevant to that Committee.

- Each **type** of source was counted once per Committee. Although the Advisory Council may have discussed an issue on numerous occasions, thus, recording discussion in several different meeting minutes, “Advisory Council meeting minutes” was counted once as a source for that issue for that Committee.
- During the document review process each discussion item was coded according to which aspect of the process model it addressed. While it is not possible to indicate how much time any given discussion may have occupied on the agenda, the percent of discussion items serves as a proxy for the degree of attention focused on that aspect of Consortium process.

A sample of the document review contents illustrates how these guidelines were used in Table 4.

Table 4: Sample of Document Review: Colorectal Committee					
Process Model Category	Process Model Subcategory	Date	Initiative	Description	Source (s)
Data Development and Use	Cancer Registry	Mar-02	Committee	Graph of Delaware age-adjusted incidence rate of cancer (including colorectal) per 100,000 as percent above U.S. estimate for 1994-1998. Pie chart of cancer by type in Delaware from 1995-1999	Green Book 2002; Delaware Cancer Registry
Leadership and Priority Setting	Issues Identification and Priority Assessment	Mar-02	Committee2	Reported that if 80% of Delawareans age 50 and older received a colonoscopy and appropriate follow-up every 10 years than Delaware would have the lowest colorectal cancer death rate in the country	Green Book 2002; National Center for Health Statistics; Ranshohoff & Sandler, 2002; Colditz, 2000
Communication and Reporting	Educate Public on Importance of Screening and Screening Options	Mar-06	Statewide screening/ advocacy program	Christiana Care Coordinator has provided information to churches, put table top cards in cafeteria, and established a dedicated telephone line for Champions of Change program	Meeting Minutes
Committee Structure and Management	Develop and Use Documentation	Apr-06	Committee	The Database Working Group is moving forward and will enter past data into the database	Meeting Minutes
Etc.	Etc.	Etc.	Etc.	Etc.	Etc.

### C. Observation of Meetings

Over the period 2003 to 2006, CSI staff members attended approximately eight meetings of the Council, and facilitated two Consortium retreats. These observation opportunities helped inform the development of the process model, the document review approach and the interview protocols; and provided vital context and background to anchor the findings by Committee discussions and the observations and recommendations section. CSI was also able to confer regularly with DPH staff and the Council Chairman at various stages between 2003 and 2006 in the development and progress of the Consortium.

### D. Measures

Specific measures were developed for each of the process model categories, to operationalize the concepts of interest. The following definitions, when considered with the process model, provide a legend for the process model areas, and how they were measured:

*Committee structure and management:* is defined by frequency of meetings, attendance rates at meetings; and staffing support for coordinating communication, organizing activities and meetings, preparing materials; and making good use of members' time.

*Leadership:* is defined through the interview protocol as acting responsibly on behalf of the Consortium, inspiring and motivating people, communicating vision, developing common levels of commitment, fostering respect, combining diverse perspective, and helping to look at issues differently.

*Program and intervention planning:* looks at progress on the recommendations, assessing the extent to which there was observable progress on agenda items and recommendations and members' satisfaction with progress. It does not focus on evaluating the outcomes of Committee activities or programs. The Green Book provides annual updates on the status of recommendations and their associated activities and other parts of Delaware's comprehensive evaluation plan address outputs and outcomes.

*Data development and use:* focuses on the extent to which a Committee used data in its work and decision-making. Data development and use references included such things as developing and/or reviewing survey results and reviewing national or state surveillance data.

*Partnerships:* is defined by the breadth and depth of involvement of both traditional and non-traditional communities of interest in the Consortium. The Consortium is itself the key partnership; and the first process variable is whether and how partners who represent a variety of sectors and organizations across the state with an interest and ability to contribute to cancer control and prevention are included. Sectors represented in the Consortium are the following, in alphabetical order:

- |                                 |   |
|---------------------------------|---|
| • Academic                      | • Government Public Health                        |
| • Business/Industry             | • Hospital  |
| • Colorectal Cancer Coordinator | • Legislature                                     |
| • Community Based Organization  | • Non-Governmental Organization or Not-for-Profit |
| • Consultant                    | • Professional Association                        |
| • Executive Branch              | • Provider  |
| • Government                    |   |

The interview protocol, a second source for partnership feedback, queries members on their satisfaction with the way people and organizations interact, their own influence, the Consortium's success at recruiting diverse people and organizations, and satisfaction with the way decisions are made. Specific questions focus on the Consortium's effectiveness at creating linkages with the medical community, educational institutions and community based organizations and advocates.

In some cases, these measures required secondary coding. For instance, for Communication and Reporting, press releases, AB&C marketing materials and reports were developed and distributed to the public. These were counted separately in the analyses to provide a richer picture of the variety of approaches to outreach taken by various Committees.

Each Committee process model represents all of the above categories of measurement. Assessing each Committee shows the manner in which each Committee addressed its own priorities, and demonstrates variation from Committee to Committee on these key process constructs.

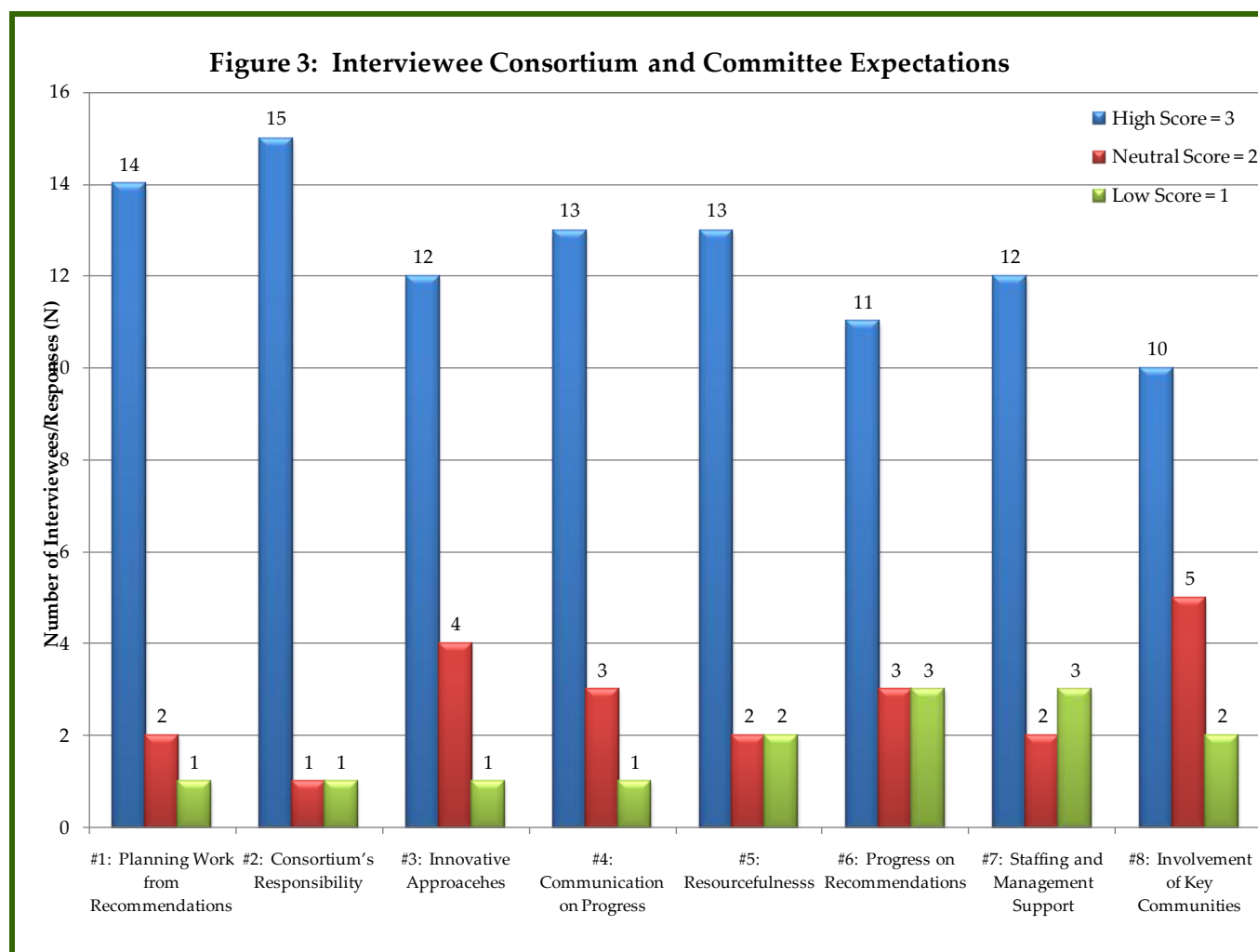
### *E. Evaluator's Role*

CSI was the primary contractor for the development of the concept map, which provided the overall Committee structure and the foundation for the Committee recommendations. CSI's attendance at Council meetings and retreats was often in the role of giving a presentation related to the concept mapping process, or in the course of conducting retreats. CSI also served as adjunct support for certain Committees on occasion. In addition to the sections of the agenda for which CSI was responsible, there was opportunity for observation of other parts of the meeting as a true observer, rather than participant observer.

## VIII. Consortium Expectations

To begin the evaluation, we reviewed two sources to answer the question: “What did we expect to happen in the first phase of the Consortium?” The original Green Book (March 2002) articulated the Committee activity and achievement priorities. The interview input asked respondents to identify their expectations of the Consortium’s capacity to organize well, involve partners, and deliver on the priorities described.

This report reflects the process and progress of the Committees regarding the original Green Book priorities. Figure 3 is a summary by interview query on the expectations of the respondents.



Since this is retrospective feedback, it is to be expected that high scores would result, especially from those most intimately involved in the Consortium. Taking that into account, we are still able to point to the lesser expectations, specifically on innovative approaches, progress on recommendations, involvement of key communities of interest, and, to a less noticeable degree, staffing and management



support. The numbers associated with these differences are quite small, due to the size of the interview roster. But the process evaluation does bear out some of these slight differences.

## **IX. Findings Across Committees on Key Measures**

In this section, we summarize findings across Committees on the key measures identified in Table 2 above for each of the categories of the process model.

Please note that we represent certain summary data with two different averages. This reporting approach takes into account the particular case of the Insurance Committee, which had, in essence, completed its charge early in the life of the Consortium. Two different averages are shown: including Insurance as a unit of measure, and without Insurance counted as an ongoing Committee.

### ***A. Committee Structure and Management***

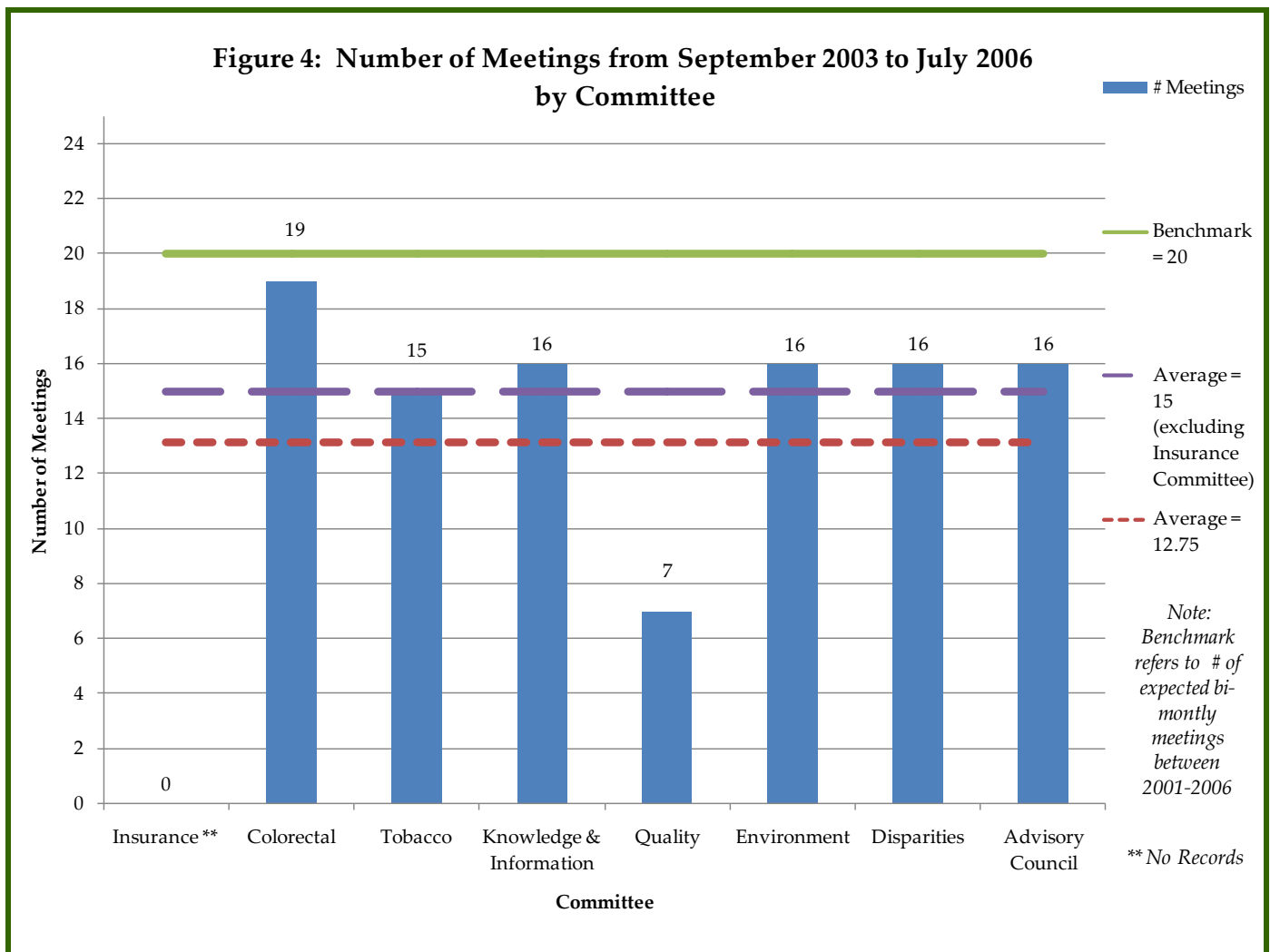
Committee structure and management is assessed using four key measures:

- Meetings held
- Attendance at meetings held
- Range of sources used for each Committee's work
- Management effectiveness for each Committee according to interviewees

#### **1) Meetings Held**

The first measure examines the number and regularity of Committee meetings. The expected schedule of meetings was bi-monthly, with Advisory Council meetings alternating with Committee meetings. This schedule allowed for Committees to take action between Advisory Council meetings and meant that Committee Chairs, who also serve on the Advisory Council, had responsibility for attending, on average, one meeting each month. This is a rule of thumb; in some cases a Chairperson of one Committee is also identified as a member of another Committee, so attendance was expected at more than one Committee and the bimonthly Council meeting

Figure 4 illustrates the number of meetings held by each Committee over the period 2003 through 2006. It is worth noting that most Committees did not begin meeting regularly until September 2003. For the period from September 2003 to July 2006, a benchmark of a total of twenty possible meetings was calculated, based on the meeting schedule if each Committee did in fact meet bi-monthly. This benchmark is noted on the graph. No Committee met every possible time. Rather, the average number of meetings held by Committees was just over twelve and ranged from zero (Insurance) to nineteen (Colorectal). Taking the Insurance Committee out of the active committee configuration, the average number of meetings across committees was sixteen. Most (six out of eight) Committees met between fifteen and nineteen times. Recall that these graphs are based on the document review and were verified or corrected via interviews with Committee Chairs. Figure 4 supports this summary. Institutional memory suggests that the Insurance Committee, in fact, met once. However, agenda or meeting minutes were not available; and the Committee Chair was not able to participate in the targeted interviews.



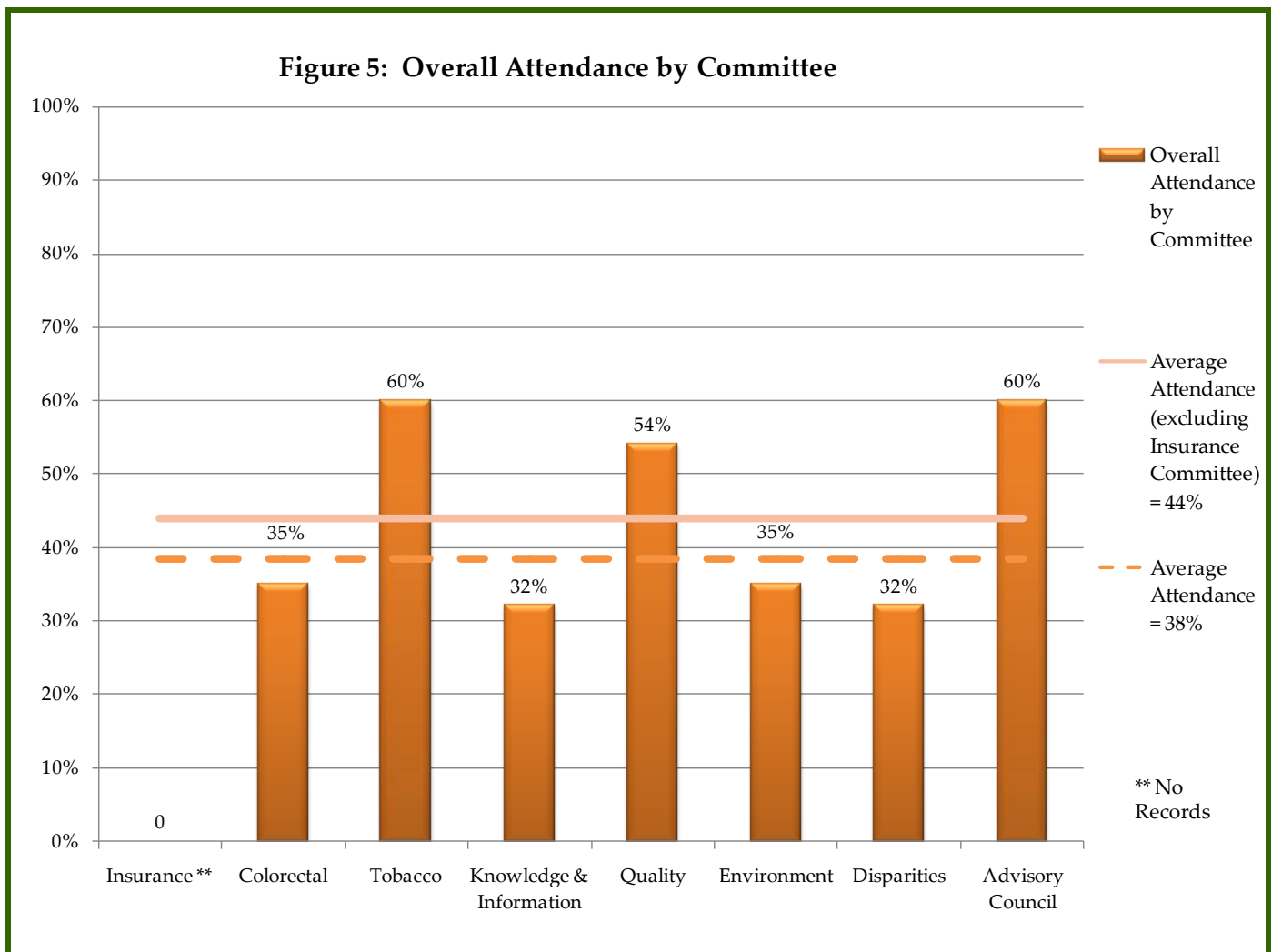
The pattern of meetings held is also instructive. In some cases, even a Committee that met a typical number of times (sixteen) may have gone for as many as six months without meeting. Four months without a meeting was common across Committees and is the result of missing just one bi-monthly meeting.

Influences on the meeting schedule included:

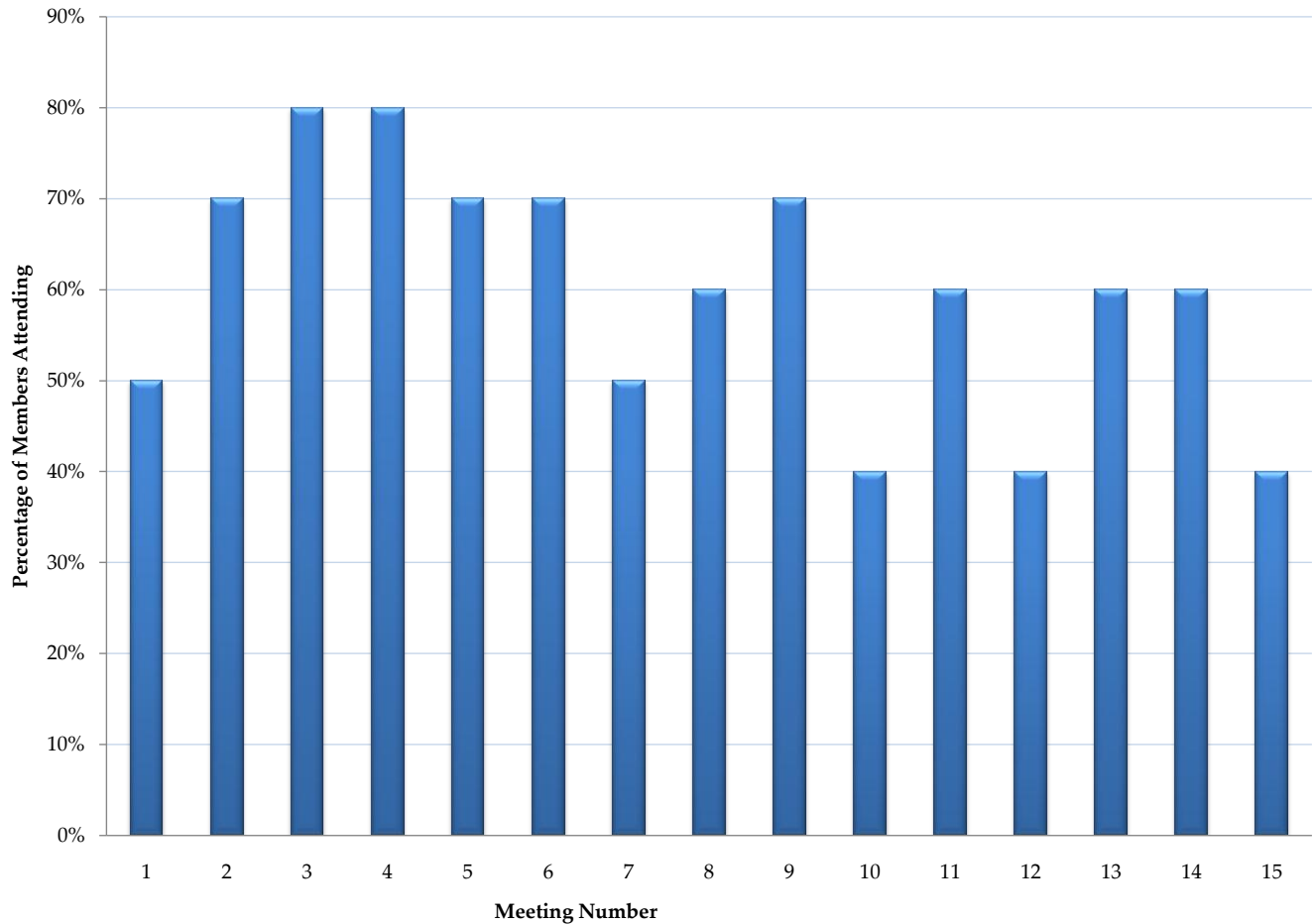
- Cancellation of meetings in favor of members' attendance at other events
- Cancellation due to weather
- Cancellation due to staff information regarding members' planned attendance
- Combination of a Committee's meeting with that of another Committee.

## 2) Meeting Attendance

Another indicator of Committee structure and management is the attendance of its members. Good attendance is needed to ensure member awareness of and diverse input on critical decisions, to maintain momentum, and feed partner organization engagement. Figure 5 shows that average attendance by Committee, across its held meetings, varied from 32% to 60%, with an average of 44% (excluding the Insurance Committee). The Advisory Council attendance was the highest reported, with an average attendance of 60%. Advisory Council attendance ranged from 38% to 75% and held steady throughout the life of the initiative. Closer examination of the attendance by Committee did not reveal attendance patterns or trends over time for most Committees. An example of typical committee member attendance is shown in Figure 6.



**Figure 6: Committee Member Attendance Example: Tobacco Committee**



### 3) Sources Used

Most of the measures reported in this process evaluation depend upon the quality of Committee documentation. Table 5 summarizes the number of document sources by Committee. Sources here refer to the variety of different information vehicles that are included in the document review. These sources include meeting minutes, reports presented during the meeting, marketing collateral and any other sources mentioned in the methods section above.

There is no documentation of any meetings of the Insurance Committee. But since the Advisory Council continued to monitor the Insurance Committee's charge and relate it to other committees' work, the graph indicates sources from both the Advisory Council's minutes and the Green Book.

Each type of source was counted once per Committee. Although the Advisory Council may have discussed an issue on numerous occasions (thus, recording discussion in several different meeting minutes, "Advisory Council meeting minutes" was counted once as a source. This decision was made to ensure that that this measure did not duplicate the information provided regarding the regularity or

frequency of meetings.) The table gives a rough indicator of the strength of documentation relied upon to assess each of the Committees.

**Table 5: Sources of Documentation for Committee Assessment**

<b>Source</b>	<b>Insurance</b>	<b>Colorectal</b>	<b>Tobacco</b>	<b>Knowledge and Information</b>	<b>Quality</b>	<b>Environment</b>	<b>Disparities</b>	<b>Advisory Council</b>
"Selected Cancer Trends" Presentation by Paul Silverman 2006		x	x				x	x
"Development of Evaluation Plan for State CRC Program"		x						
"Updates on Colorectal Cancer" PowerPoint presentation 2006		x						
2001 Action Planning Retreat Presentation: "The Delaware Advisory Council on Cancer Incidence and Mortality- Planning for a Comprehensive Cancer Control in Delaware: Identifying the Issues"						x		x
2001 Concept Mapping Results		x	x	x	x	x		x
2004 Cancer Care Coordinators Presentation					x			
2005 "Comprehensive Control Plan" by CDC							x	x
2005 Concept Systems, Inc. Presentation on Disparities							x	x
2005 DCC Retreat Presentation	x	x			x		x	
2005 Retreat Report	x	x	x	x	x	x	x	x
2005 Retreat Survey Instrument	x	x	x	x	x	x	x	x
2005 Retreat Survey Results		x			x			x
2006 Advisory Council Meeting Presentation by Concept Systems Inc.							x	x
2006 Cancer Clinical Trials Presentation					x			
2006 DCC Survey Results Report		x	x	x	x	x	x	x
2006 DPH Presentation							x	
2006 DPH Press Release "Declining Cancer Rates, Decreasing Racial Disparities, Top Consortium's Second Year Accomplishments"	x	x	x		x	x	x	

Source	Insurance	Colorectal	Tobacco	Knowledge and Information	Quality	Environment	Disparities	Advisory Council
2006 Alliance Pamphlet				x				
2006 Retreat Notes and Summary Recommendations	x	x	x	x	x	x	x	x
2006 TMF Presentation					x			
AB&C Marketing	x	x	x		x	x		x
Advisory Council Meeting Minutes	x	x	x	x	x	x	x	x
Advisory Council Meeting Minutes Cancer Request for Proposals				x			x	x
Behavioral Risk Factor Surveillance Survey, 1999		x						
Brown, Riley, Schussler, Etzioni, Estimated health care costs relating to cancer treatment from SEER-Medicare data, Med Care 2002	x							
Center on Aging and Society, 2000				x				
Colditz, 2000		x						
Delaware Business Magazine 2005 "Solving Delaware's Cancer Puzzle"	x	x			x			x
Delaware Cancer Registry, Delaware Division of Public Health	x	x		x				
Delaware Chamber of Commerce Flyer								x
DPH Data Report							x	
Eddy, 1990	x							
Email communication from DPH		x		x				x
Green Book 2002	x	x	x	x	x	x		x
Green Book 2004	x	x	x	x	x	x	x	x
Green Book 2005	x	x	x	x	x	x	x	x
List of Delaware Sources							x	
Meeting Minutes		x	x	x	x	x	x	x
Membership Application Form							x	
Memo from Betsy Wheeler to Advisory Council Members 6/11/03	x			x				

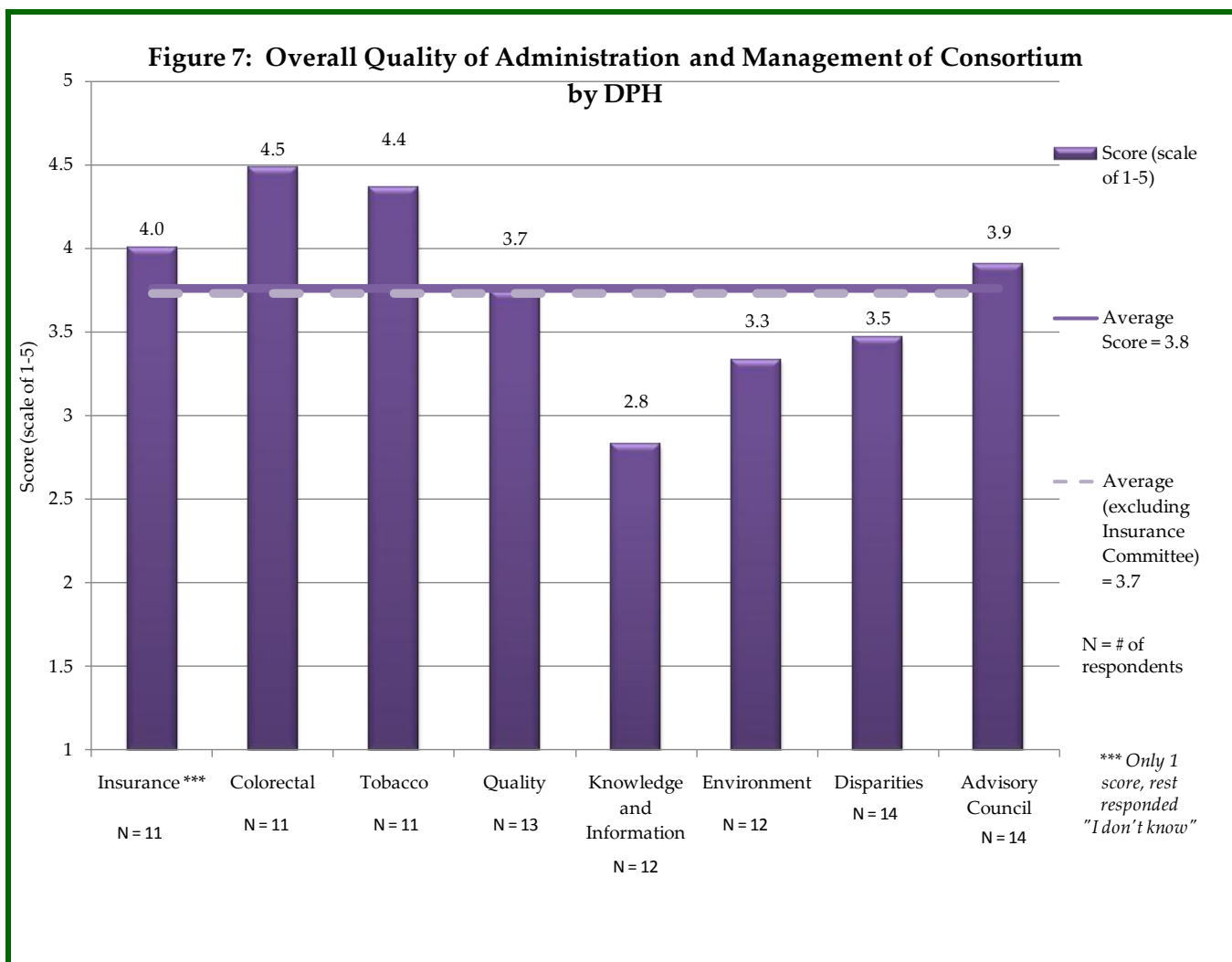
Source	Insurance	Colorectal	Tobacco	Knowledge and Information	Quality	Environment	Disparities	Advisory Council
National Center for Health Statistics		x						
ORC Macro Draft Disparities Report- Disparities in Cancer Incidence and Mortality Among Delaware Residents, 1998-2002							x	x
Penberthy, Retchin et al., 1999	x							
Ransohoff & Sandler, 2002		x						
Ries, et al.		x						
Summary Meeting #1 Presentation					x			
Surveillance, epidemiology and End Results (SEER) Program, National Cancer Institute				x				
Synopsis of Deliverables Champions of Change Contracts							x	
Taplin, Barlow et al., 1995	x							
University of Delaware's Center for Applied Demography and Survey Research 1994-1998	x							
Visual Depiction of Purple Book (Year 4) Priorities Document							x	
Working Group Meeting Minutes						x		
<a href="http://www.delawarecancerconsortium.com">www.delawarecancerconsortium.com</a>	x	x	x	x	x	x	x	x

#### 4) Management Effectiveness

Data regarding Committee administration and management was the focus of Section C of the interviews. In general, Department of Public Health staff or contractors provide staff support to the Committee.

The interview queried on the administrative support and management provided to each Committee on a scale of 1 to 5 where 1=poor; 2=fair; 3=good; 4=very good; 5=excellent. A summary of responses by Committee is provided in Figure 7. With average scores of 4.48 and 4.36 respectively, the Colorectal and Tobacco Committees stand out as well above the average of 3.76. The Knowledge and Information (2.82) has the lowest rating. Ratings of the Consortium as a whole are very good (3.90).





Interviewees also answered specific questions pertaining to particular dimensions of Committee administration and management. Those responses are aggregated across Committees in Table 6 and give an indication of the relative strengths and weaknesses of particular aspects of this broad topic.

**Table 6: Summary of Interview Responses to  
Specific Committee Administration and Management Questions**

Question	Average Rating	Answers	Respondents	Lowest value	Highest value
Please rate the level of effectiveness that DPH, working with the Consortium, has achieved in...					
Coordinating communication among members	3.59	22	17	2	5
Coordinating communication with people and organizations outside the Consortium	3.15	20	16	2	5
Organizing Consortium activities, including meetings and projects	4.00	22	17	2	5
Preparing materials that inform Consortium members and help them make timely decisions.	4.05	22	17	2	5
Providing orientation to new members as they join the Consortium.	2.50	12	9	1	4
Making good use of members' time.	3.91	22	17	2	5

Interview comments also shed light on some important dimensions of Committee management and structure:

*Staff support* is critical to the success of such an endeavor, and this has varied across Committee and over time. Of the seven active Committees, over half have experienced significant changes in staffing, which affected ratings of this aspect of the Consortium's process.

Providing the right *balance of staff support and Committee involvement* is a challenge in an effort like this. On the one hand, an interviewee felt that "the contractor was force-feeding us a structure." Another interviewee, from a different Committee, said meetings felt rushed and that they were "overly respectful of [members'] time...We really didn't have any responsibility for projects." On the other end of the spectrum, interviewees expressed concern about the lack of authority of staff or administrative barriers that prevented staff from communicating on behalf of the Consortium or taking the initiative on projects. In general, interviewees felt that their time was respected, rating that a 3.91 on a five point scale.

A few interviewees took the opportunity to discuss the unique *challenges of providing staff support* to such an initiative. "On balance it has been good; we've gone through periods where it has been excellent and other times where we didn't hit the mark at all. Part of this is that it is a different animal,

with a lot of moving parts. The breadth and depth is more than what most of us think of when providing staff to an effort. The consultants have also struggled with the breadth and depth. For example, we had one group that had done a lot of staff support for another agency and they were just not prepared for this. There isn't an ebb and flow of work. It is steady. It has been full steam ahead for seven years. It can be exhausting – for staff and for contractors.” Another respondent observed: “The DPH has been struggling to support the Consortium, which is probably why they added contractor[s] to do that. Part of it is growing pains. When a fledgling organization starts to get things done, then they have to figure out how to support it.”

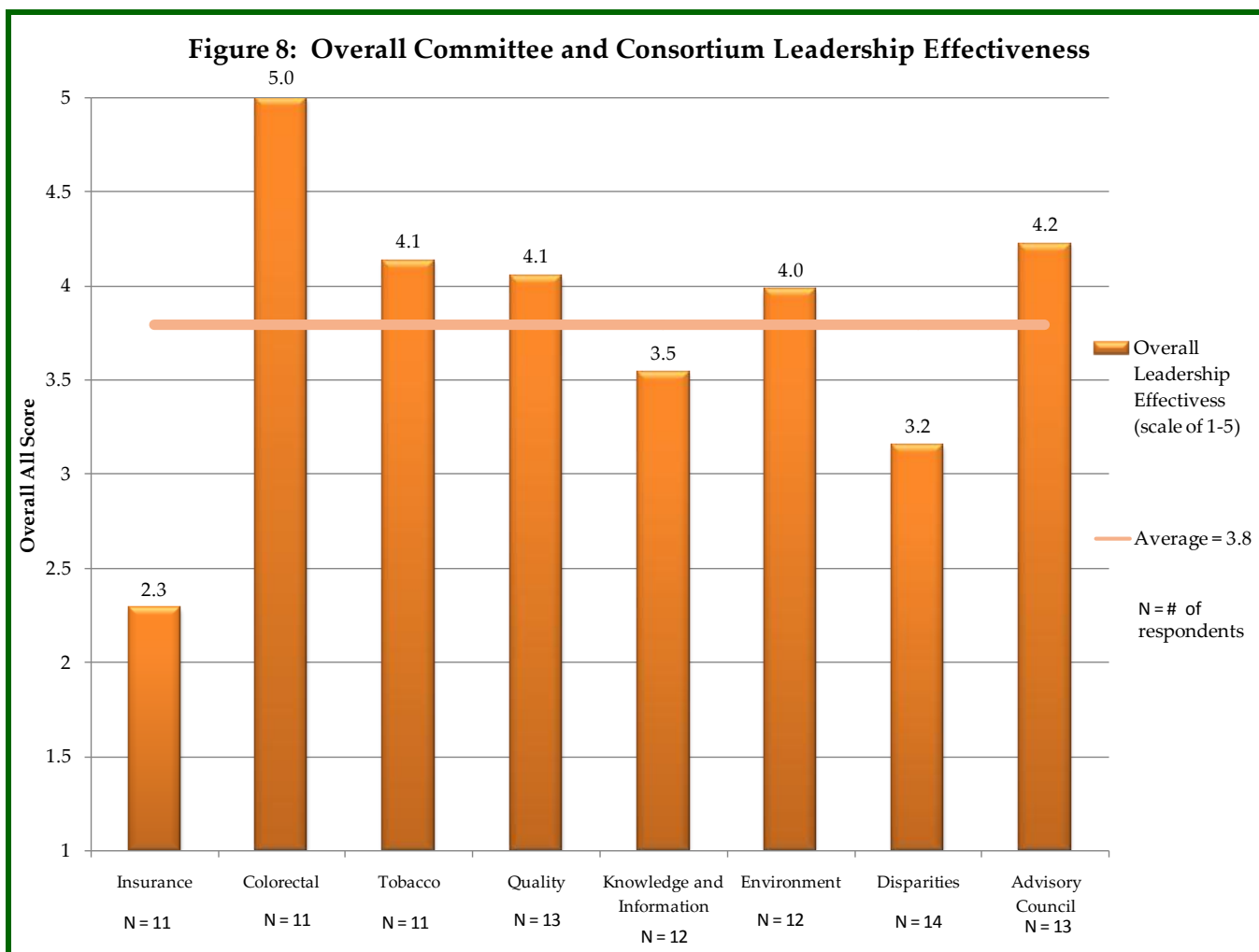
Interview comments also suggested other measures of the effectiveness of the overall Committee structure, administration and management:

The Consortium as a whole has a process for *selecting and inviting members* that is consistent across Committees. This is in part because appointment to the Consortium is, in essence, appointment to a government volunteer position. However, there is no formal or identifiable process for orienting members to the Committees or the Consortium as a whole. In part, this may be because there has been relatively little turnover for the Consortium as a whole, with fifteen out of eighteen of its original advisory council members still serving, according to a DPH staff member. This lack of turnover is remarkable in itself, as the Consortium or its precedent organization has been operating for seven years.

Finally, the *degree and level of specificity* of Committee charges varies. In part, this reflects the differences in the maturity of the field of certain issues, and relative lack of consensus models or research in other areas. For example, the issue disparities is an intractable, systemic issue for which there are relatively few proven interventions. Efforts and approaches to tobacco control, on the other hand, are much better defined and organized. Guidance on interventions is much clearer and evidence regarding various interventions is relatively well-developed. So depending on the level of maturity of the Committee's focus, Committee charges varied in the degree to which they were accompanied by a clear set of discrete tasks to achieve the goals.

## ***B. Leadership and Priority Setting***

*Leadership* is assessed through the interview ratings, summarized by Committee in Figure 8. In general, the scores are quite high, with an average of 3.80, just short of “very good.” Most striking is the unanimous excellent rating for the Colorectal Committee. The Insurance Committee, which held only one meeting, is the lowest. The Disparities Committee (3.15) The Provide Knowledge and Information Committee are rated slightly lower than average; we explore reasons in the Committee-specific section.



We note that the Disparities and Knowledge/Information Committees are slightly less well rated on a few factors. These committees were challenged by agenda changes, the addition of committee charges and other elements that we discuss in more detail in the Committee section.

As shown in Table 7, respondent ratings on specific dimensions of the Consortium's leadership were also quite high. The lowest average rating for a series of eight leadership questions was 3.5. Across Committees, feedback is highest for acting responsibly for the Consortium (4.38), fostering trust and inclusiveness (4.14), and communicating the vision of the Consortium (4.00). The lowest scores are on working to develop a common level of commitment to the Consortium's responsibilities (3.5) and helping the Consortium to innovate and look at the issues differently (3.68).

**Table 7: Summary of Interview Responses to Specific Leadership Questions**

Question	Average Rating	Answers	Respondents	Lowest value	Highest value
Please rate the total effectiveness of the Consortium's leadership in each of the following areas...					
Acting responsibly for the Consortium	4.38	21	16	1	5
Inspiring or motivating people involved in the Consortium	3.77	22	17	1	5
Communicating the vision of the Consortium	4.00	22	17	3	5
Working to develop a common level of commitment to the Consortium's responsibilities	3.50	22	17	1	5
fostering respect, trust, inclusiveness, and openness in the Consortium	4.15	21	16	1	5
Resolving conflict among Consortium members	3.95	20	15	1	5
Combining the perspectives, resources, and skills of Consortium members	3.71	21	16	2	5
Helping the Consortium to innovate and look at the issues differently	3.68	22	17	1	5

Comments are often Committee-specific and will be touched on in the discussion by Committee section of this report. About the Consortium as a whole, interviewees were positive about the leadership. Since the Advisory Council is, effectively, the leadership group of the Consortium, general questions about Consortium leadership relate to the Council. Respondent comments illuminate some of the ingredients of success in leading such a Consortium:

- “There isn’t any single organization benefiting unequally from the Consortium. This illustrates their responsibility as leaders in the state. They take that seriously.”
- “These people came from different perspectives and have consistently decided in favor of the good of the Consortium and public rather than their own agenda.”
- “An advantage is that [the Chairperson] doesn’t have anything else at stake other than wanting patients’ experience with cancer to be better...His central and primary goal is and always has been has been reducing the burden of cancer in Delaware and he keeps bringing the group back to that purpose.”

We asked respondents to name both formal and informal leaders at the Consortium level. The Chair of the Consortium was named by all who responded; in addition, key informal leaders were considered to be the Chairs of the CRC and Quality Committees, as well as key DPH staff.

### *C. Program and Intervention Planning*

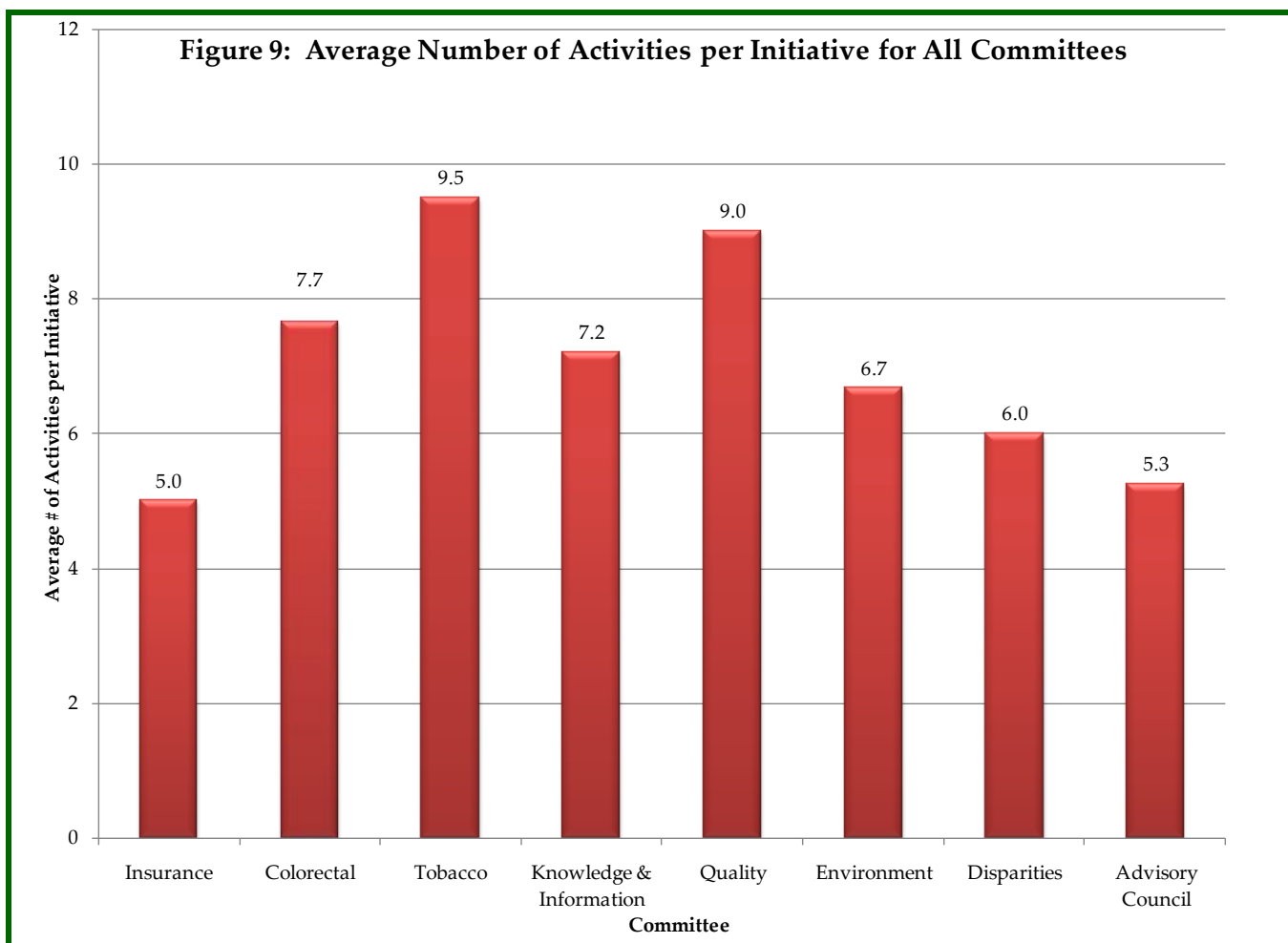
The number of charges varied by Committee, as illustrated in Table 1 above. The Insurance Committee, for instance, had just one charge that was quickly addressed. The Tobacco Committee, on the other hand, had six charges.

In the document review, activities and discussions were coded by their content according to initiative. In most cases, the coded initiatives correspond to the charges of the Committee. For instance, the four major initiatives coded for the Quality Committee correspond reasonably to the four charges of the Committee, as described in the Green Book. In the case of other Committees, charges, or the priority actions to address those charges, were refined in the process of investigating the Committee's priorities; thus, there is not always a direct correspondence between the stated charge and the work focus. It should be clear that in every case, the revision of charges and foci was considered and approved by the Consortium to ensure that the Committees in question were able to fulfill the spirit of their charge.

In all cases there were multiple activities to address each initiative. For instance, the Tobacco Committee was charged with the recommendation to "formally adopt, implement, and enforce the CDC model policy for tobacco control in all Delaware schools." It pursued nine distinct activities related to schools and youth, which are traced through the document review. These activities included tobacco-free school zone signs, a merchant booklet "Delaware Law Prohibits Youth Access to Tobacco" and re-educating school leadership regarding the content and merits of the CDC model school policy.

Figure 9 illustrates the average number of activities per initiative that each Committee undertook. These numbers are an indication of the depth of each Committee's attention to their initiatives. These averages range from 5 (Insurance) to 9.5 (Tobacco). Interestingly, the Tobacco Committee, which had the largest number of charges, also had the most activities per initiative. The number of initiatives each Committee addressed taken together with the number of activities per initiative shows the breadth as well as depth of program effort. There was a total of one hundred nine-two activities across the Consortium. Figure 9 suggests the degree of multi-tasking necessary to accomplish these complex recommendations.

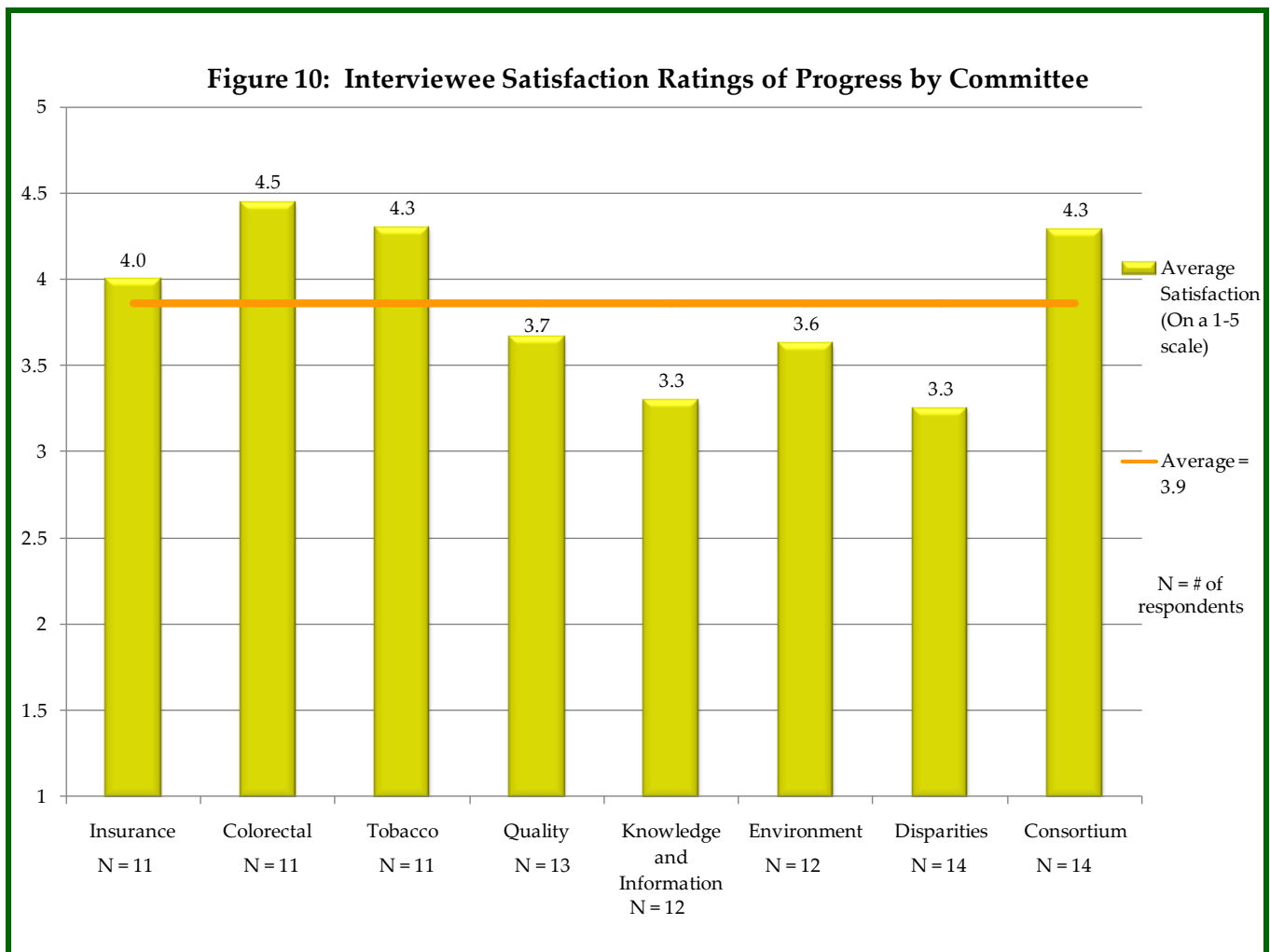
In Section X, Discussion by Committee, a table showing the number of activities per initiative for each Committee is displayed.



The document review provides information about the depth and breadth of program intervention activities, as described above. However, these numbers do not tell us *how productive these activities were* toward accomplishment of Consortium goals.

In the interview process, respondents rated the progress of each Committee toward its goals. Recall that for each Committee, the results reflect the ratings of the DPH staff, the Committee Chair and the perspectives of other Committee Chairs, in a 360-degree type of assessment. The results are presented in Figure 10. A list of interview respondents can be found in Appendix 3.

Interviewees are very satisfied to extremely satisfied with the progress achieved by the Colorectal Committee (4.45), Tobacco Committee (4.30) and the Consortium as a whole (4.29), all of which exceed the average of 3.86. The Disparities Committees (3.25) and Knowledge and Information (3.30) are the lowest rated, but still in the satisfied range. Of interest, this pattern of results strongly resembles interviewee perceptions of administration and management. While one might also expect a relationship between progress ratings and the number of initiatives or number of efforts per relationship, there is no discernable pattern of relationship. One interviewee summed it up, “We’ve achieved so much, but there is a lot to do.”



#### *D. Data Development and Use*

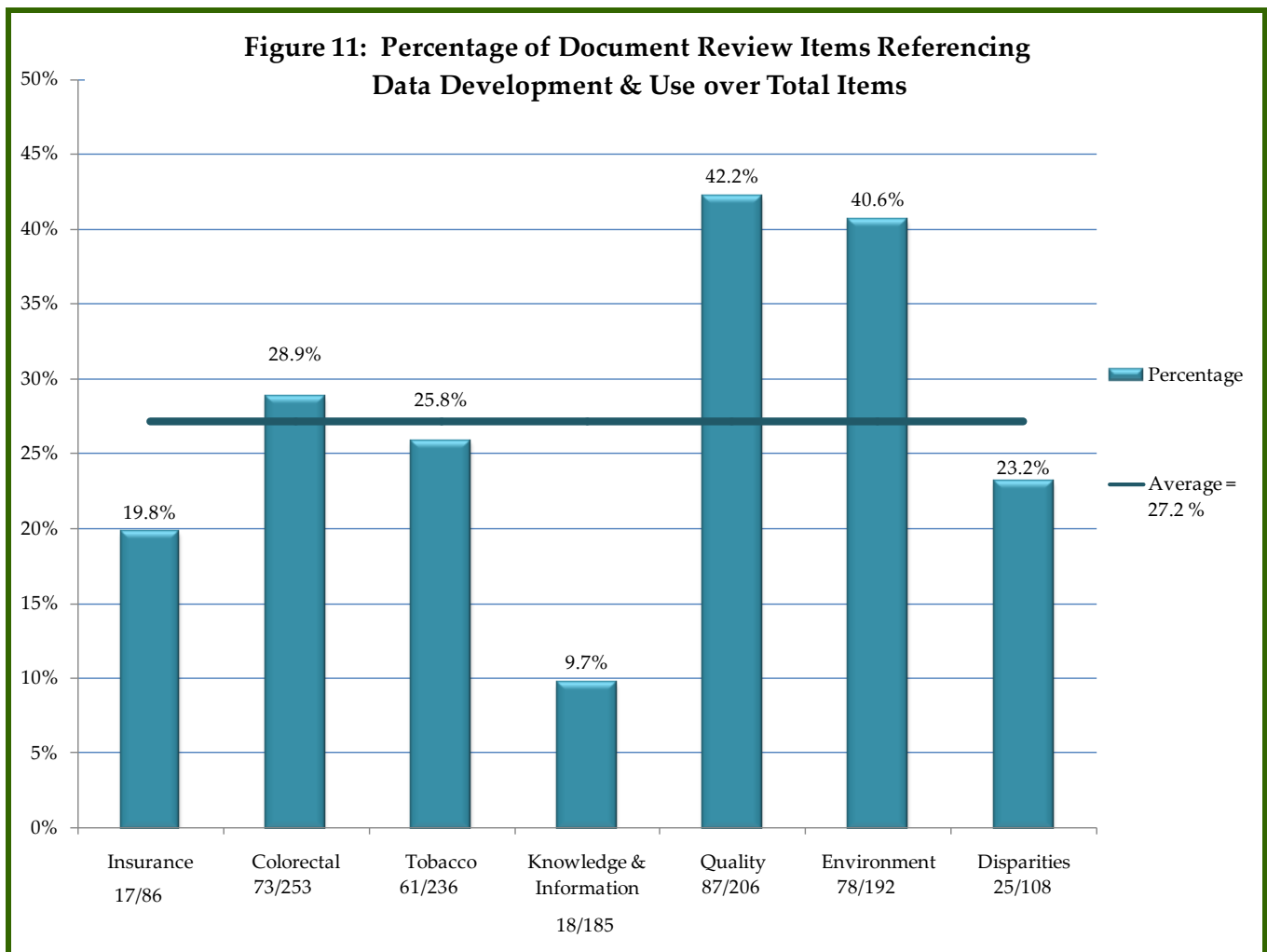
A key operating principle of the Consortium is a focus on using data and evidence in decision-making. When data is not available, Committees are expected to contribute to the development of data that would support decision-making. Thus, one would expect Committees to dedicate significant portions of their effort to the development and use of data. Figure 11 illustrates the percentage of document review items referencing data development and use for each Committee, compared to the total number of document review items. For example, the document review indicated the cancer registry was referred to or used as a data resource for the Knowledge and Information Committee.

The percent of effort focused on data development and use by Committee topic ranged from 10% for the Knowledge and Information Committee to 43% for the Quality Committee, with an average of 25%. The Advisory Council as a whole is not represented here because Committee-specific discussions by the Advisory Council were coded with the Committee it addressed.

Again, we find that the Insurance Committee's charge was addressed in a different way than those of other Committees. Seventeen discussion items out of the total of eighty-six discussion items were



identified as related to the Insurance Committee, although the Insurance Committee met just once. The Advisory Council collaborated with the Insurance Committee, and continued to monitor activities and data related to the Insurance Committee's charge, when the Insurance Committee itself became inactive.



To augment this data, respondents in the interview process also rated how effectively the Committee(s) with which they were most closely affiliated used evidence in its decision-making, on a scale of 1 to 5 where 1=poor; 5=excellent. The average rating for this question was 4.0. No one rated this question less than a 3 (good).

Ten out of eighteen interviewees also volunteered to comment on this question, suggesting a moderately high level of awareness of this priority. Comments pointed to challenges in the process because the data required for decision-making was not available, of reliable quality or in a format that made it readily usable for decision-making:

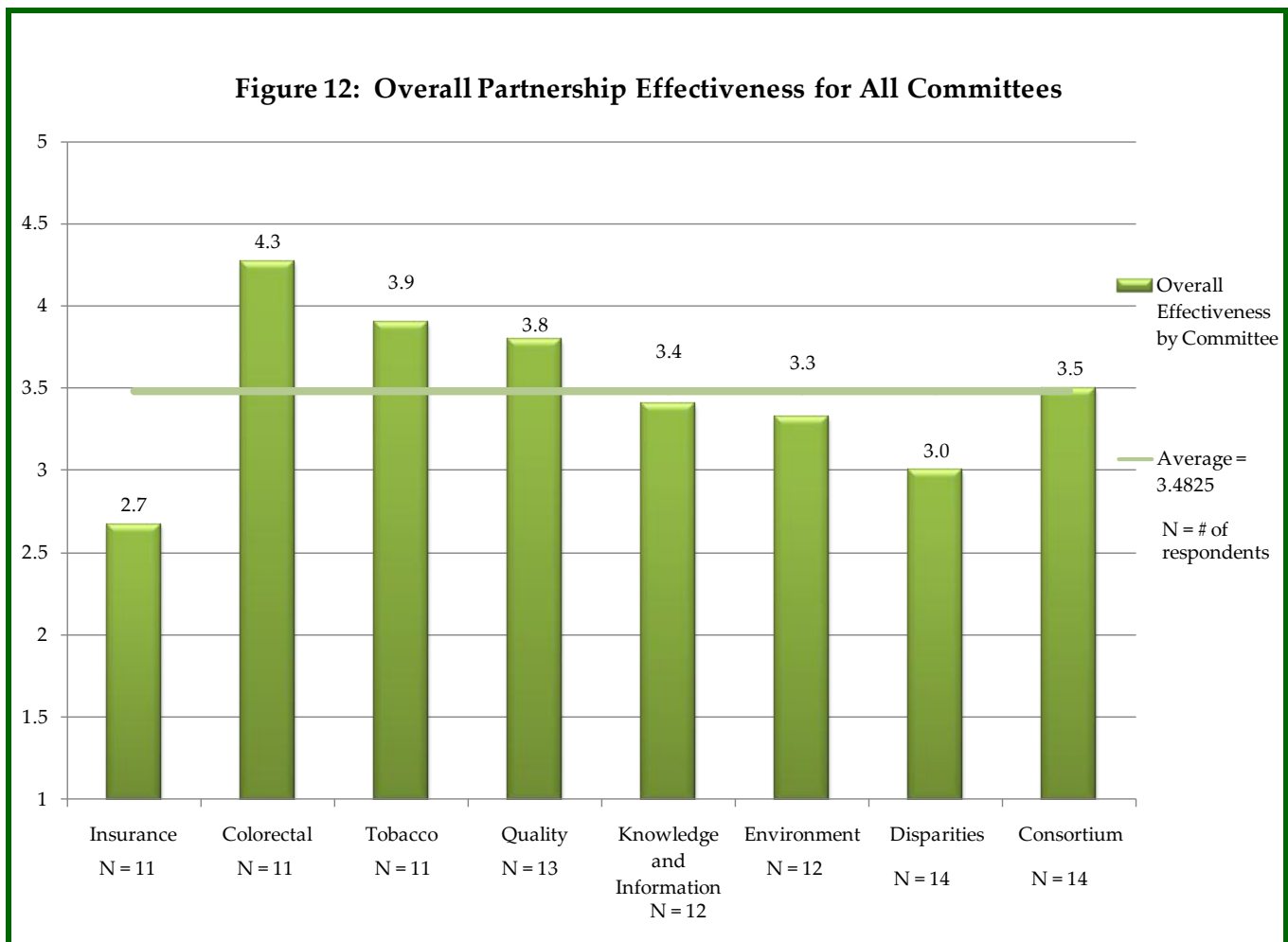
- “I’ve learned how often we have to create our own data to make it usable for decision making. This has delayed decisions. No one in the system is prepared for the questions we need

answers to; data is unreliable or incomplete. The theory is great; the big disappointment is that it is so hard to use.”

- “Data acquisition is slower than we would like.”
- “We had data, but having data is different from having confidence in the quality of the data.”

### ***E. Partnerships and Relationships***

The interview data provides insight about the overall effectiveness of the Committees on partnership building. Figure 12 summarizes the ratings on overall partnership effectiveness by Committee. Overall, partnership is rated between good and very good (3.48). The Colorectal Committee stands out for the quality of its partnerships (4.27). The Insurance (2.67) and Disparities (3.00) Committees are rated lowest on this dimension of Committee process. Tobacco (3.90) and Quality (3.80) also are noted as above average. Feedback related to Insurance Committee partnerships is retained in this graph, because the partnership approach was relevant to the work that the Insurance Committee led.

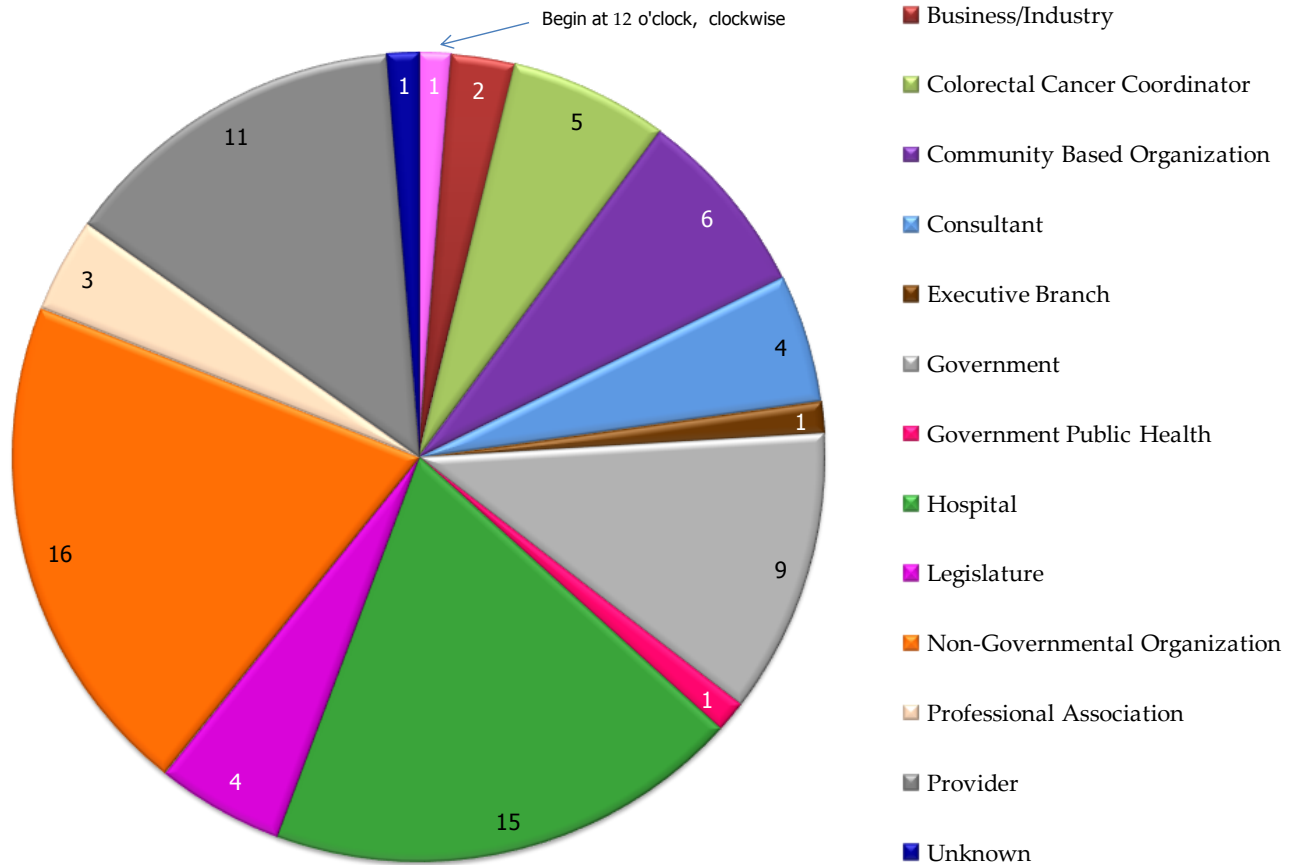


Interviewees also rated a number of specific aspects of partnership, shown in Table 8. Aggregating ratings across Committees, the interviewees thought, in general, that the Consortium was doing best at creating linkages with community-based organizations and advocates (average rating=3.63) and with the medical community (average rating 3.59). Creating linkages with educational institutions was rated lower (2.61). The average rating on recruiting diverse people and organizations into the community was in the middle of the range (3.14).

<b>Question</b>	<b>Average Rating</b>	<b>Answers</b>	<b>Respondents</b>	<b>Lowest value</b>	<b>Highest value</b>
How comfortable are you with the decisions are made in the Consortium?	3.86	22	17	2	5
How often do you support the decisions made by the Consortium?	4.32	22	17	3	5
How satisfied are you with the way people and organizations in the Consortium work together?	3.95	22	17	1	5
How satisfied are you with your influence in the Consortium?	4.14	22	17	2	5
Please rate the total effectiveness of the Consortium's relationship efforts in... Recruiting diverse people and organizations into the Consortium?	3.13	22	17	1	5
...Creating linkages with the medical community?	3.59	22	17	1	5
...Creating linkages with educational institutions	2.62	21	16	1	4
...Creating linkages with community based organizations and advocates?	3.64	22	17	1	5
... Being recognized as a respected entity that can speak to cancer control issues in Delaware?	3.71	21	17	2	5

These perceptions by interviewees are consistent with an analysis of the Consortium membership, which is the primary partnership of note. Figure 13 shows Consortium membership by sector.

**Figure 13: Partnerships by Sector**



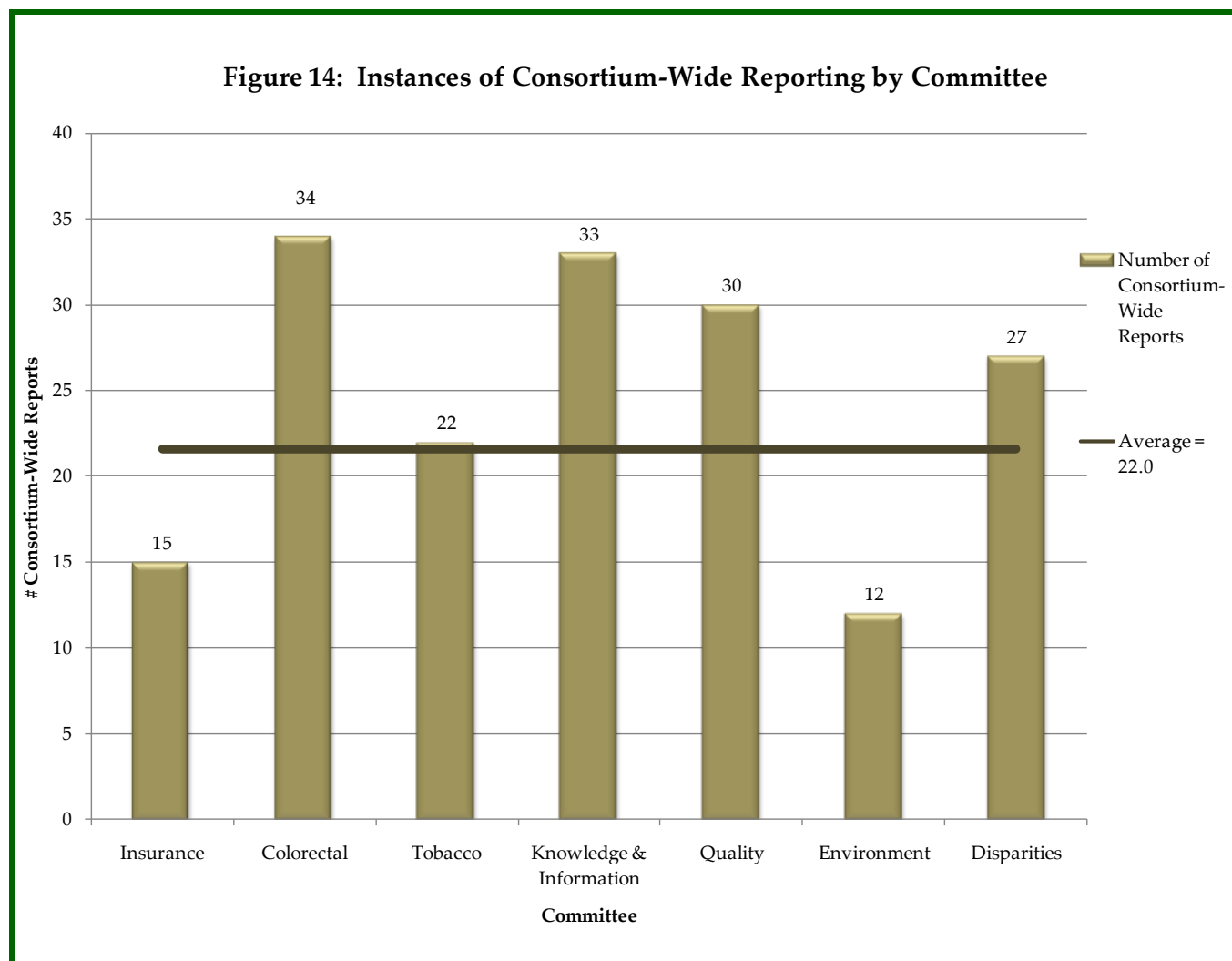
Partnerships, though, involve more than just whether the right people come to the table. There must also be a commitment to work together to achieve a high level of effectiveness through partnerships. One interviewee noted, “We came into this with a group of organizations who had what we called the “my agency’s got a plan” syndrome. No one was on about collaborating and coordinating and they didn’t see the value of it.” This interviewee thought that this attitude of promoting one’s own agenda has been largely overcome, in part because the leadership simply didn’t tolerate it. In general, interviewees are very satisfied with the way people and organizations in the Consortium work together (3.95), with their own influence (4.14) and the way decisions are made (3.86). Thus, effective partnership involves actively establishing a culture of collaboration and coordination.

As indicated above in Figure 13, representation in specific potentially vital sectors is uneven.

#### ***F. Communication and Reporting***

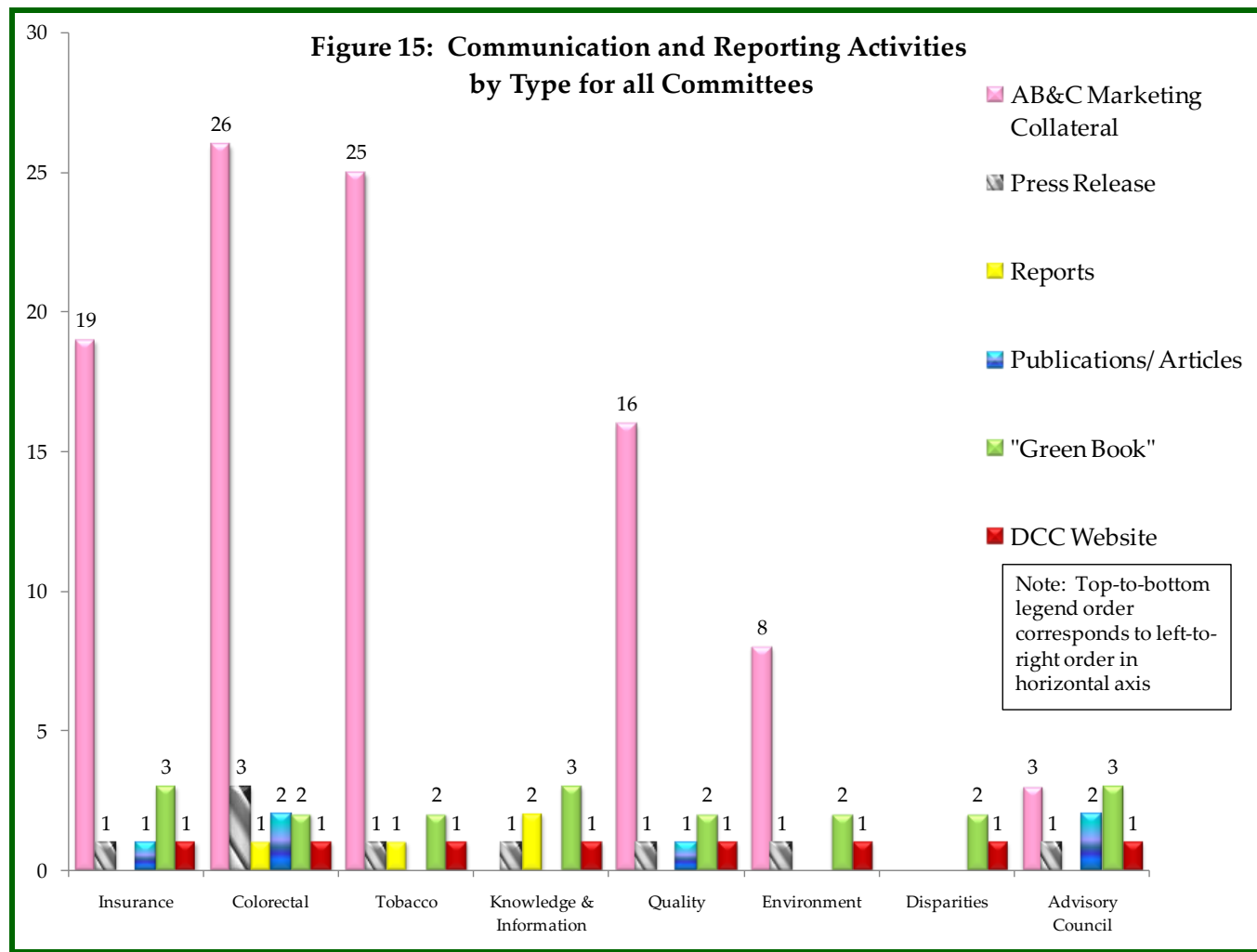
The function of communication and reporting has two distinct dimensions. The first dimension focuses on reporting *within the Consortium*. Each Committee is expected to report regularly to the Advisory Council for the Advisory Council’s response and decision-making. Figure 14 shows how many times

each Committee has reported to the Advisory Council during the document review period. The average number of reports is just under twenty-two. The Colorectal (thirty-four), Knowledge and Information (thirty-three) stand out as the highest. Insurance (fifteen) and Environment (twelve) had the fewest reports to the Advisory Council, according to the documents available.



A second dimension of communication and reporting focuses on *public education, outreach and communication*. Figure 15 summarizes the communication and reporting activities by type for all Committees. Each type of outreach product (each television advertisement, brochure, radio ad) is counted separately. It is expected that Committees with charges that include public programs, such as the care coordinator program of the Quality Committee, or the colorectal cancer screening program of the Colorectal Committee will generate marketing collateral. The Tobacco Committee was charged with a public awareness campaign. In fact, the Colorectal and Tobacco Committees each had the largest number of activities (35 and 30 respectively), the bulk of which was taken up by consumer collateral produced by AB&C Marketing. The Insurance and Quality Committees also had a substantial number of outreach products.

Three Committees and the Advisory Council generated publications or articles as a result of their work, totaling six publications or articles. Three Committees issued public reports. All but the Disparities Committee issued at least one press release during the period under review.



According to interviewees, coordinating communication with people and organizations outside the Consortium (3.15) is one of the weaker areas of Committee administration and management. Several interviewees commented on this issue, noting that internal communication is better than external communication and that “we need to focus on this going forward – [engaging] the public and people who are not involved”. One interviewee postulated that there are “administrative barriers to getting information out.” While some interviewees doubted that the general public is aware of the Cancer Consortium, in general, the interviewees feel satisfied that the Consortium is recognized as a respected entity that can speak to cancer control issues in Delaware (average rating of 3.71).

## **X. Discussion of Findings by Committee**

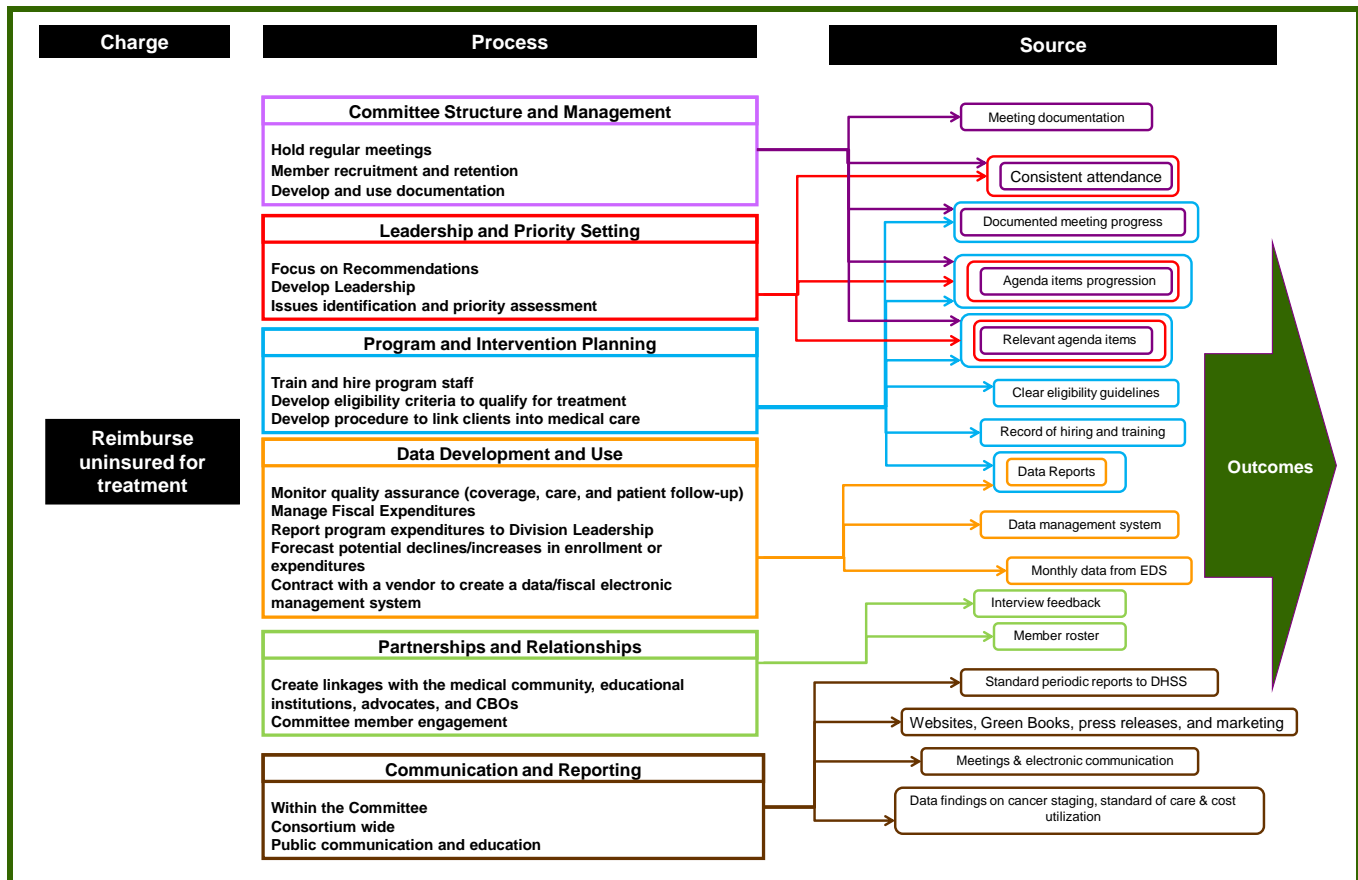
The following section is organized by committee, and within each of the committee reports the structure of the process model is used to guide the reporting of data and interview feedback. We identify the charges of the committee and present the committee process model. Following background information captured through the document review and interviews, we provide findings regarding the Committee's performance on relevant areas of the process model.

## A. Insurance Committee

The Insurance Committee was charged with one recommendation:

- Reimburse the cost of cancer treatment for every uninsured Delawarean diagnosed with cancer up until one year after diagnosis.

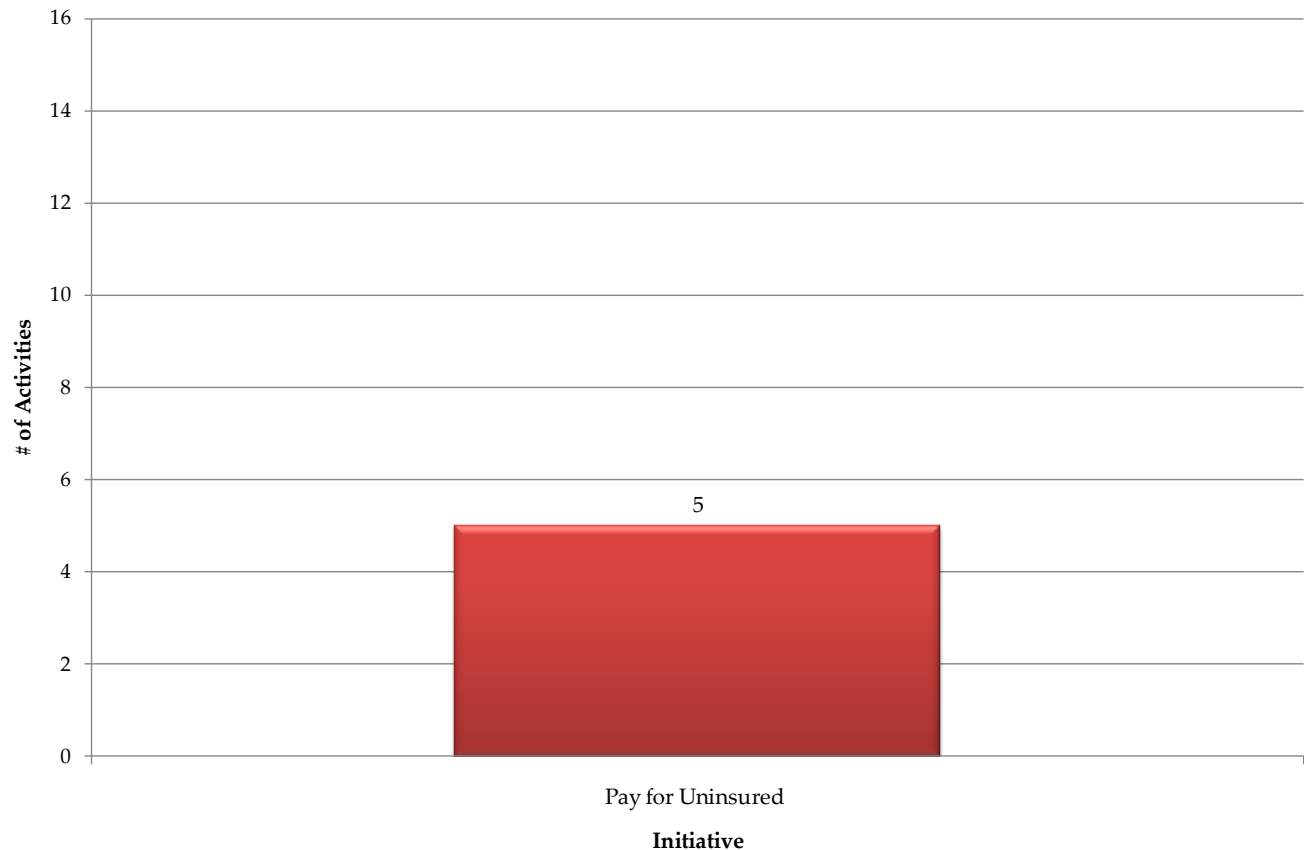
**Figure 16: Insurance Committee Process Model**



Background: This recommendation was successfully achieved early in the life of the Consortium. Legislation was introduced to establish the Delaware Cancer Treatment Program in 2002. A billing and payment system for the Delaware Cancer Treatment Program (DCTP) was put in place as of July 2004. As indicated in Figure 17, there were four discrete activities pursued to address this charge, including making cost estimates and revising funds allocations, establishing billing and payment systems and marketing the program to the public and providers. The process model anticipated a record of evidence of training and hiring staff, which was not borne out in the document review.



**Figure 17: Activities by Initiative: Insurance Committee**



By June 2005, a report to the Council indicated that a total of seventy-four clients had received benefits through the DCTP with a total of \$1,031,392.63 reimbursements given to providers. At that time, the Consortium called for investigating the potential for expanding the Delaware Cancer Treatment Program beyond one year of care as a priority for continued action in the following year. According to the Green Book (Nov 2005), \$3,839,000 was allocated through tobacco excise tax in Year Two for the continued reimbursement through the DCTP.

*Committee Management:* Notwithstanding the recollection of some Council members that one Insurance Committee meeting was held, according to the record of meetings held and attendance records, the Insurance Committee did not meet independently. Instead, they collaborated with the Advisory Council and DPH staff to develop and monitor the Delaware Cancer Treatment Program. Scores on various measures presented in the cross-Committee analysis in the previous section of the report reflect the unique situation of this Committee.

*Program:* According to interview input, Consortium members are satisfied with progress on the Insurance Committee charge. Legislation was passed and nineteen discrete pieces of information were developed to inform the public and providers of the resulting Delaware Cancer Treatment Program (DCTP).

*Leadership:* One interviewee suggested, though, that “we could be more ambitious...while we have done an excellent job with goals set in year one, we could set some new additional goals. DCTP is amazing but we could do more...” The required structure for such enhancements is unclear, given that “the goals are happening in the absence of a Committee.”

*Partnership:* Although no specific evidence of partnership, the establishment of the program indicates that the Insurance Committee made good use of existing relevant parties to put the program in practice.

*Communication:* Since the Insurance Committee was not active, communication regarding this program typically originated either at the DPH staff level or at the Advisory Council.

## B. Colorectal Committee

The Colorectal Committee was charged with three recommendations:

- 1) Create a comprehensive statewide colorectal cancer screening and advocacy program.
- 2) Reimburse for colorectal cancer screening of uninsured Delawareans age 50 and older.
- 3) Case manage every Delawarean with an abnormal colorectal cancer screening test.

These are illustrated in the process model in Figure 18. The process model also shows, under Program and Intervention Planning, the three primary programs that are related to these charges: Champions of Change, Screening for Life and Screening Coordinators.

**Figure 18: Colorectal Committee Process Model**

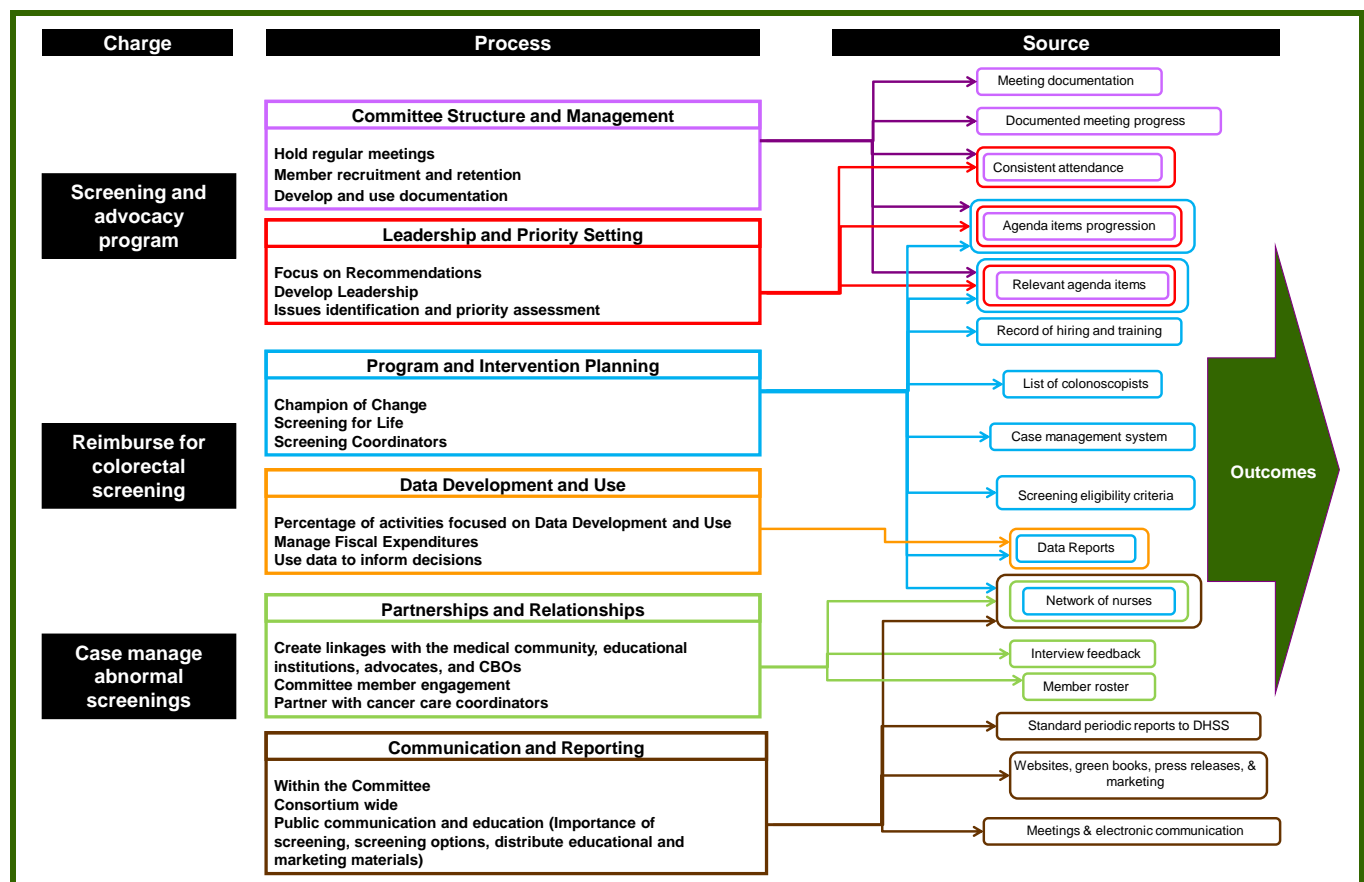
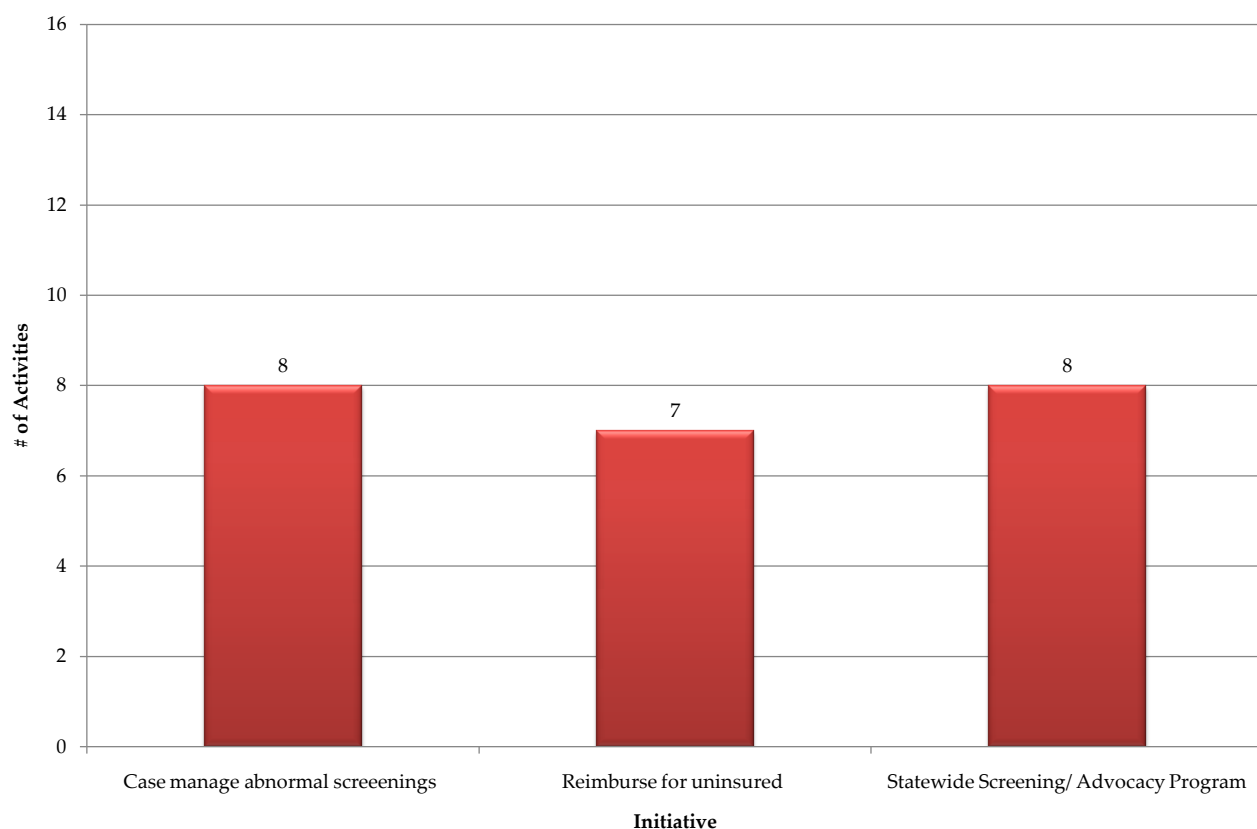


Figure 19 below, shows that the Committee engaged in seven or eight activities to address each of the three charged initiatives. The document review shows evidence of steady progress on each of the initiatives over time. Some goals were met ahead of schedule.

**Figure 19: Activities by Initiative: Colorectal Committee**



*Management and Leadership:* This Committee was very active, holding the greatest number of meetings of any Committee (19). With an average attendance of 35%, participation in meetings was below the average across Committees. The pattern of attendance over time also suggests a slight downward trend.

Interviewee ratings were particularly high for the Colorectal Committee, across several different measures. They received the highest ratings of any Committee on overall effectiveness of administration and management. The leadership of the Committee was unanimously rated as excellent (rating of 5) by eleven interviewees.

*Program and Partners:* The Committee was also highly rated regarding satisfaction with Committee progress, and overall partnership effectiveness. The targeted nature of the Committee's charges, and the match of appropriate committed members to the program development, may have contributed to the good progress on the development of the committee's programs.

*Communication and Reporting:* The Committee also had the highest level of communication and reporting activities, with the highest number of instances of Consortium-wide reports and public communication and reporting. All of their initiatives had outreach and education components; the

high number of marketing pieces is consistent with this emphasis. The Committee Chair praised the support of AB&C marketing in reaching their marketing goals. However, in addition to the AB&C marketing collateral, which comprised the majority of the public communication and reporting activities, the CRC also had the largest number of other communication and reporting activities, including three press releases (more than any other Committee), two publications or articles and one report.

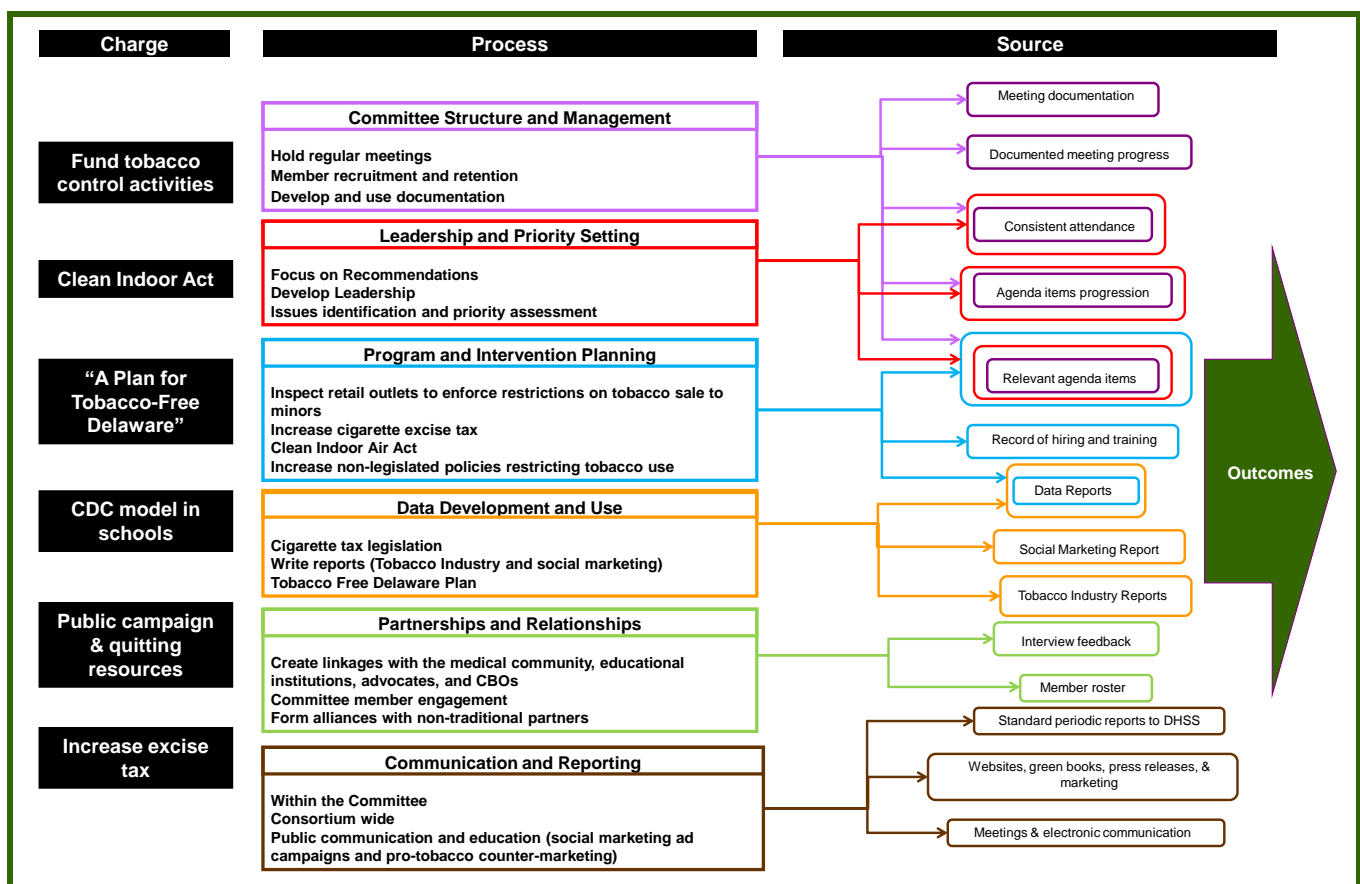
*Staffing:* Interviewee comments suggest that there was a major shift in staffing support to the Committee in late 2006 that has resulted in a more consistent level of support to this Committee.

## C. Tobacco Committee

Figure 20 shows the process model for the Tobacco Committee. The six recommendations with which the Committee was charged are summarized in the first column of the process model. They are:

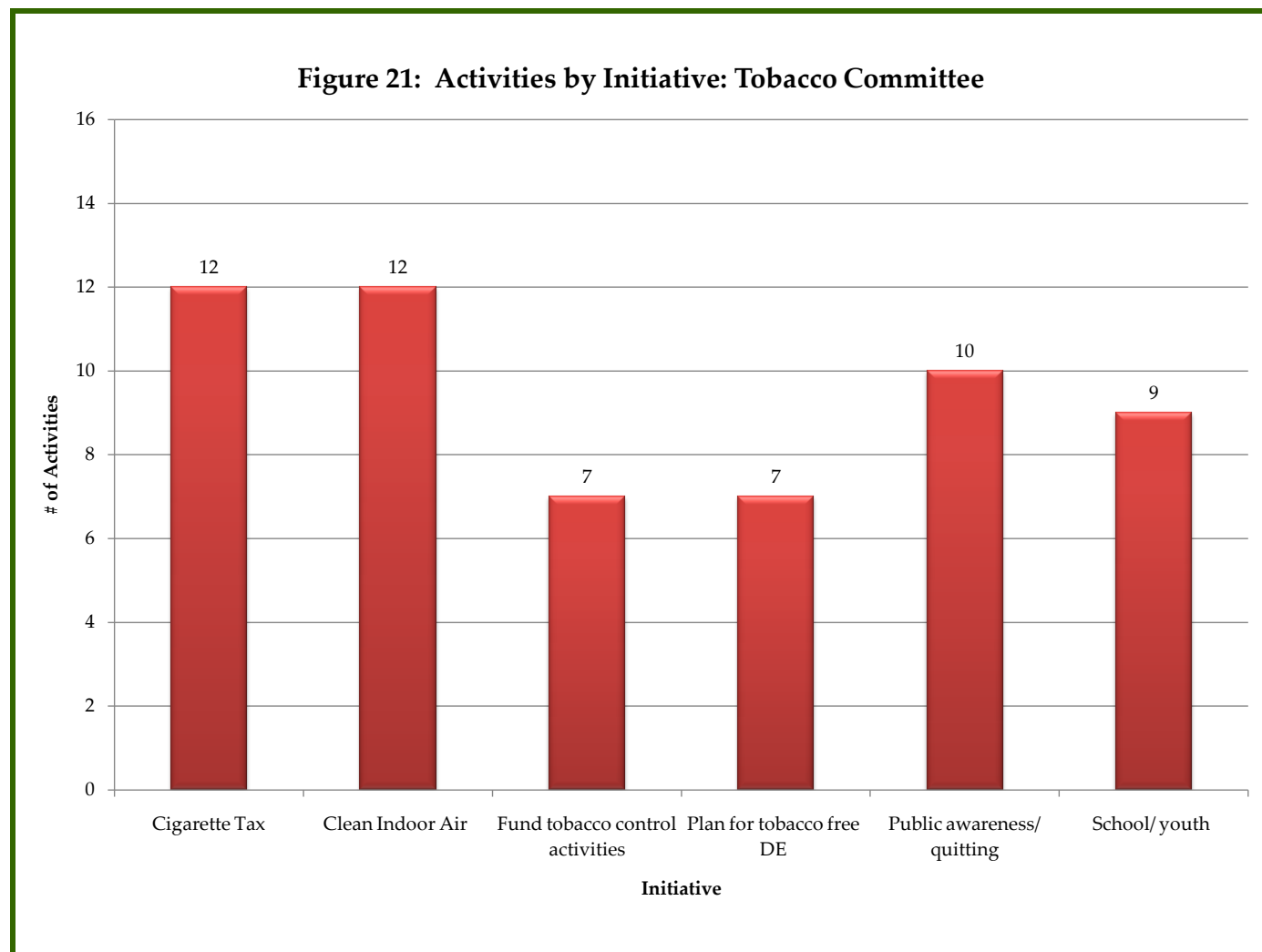
- 1) At a minimum, fund comprehensive statewide tobacco control activities at \$8.6 million (CDC-recommended minimum).
- 2) Strengthen, expand, and enforce Delaware’s Clean Indoor Air Act to include public places and workspace environments.
- 3) Strongly endorse, coordinate, and implement the action plan recommendations presented in “A Plan for a Tobacco-Free Delaware.”
- 4) Formally adopt, implement, and enforce the CDC model policy for tobacco control in all Delaware schools.
- 5) Expand and sustain a comprehensive public awareness campaign on the health risks of tobacco use and support resources available to help quit smoking.
- 6) Increase the Delaware excise tax on tobacco products to be comparable to bordering states and seek to identify other potential funding sources to support tobacco and cancer control efforts.

**Figure 20: Tobacco Committee Process Model**



The Tobacco Committee had the largest number of charges of any of the Committees. In addition to having the largest number of recommendations to address, this Committee also had the largest average number of initiatives per recommendation (with 9.5) of any Committee. Figure 21 summarizes the number of activities per charge (initiative), which ranged from seven to twelve.

Tobacco control and prevention is a relatively well-developed sub field of public health, enabling this Committee to build on established literature, existing leadership in partner organizations, and proven interventions. The level of structure in the approach to tobacco use prevention is reflected in the specificity and relative clarity of the recommendations and tasks, and indicates engagement of seasoned partners.



*Management and Leadership:* This work was accomplished over fifteen meetings, which is one less than the average. The Committee did benefit from the highest average attendance of any Committee, at an average of 60% suggesting a relatively high level of commitment from members.

This Committee was rated above average by interviewees on effectiveness of Committee management and administration, and leadership.

*Program:* Supporting the feedback on overall satisfaction with progress toward goals, which was also rated above average, two interviewees mentioned the Clean Indoor Air Act as an area of specific progress. That initiative was passed, has been enforced, extended to casinos and preserved. The Committee is building on that success to look at public spaces and expanding to campuses of businesses, organizations and hospitals.

*Communication:* Like the Colorectal Committee, this Committee's programs had a heavy emphasis on public outreach. As such, they had the second largest number of public communication and reporting activities of any Committee, the bulk of which is made up of AB&C marketing materials.

*Partners:* The process model suggests that working with non-traditional partners was expected to be an important dimension of this Committee's work. Interviewee ratings and comments suggest that partnerships with non-traditional partners have not been established. Relatedly, ratings of recruitment of diverse people and linkages with the medical community suggest room for improvement. While the Committee is a "tight knit group" the drawback of it being "always the same people" is that "diversity of thought is missing." Interview comments suggest there may be some tension emerging via the informal leadership of the Committee.

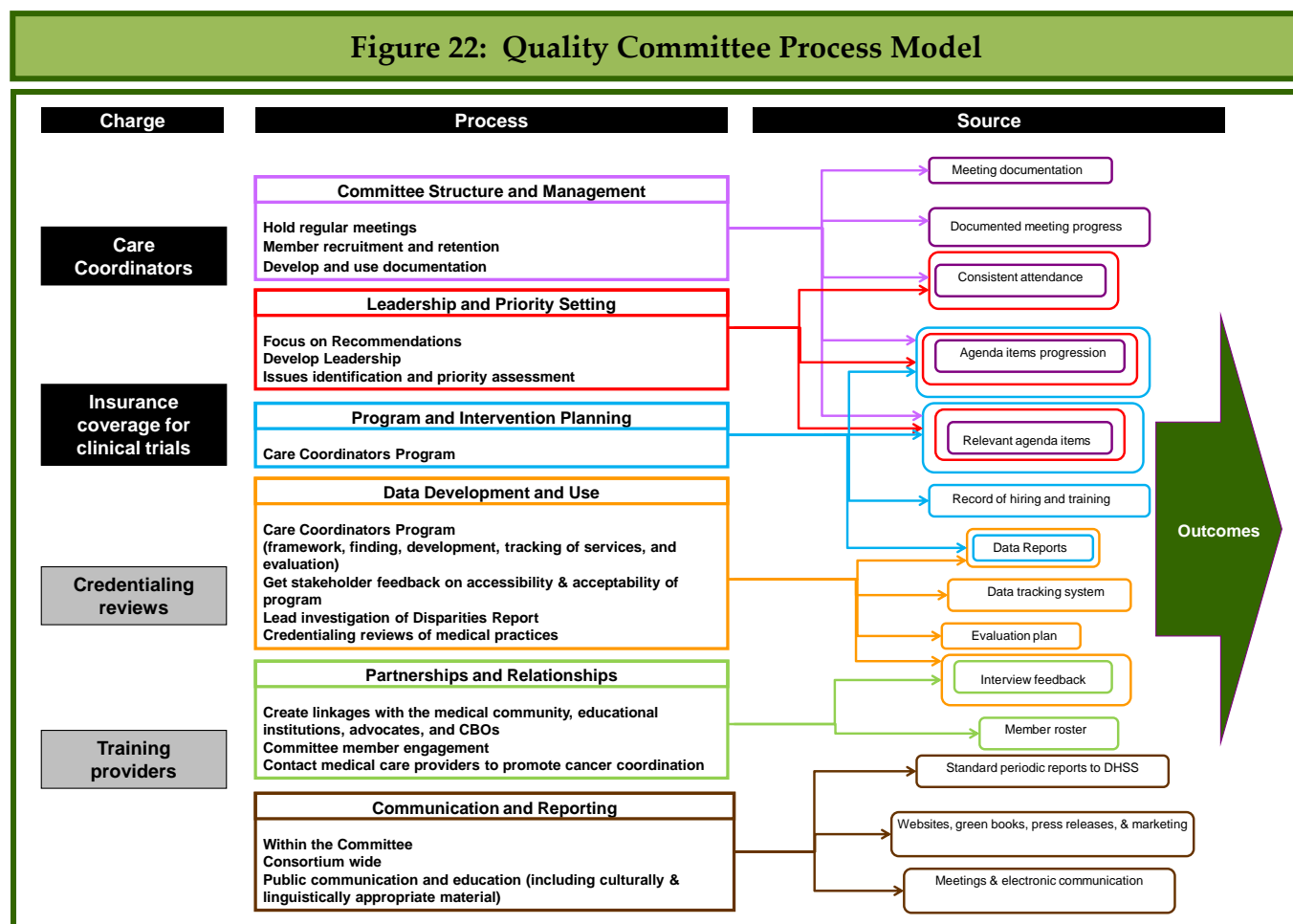


## D. Quality Committee

The Quality Committee was charged with the following recommendations.

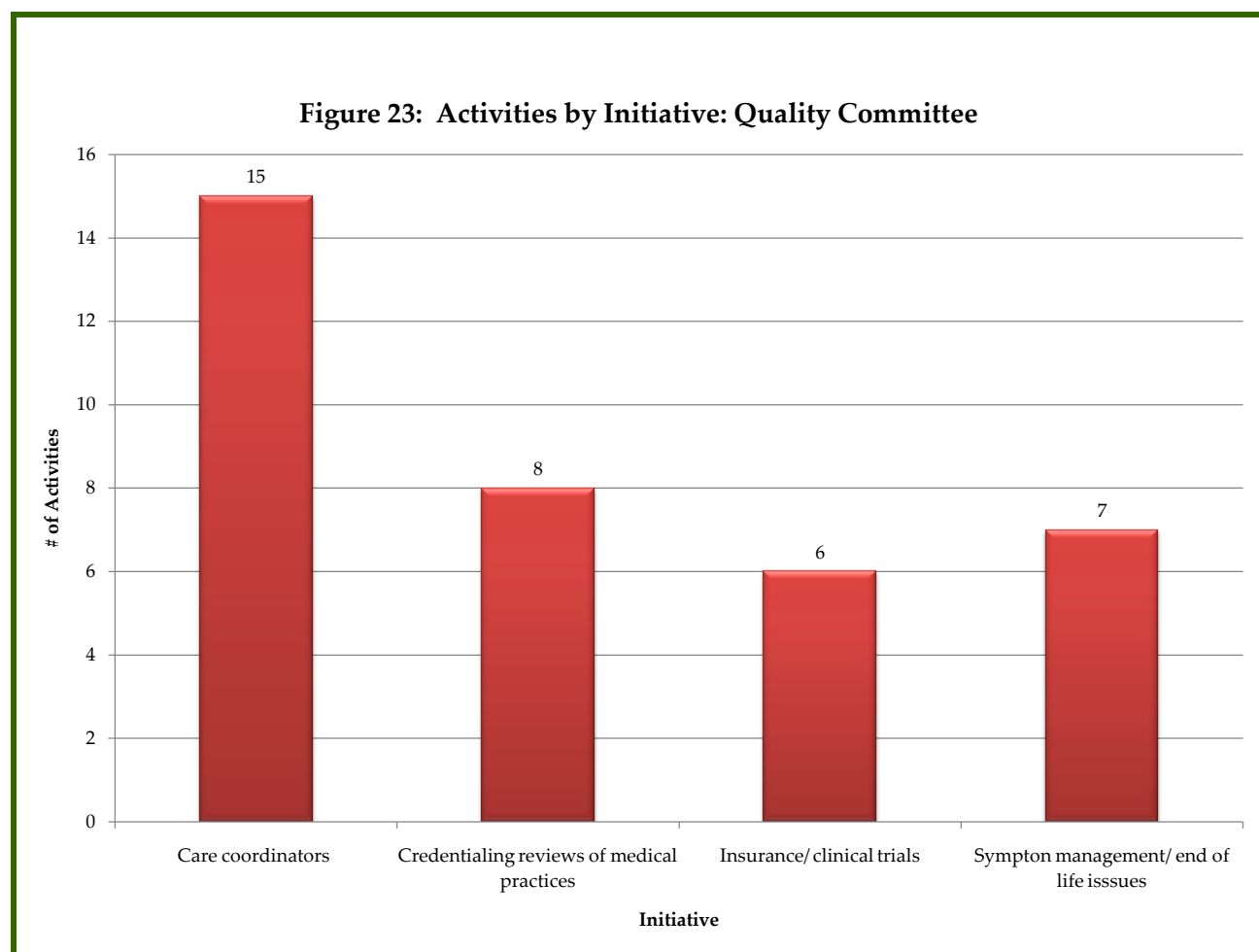
- 1) Provide a care coordinator who is part of a statewide-integrated system to every person diagnosed with cancer in Delaware. Care coordinators will be culturally competent to overcome the language, ethnicity and gender barriers
- 2) Assure insurance coverage for state-of-the-art cancer clinical trials.
- 3) Institute centralized credentialing reviews of medical practices by third-party payors that include cancer screening, prevention, early detection, and treatment practices as well as ongoing provider education.
- 4) Support training for physicians and other health care providers in symptom management and end-of-life care approaches.

These recommendations share a common goal of providing the highest quality of care for every Delawarean with cancer. These recommendations are provided in summary form in the Committee process model in Figure 22.



In addition to these recommendations, The Quality Committee leadership has been involved with the investigation of the data identified as relevant to the *Disparities in Cancer Incidence and Mortality Among Delaware Residents, 1998-2002* Report. Quality Committee and Colorectal Committee leaders reviewed medical charts to understand the cancer registry and epidemiological data, to clarify the basis of the disparity data presented by the Disparities in Cancer Incidence and Mortality Among Delaware Residents, 1998-2002 Report contractor, ORC Macro. (See Disparities Committee, below.) As a matter of committee focus, this task required significant additional attention of the members.

Figure 23 shows the number of activities per initiative (charge) for this Committee, ranging from six to fifteen activities per initiative. With an average of nine activities per initiative, this Committee is more active per initiative than six of the other Committees.



*Management and Leadership:* Aside from the Insurance Committee, the Committee has met the fewest times with seven meetings on record, according to the documentation available. Its attendance, however, has been relatively high at 54%. Interviewees rated this Committee near the cross-Committee average on administration and management and leadership. Responses suggest that while the Committee is “on board with the goals and direction of the leadership” the Committee may not be working to its full potential.

According to respondents, the Committee leadership brought issues to be addressed and made suggestions about how to proceed. Staff added their input, but “real and substantial thought was given to issues by the Committee leadership....”

*Data Development:* This Committee spent a higher percent of its efforts than any other Committee on developing and using data. While there was attention to data across its initiatives, this number may be high because one of its major recommendations (3) focused specifically on the development of data about physician screening practices.

*Program:* The Committee was also rated near the cross-Committee average on satisfaction with progress toward program goals. The simultaneous attention that key members of this Committee devoted to the Disparities treatment data activity may account for the average rating on program progress.

This Committee also needed to revise its strategies to address one of its four major recommendations. The original intent of its third recommendation was to institute centralized credentialing reviews by third party payors. When the Committee met opposition from the insurance provider and the state agency that regulates insurance companies, they developed an alternative approach. They hired a contractor to conduct targeted chart reviews and develop a methodology for gathering data about cancer screening from primary care providers. The credentialing project has been carried over into the Committee’s work plan for the next four years.

Although the fourth charge was not addressed directly, respondents observed that training for care providers in symptom management and end of life approaches is supported informally by this Committee, working through a partner organization that is represented on the Committee to provide access to such training. The focus on standardizing and the development of a credential program for these programs has not been targeted for action as yet.

*Partners:* The Committee was rated above average on partnership effectiveness. However, use of the Committee members was not regarded as strong; one interviewee commented that “some members did not make meaningful contributions to the work of the Committee.” Noting that key member strength may have inhibited partner input at the Committee level, a respondent noted that “A couple of members see things their way based on their institutional interests and are unable to change or move toward the views of others. There is a lot of talent that is not utilized.”

It is interesting to note that the membership roster of this Committee is by far the largest, which may contribute to the relative high percentage of attendance at meetings that are held, as well as the relative few meetings held, if coordinating availability was a factor in holding meetings. The size of the Committee may also have affected the varied level of involvement, as observed by interview respondents, above.

*Communication:* The Committee had a substantial public communication and reporting emphasis, with 16 discrete pieces of marketing collateral developed to support its programs. The Committee also had a publication based on one of its major initiatives, the Care Coordinators program.

## E. Knowledge and Information Committee

Figure 24 shows the process model for this Committee, with abbreviated versions of its five charges indicated in the column on the left. In full, the charges are:

- 1) Initiate and support statewide and district-level school health coordinating councils. The statewide council will serve as a model, resource, and funding vehicle for the district councils.
- 2) Form a statewide, permanent alliance to coordinate and promote public education on cancer.
- 3) Estimate the number of cancers that can be prevented and the number of deaths that can be avoided by primary prevention and early detection. Prioritize our common and preventable cancers.
- 4) Improve the collection and reporting of cancer incidence and mortality data.
- 5) Conduct a survey to examine the importance of past exposure to today's cancer rates.

**Figure 24: Knowledge and Information Committee Process Model**

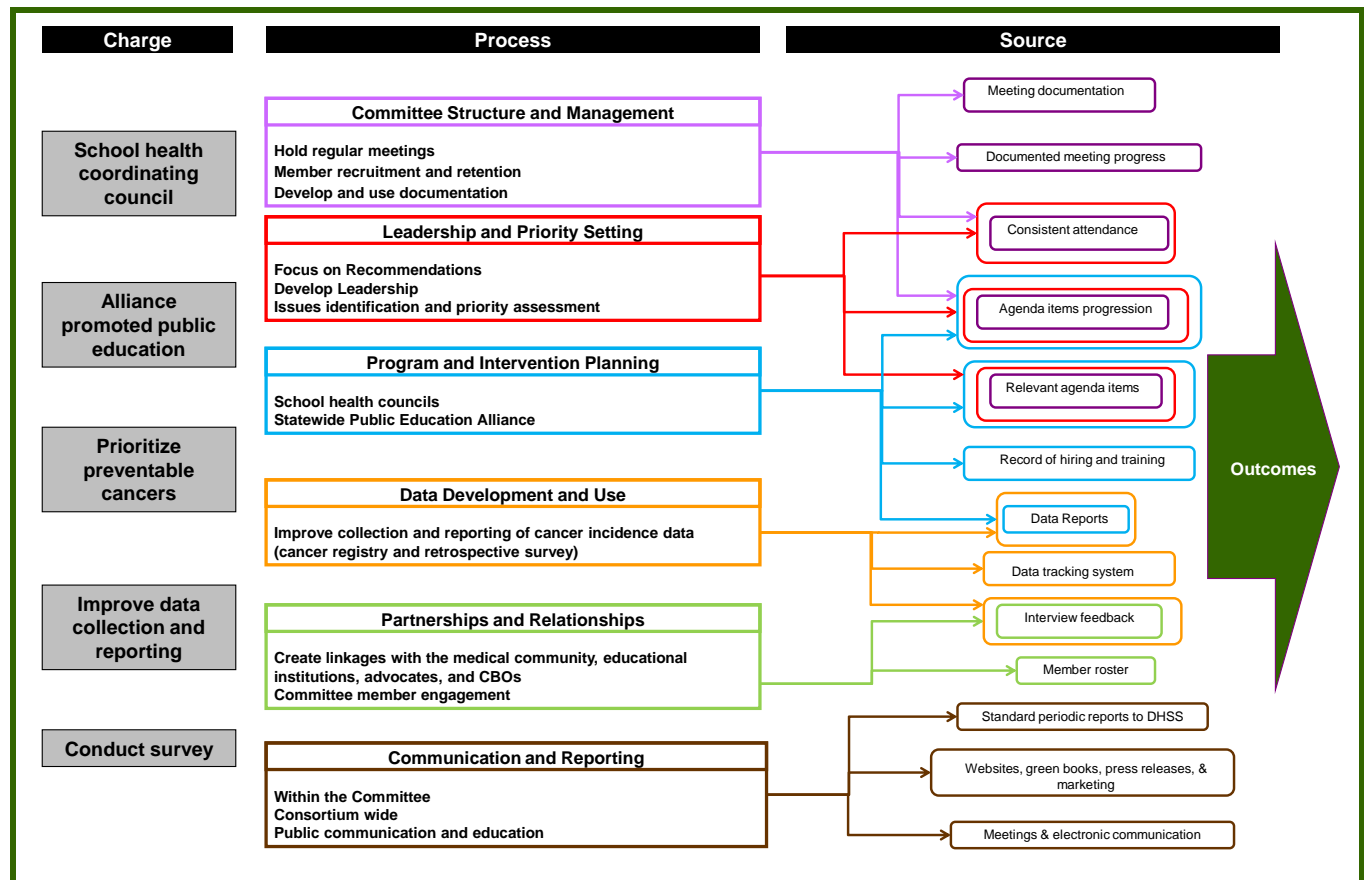
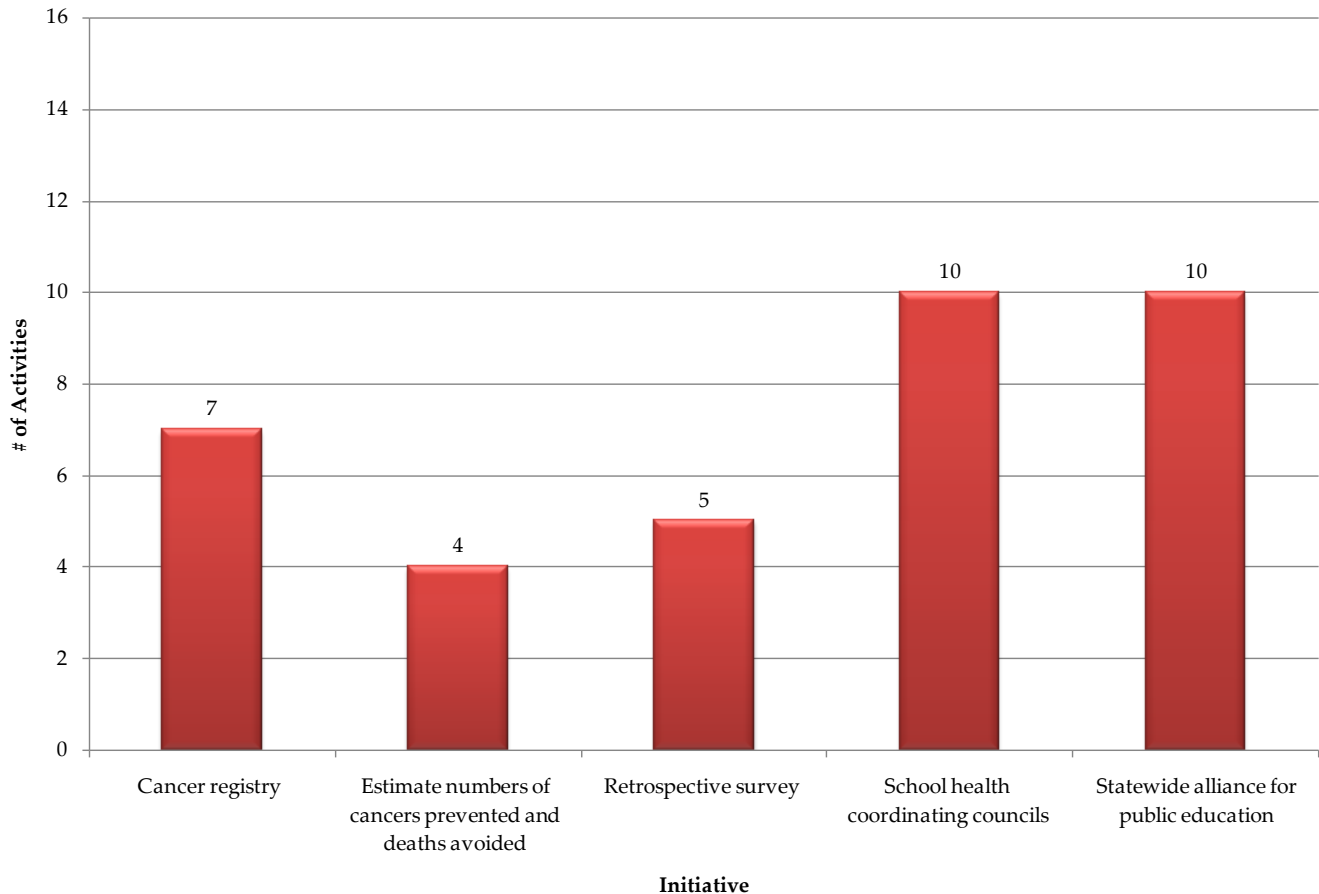


Figure 25 shows the number of activities per initiative (charge) for this Committee, ranging from four to ten activities per initiative. This Committee has been very active, logging a total of thirty-six activities over its life.

**Figure 25: Activities by Initiative: Knowledge & Information Committee**



*Management and Leadership:* The Committee has met sixteen times, on par with other Committees. Its attendance has been below average at 32% across those meetings.

Interviewees rated this Committee the lowest of the six Committees on the effectiveness of its administration and staff support. Leadership and management, satisfaction with progress toward goals and overall partnership development were rated below the cross-Committee average.

This Committee is unique in the structure of the Consortium. In the charge development stage, there were separate Committees: one for Public Awareness and one for Research and Data Analysis. The current Committee represents a merger in September 2003 of what were initially two separate Committees, each of which experienced a transformation, name change and leadership change in May 2003. The current Committee focus is on “Increase Knowledge and Provide Information.” This name reflects another recent shift in emphasis from collecting data to “making sense of the information and translating it into something for people to do,” according to an interviewee.

*Program:* Our review indicates that the Committee has found it hard to harmonize the two discrete elements of its charge: one element—the establishment of *public awareness* through partnership involvement and buy-in to a new organization, either through the Alliance or the school-based

councils—requires skill sets and attention that are more political, organization-building and public relations focused, requiring an external-facing emphasis for the Committee. The emphasis on *data clarity, quality, harmonization* and use is an internal, or research, focus; and requires a different set of skills and capacities.

After this dual role was assigned to the Information Committee, the Advisory Council--with Quality Committee and Colorectal Cancer Committee and Cancer program staff--took on important roles in data quality review and reporting relative to the *Disparities in Cancer Incidence and Mortality Among Delaware Residents, 1998-2002* Report, and the subsequent Council-requested investigation of hospital records to support the report's findings. This took the priority of focusing on data out of the hands of the Information Committee, at least for that period of time. In addition, each Committee was, as a matter of routine, accessing data and developing reporting or access tools as appropriate to their work on their own Committee's charges, as we have noted in this report.

The Committee's priorities, then, were the first two charges, above. Based on observations and leadership comments during Consortium retreats, the Committee established a sequential approach for addressing these two charges. The Committee established the alliance development and public forum as near term goals, and has been working to address those. A milestone was the "Alliance for Public Health Information" Forum in April 2006. Fifty-four of those who attended committed to work actively with the Public Health Alliance.

The Alliance is intended to act as a data and information channel and resource, as well as supporting common action. According to the Chair, "dissemination [through the Alliance] will be a next step. There is still a lot of work to do. We are working with other Committees to ensure that [we] have information available on other Committee initiatives." Once the alliance is fully functioning, there may be additional evidence of public education, communication and outreach.

As to the second charge: the work required to initiate and support statewide and district level school health coordinating councils was "stymied for a while" due to "lack of direction." This recommendation has been revised and, with the alliance underway, the Committee is shifting its emphasis to take action on the development of the school councils.

*Partners:* Although the Committee is to have focused on Knowledge and Information, its prioritized activities were on partnership and common structure development through the Alliance and, incipiently, the school councils.

During the various transitions, "members dropped out and then we picked back up membership with new people." One interviewee noted "there were some questions about the role of the Committee.

*Communication:* The Committee had just 10% of its records coded as having to do with data development and use, the lowest of any Committee. No marketing materials were supplied by the Council's marketing firm, AB&C. This finding supports the observation that the Committee's emphasis was on process and structure development *in order to have a permanent base for developing and sharing knowledge and information*; rather than the development of that knowledge itself. Similarly, the Committee discussion did include focus on the cancer registry, but those conversations often focused

on the *administration and management of the registry* – certifying hospital registrars, enforcement of reporting requirements, staffing the registry – which were not coded in the data development and use category, although they are important parts of the infrastructure that assure appropriate and comprehensive surveillance.

While the Committee shows evidence of progress on some of its recommendations, it has struggled to clarify the issues with which it is charged and to achieve the best Committee structure and staffing and membership configuration to support those recommendations. Interview respondents weighed in about the structure of this Committee, indicating that “...many thought that [Data] should be a thread throughout all of the Committees.”

The Council has also formed a separate Committee to look particularly at data quality to address its charge related to estimating the effects of primary prevention and early detection. This shift harkens back to the original structure, which held one Committee responsible for education and awareness and a separate Committee responsible for research and data.

## F. Environment Committee

The Environment Committee's process model is displayed in Figure 26.

The Environment Committee was charged with three recommendations:

- 1) Reduce exposure to carcinogenic substances in the ambient environment.
- 2) Coordinate with OSHA to reduce workplace carcinogenic risk and exposure.
- 3) Reduce exposure to carcinogens in the indoor environment.

**Figure 26: Environment Committee Process Model**

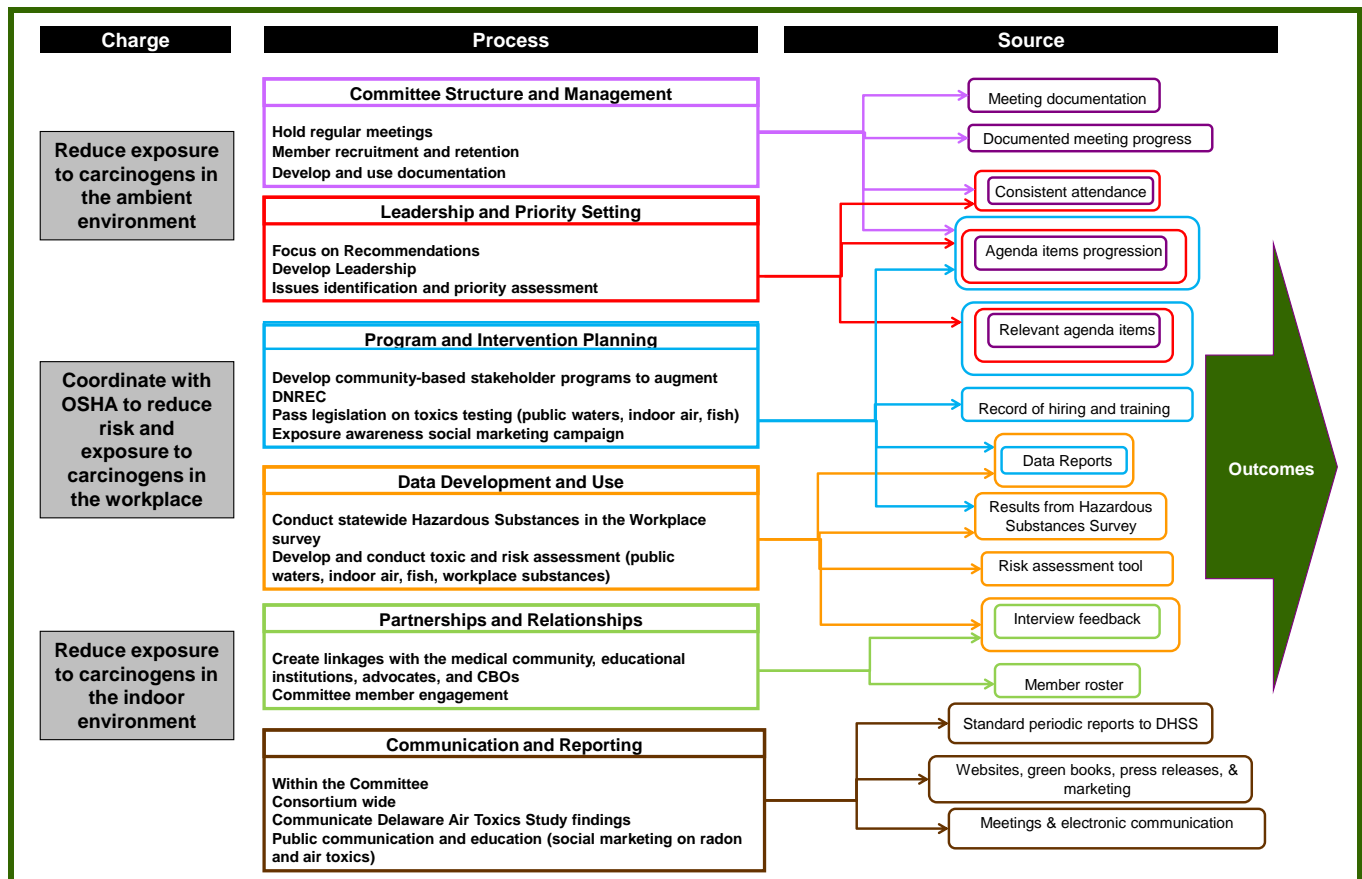
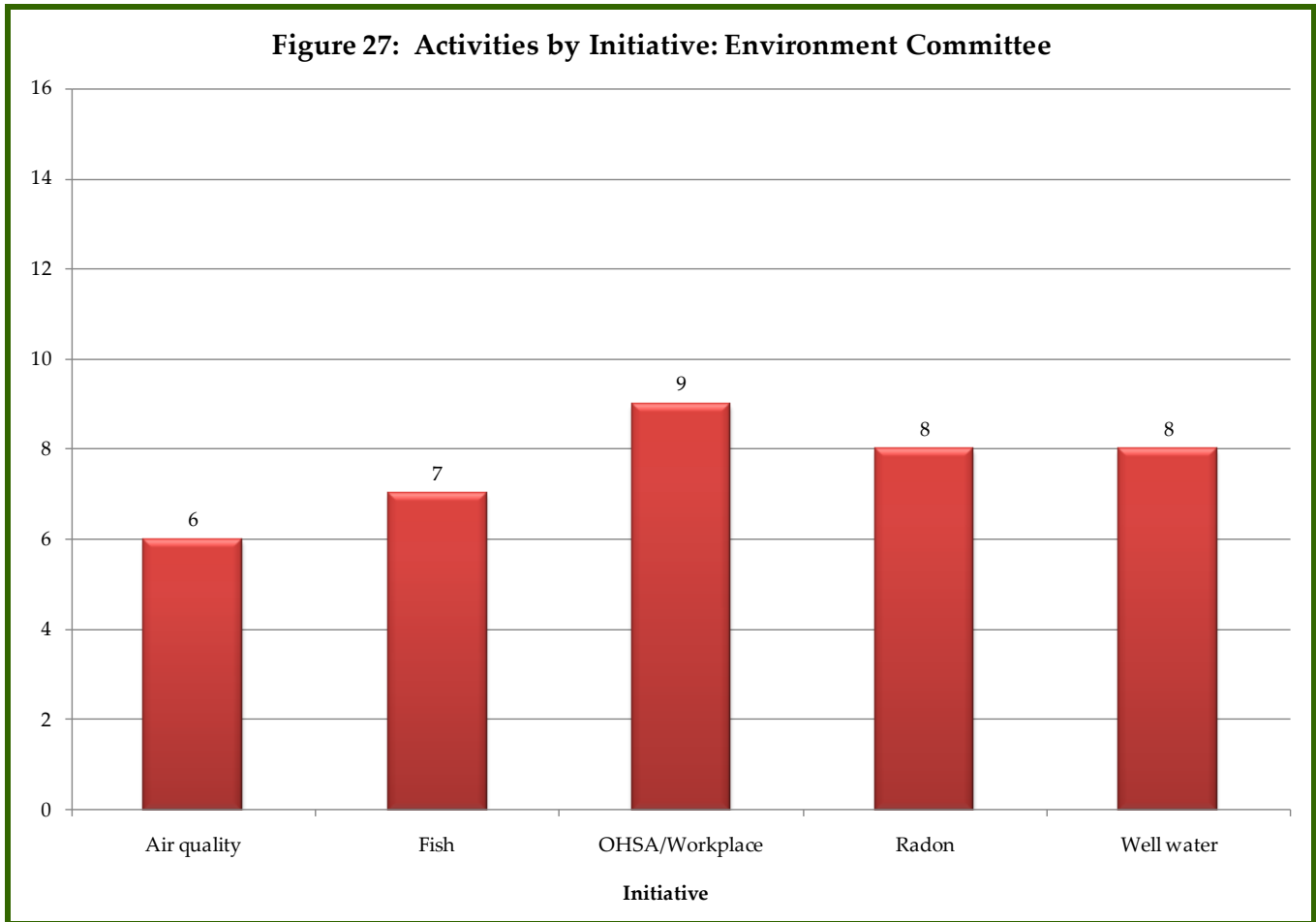


Figure 27 below, shows that the Committee engaged in thirty-eight activities to address all of the three charges. The document review shows evidence of steady progress on each of the initiatives over time. The five initiatives noted in Figure 27 addressed the three charges listed above. More specifically, water, fish and air quality addressed the charge of reducing exposure in the ambient environment; radon and air quality initiatives address the charge of reducing exposure indoors, and OSHA/Workplace initiatives address the charge of reducing workplace risk and exposure.



**Figure 27: Activities by Initiative: Environment Committee**



*Management and Leadership:* The Committee met sixteen times, which is on par with other Committees. Its members maintained an average attendance of 35%, lower than the cross-Committee average. Interviewees rated effectiveness of administration and management of the Committees as slightly below the cross Committee average. Leadership effectiveness was rated slightly above the cross Committee average.

*Program:* As mentioned above, the Committee undertook three distinctly different topic foci (air quality, fish monitoring and well water) to address the first recommendation to reduce exposure to carcinogenic substances in the ambient environment. Data shows five initiatives, to indicate that work plan revision. The Committee has an average of 6.7 activities across its five topical initiatives, which is near the cross-Committee average. Interviewees rated satisfaction with program progress as slightly lower than the cross-Committee average. This may be indicative of the extension of the scope of the Committee's work, which may not have been obvious to the Council members who took part in the interviews.

The decision of the Committee to parse the first recommendation required, in essence, three different topical foci for investigation. The Committee work was "in progress" for much of the period under review, rather than "in action" in a way that might be evidenced by products or events, as other Committees may have developed.

*Data Development and Use:* As Figure 11 (Percent of Discussion Items Focused in Data Development and Use, by Committee) indicates, the Environment Committee focused on data development and use more often than most Committees; much of that discussion focused on information gathering about exposure to carcinogens in the ambient environment, including data collection efforts for all three areas of inquiry. These observations bear out the sense of the Committee, that more focused design to fulfill the charges, more targeted data collection and harmonization, and more public information materials development was necessary to make progress on the Committee's charges.

*Partners:* Satisfaction with partnership effectiveness was also rated slightly lower than average. On particular dimensions of partnership, interviewees are satisfied with the involvement of some partners, including DNREC and the medical community, but noted that they have struggled to engage community based and advocacy organizations. We've "tried to get outside advocacy groups to get involved. They are reluctant. I'd like to see improvement in this area."

*Communication:* Council records do not indicate as many reports from the Environment Committee as from the other Committees. In terms of public communication and outreach, the Committee embarked on a significant public awareness campaign to reduce exposure to carcinogens in the indoor environment (Recommendation 3), through which six pieces of marketing collateral were developed.

*Staff:* Interviewees expressed concern with the effectiveness of Committee support they have received, referencing staff turnover and the "ad hoc" nature of support. Parenthetically, the list of staff and contractors associated with this Committee is at least twice as numerous as any other committee, but consistent attendance or assignment of responsibility for the Committee is hard to assess. A contractor dedicated to staff support for this Committee was added in early 2007, which Committee members are hopeful will provide a needed level of consistent, effective support.

## G. Disparities Committee

The process model for the Disparities Committee is displayed in Figure 28.

The Disparities Committee had one recommendation:

- Compile and analyze existing data on health disparities and cancer into a report, and inform through a public education campaign.”

**Figure 28: Disparities Committee Process Model**

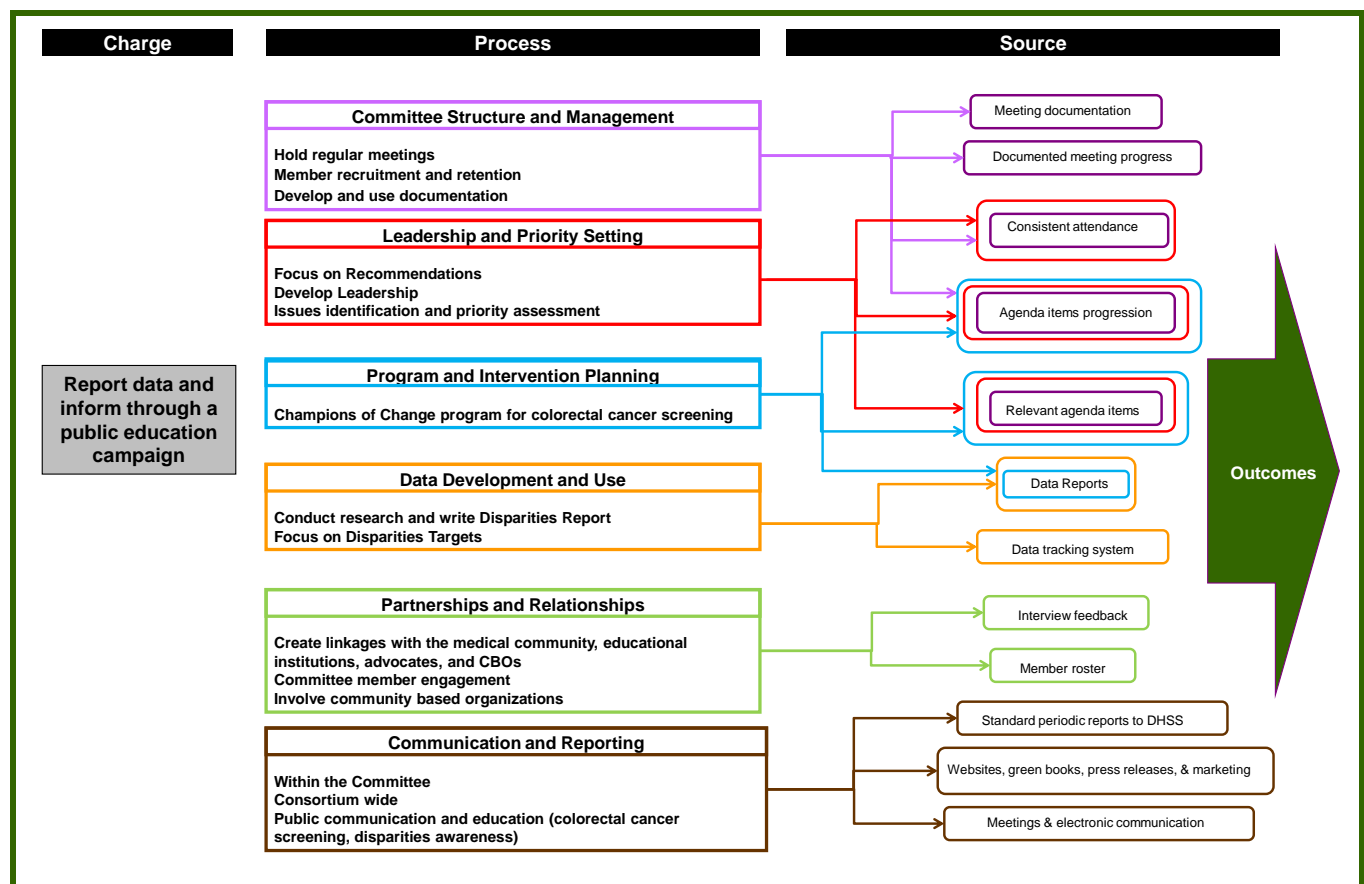
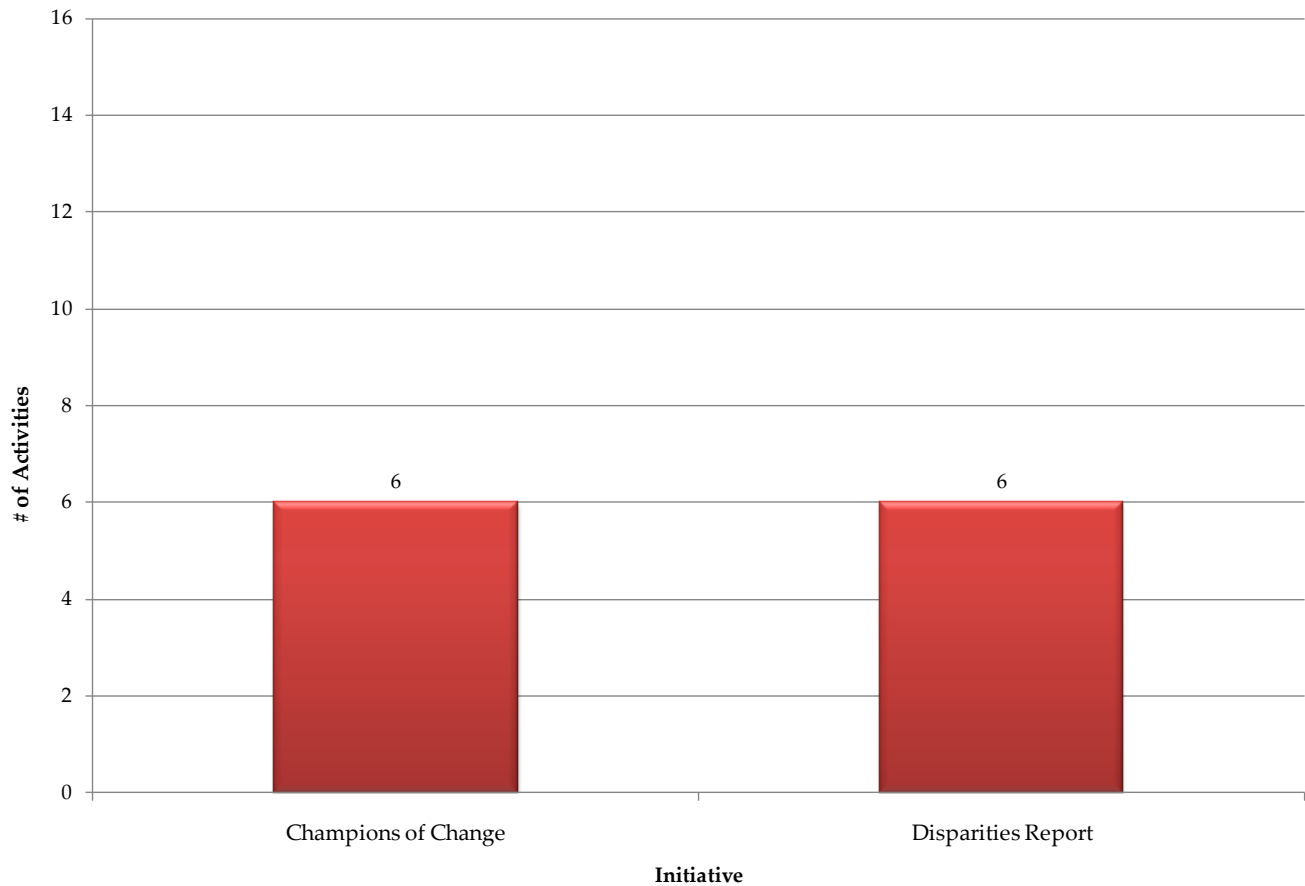


Figure 29 shows that there were six committee activities associated with this charge. In addition, the Disparities Committee worked closely with the Colorectal Committee for about six months. Through that collaboration, they became very involved with the Champions of Change program. Their discussions included six activities related to that initiative. Aside from the focus on initiatives, much of their discussion focused on internal issues to do with Committee structure, defining their goals and recruiting members.

**Figure 29: Activities by Initiative: Disparities Committee**



*Management and Leadership:* Including a number of joint meetings with the Colorectal Committee, the Disparities Committee met sixteen times, which was the typical number of meetings for a Committee.. Disparities Committee attendance was 32% across meetings, the lowest of the Committees.

Interviewees rated the Committee's administration and management, and leadership, below the cross Committee average. Interviewees rated their satisfaction with the Disparities Committee progress the lowest across Committees. Respondents noted that reasons for delay in Committee progress were often outside the control of the Committee.

These ratings reflect several challenges the Disparities Committee faced. Tracing back to the founding conceptual framework for the Committee structure, the Disparities Committee is unique among the Committees. Other Committees were assigned territories or clusters that emerged on the map, as illustrated in Appendix 1. Concept map clusters represent a set of ideas that stakeholders thought were conceptually similar and thus belonged together, enabling the development of a targeted action agenda on each topic.

Disparities issues did not emerge as a separate cluster. Instead, disparities ideas emerged across the map, reflecting the integrated and pervasive nature of these issues. The conceptual framework showed

concerns regarding disparities as connected to data, insurance and access, public information and other territories that then became the basic Committee structure. In fact, the leadership group of the original Advisory Council urged each planning subcommittee to take disparities into account in its priority development. However, to ensure that the issues were not lost in content discussions across the map, a separate Disparities Committee was established. The intent was to ensure that disparities, an area of central concern to the Consortium, received due attention.

The conceptual framework highlights one of the key challenges that the Committee faced. Reducing health disparities is an issue that is broadly systemic and pervasive and cuts across all areas of society. “No one has figured this out,” according to one respondent. In the arena of health disparities, there exist innumerable initiatives and efforts, but very few evidence-based or tested models to build upon.

*Program:* A major undertaking of the Disparities Committee was the commissioning and oversight of a report on cancer-related disparities in Delaware. There were a number of difficulties with this project, including questions about the methodology, the quality of the data and delays in data collection. The Consortium’s appropriate focus on the ***Disparities in Cancer Incidence and Mortality Among Delaware Residents, 1998-2002*** Report had a significant impact not only on the work of the Disparities Committee, but also on the Council and other Committees. In particular, at the request of the Advisory Council, Quality Committee and CRC members assisted in an additional intensive round of data collection involving chart reviews at hospitals, to assess the accuracy of the assertions made in the Disparities Report.

*Data Development and Use:* The release of the contracted Disparities Report was delayed in order to gather and assess the additional information, and to address some of the issues that the report raised in terms of population-specific risk rates in Delaware. Interviewee comments indicated that this report has not been officially released by DPH, although it has been received by the Disparities Committee.

*Partners:* Partnership effectiveness was rated low by respondents to the interview. The membership in the Disparities Committee has changed twice, to try to ensure that key communities of interest and resources are involved in the work of the Committee. Since the membership recruitment coincided with the Disparities Report issues described above, the Committee was not able to coalesce around its charge. According to interview input, this resulted in the Committee’s not using the contributions of its members effectively.

Interviewee comments and observations of the Committee summarize some of the key issues that emerged with the Disparities Committee. One interviewee noted difficulties with Committees “when we didn’t have a purpose for their time”, as the Committee waited for the Disparities Report to be finalized. Another said, “[I’m] not sure that the vision was accurate or well thought out from the beginning...The lack of clarity about vision contributed to turnover in Committee membership.”

Respondents expressed agreement on the need for the issues related to health disparities and cancer to be addressed. But one respondent pointed to clarity of purpose, and how it might be achieved: “We need to re-visit and fine tune our goals. I believe that the Disparities Committee needs to have a level of oversight or integration with all of the other Committees in order for this Committee and the others

to achieve [success].” Lack of goal clarity has led to difficulty in engaging Committee members: “One of the problems we’ve had is getting people to be committed.”

*Staff:* Staff turnover was also noted as a concern. The Division used several approaches to staffing, including Cancer program staffing, other DPH staffing and contractor staffing. No combination was satisfactory, given the needs of the Committee.

An additional structural question emerged, relevant to the development and encouragement of partners in contributing: interviewees suggested that “Committees should not be chaired by an elected official.” The perception of a power differential may cause “creativity, innovation, and healthy disagreements [to be] stifled.” Respondents felt that the intention to “send a signal” regarding the importance of this critical issue is an important position for the Consortium to take, but it may not be served in this way.

## H. *Advisory Council*

The Advisory Council is the managing group of the Consortium, linking the Committees and their work plans to the stated objectives, and providing an ongoing structure for planning, revising, and reporting on progress related to each Committee's charges. The members of the Advisory Council are the Chairs of each Committee, key representatives of other government partners, physicians with relevant knowledge and representatives of a Hospital Cancer Center. They were expected to represent their own Committee as appropriate, to provide guidance for all Committees and to contribute to the overall functioning and progress recognition of the Consortium at large. The members of the Advisory Council are noted in Appendix 2.

In this section, we discuss primarily the Advisory Council's role as the oversight and management group of volunteers, who work most closely with the Division of Public Health. Because we have discussed the Consortium at large in the early part of this report, we focus on the management role.

*Management and Leadership:* The key responsibilities of the Advisory Council include timely reporting from each Committee, ensuring that Committees were informed of the work of the other Committees, acting as the planning and management body for the Consortium and acting as conduit to the internal (Division, Department, Legislature and Executive) and external (partners, the public) audiences. The Consortium process model (Figure 1) describes the territory over which the Advisory Council has responsibility.

In general, the Council is a good working structure to support and harmonize the work of the Committees according to respondents' input. The Council also conducted two mid-course retreats, enabling a review and reconsideration of the work of the Committees. The Council approved or accepted recommendations from the Committees, and coordinated the "Green Book" Report with the Division of Public Health.

The Council as a Committee of the whole took an active role in the further investigation of data relevant to the *Disparities in Cancer Incidence and Mortality Among Delaware Residents, 1998-2002* Report. At the same time that the Council leadership was working to ensure that the secondary data collection and analysis took place, the Council was also supporting the work of the Committees at large. A perception was expressed in the interview process that the Disparities report and its fallout consumed a great deal of Council focus in a way that was unplanned, and, therefore, not adjusted for.

The Council has led the Consortium through its "growing pains," as one interviewee noted, and has maintained steady membership and attendance. Members who are not Committee Chairs are ex officio voting members representing state departments or legislature; or leadership from large provider hospitals or centers. Feedback from the interviews indicates a high degree of collaboration based on the strong leadership agenda established and agreed to early on. The Advisory Council membership has remained the same since the establishment of the Consortium.

## **XI. Observations and Recommendations**

The Cancer Consortium has made progress in all areas described in the initial planning and prioritizing documents (2001-2002). The Consortium and its Committee structure enabled focused work on all fronts simultaneously during the first three years of the Consortium, while the leadership and structure in evidence at the Council as the management group of the Consortium ensured collaboration, currency of information, cross-Committee contributions and support.

In some cases, the progress has been remarkable and Delaware's efforts are viewed as model programs by others. With the Committee structure working well, on balance, from its inception, the sum of the Committees' efforts shows noticeable progress in the development and implementation of key programs and initiatives.

When asked in 2006 what the biggest challenge the Consortium faced in Year 4, Consortium members identified the seven items; four are relevant to the process we discuss in this report. They are

- Showing tangible results with data collection and evaluation
- Ensuring that the work continues under a new administration
- Maintaining momentum, impact and member activity
- Dealing with bureaucratic barriers to progress.

The following are recommendations that correspond to each of the process model areas of interest to the Consortium in general. If taken into account, they can help address the issues mentioned above, and others of importance at this time. Although generally framed as recommendations for the system of the Consortium, these recommendations are useful for each Committee to consider, as appropriate to each. Conversely, certain recommendations emerge based on the experience of a particular Committee, but the value of the recommendation is in its application to the system of the Consortium and its related Committees.

### ***A. Management and Leadership***

We have discussed management elements at each of the sections above. Leadership of the Consortium—primarily through the Advisory Council--was considered one of its strongest characteristics. The Chairman received consistently high marks, and positive comments regarding his commitment and ability to keep the purposes of the Consortium at the forefront. "These people came from different perspectives and have consistently decided in favor of the good of the Consortium and public rather than their own agenda," noted one respondent. Referencing the interest in partnership, this comment also illuminates the focus and approach of the leadership of the Consortium.

One interviewee also spoke about the importance of receiving national recognition that demonstrates that Delaware – and the Consortium as a whole – are national leaders on the issues of cancer control and prevention. "They [the leaders] make a point of acknowledging the national recognition this group is getting – that they're different – and that recognition fuels them. When they see that the treatment program is given national recognition or the CDC person says they take the Delaware plan everywhere they go with them to show others the way to do these things or the Governor gets and



aware for the program....it doesn't hurt to have the recognition this group has gotten from the outside." Similarly, Consortium members compare their accomplishments to national and regional standards. The Chair of the Colorectal Committee noted, for instance that as of 2005 "Delaware had climbed to the 4<sup>th</sup> highest CRC screening in the U.S." and hopes to go to #1. Another Committee member said "Delaware is a national model for how to do cancer control."

It was noted that the leadership of the Consortium, including but not limited to the Chair, was consistently able to engage others in the mission of the Consortium. Considering the concept of innovation as a stated desire, it was observed that, although the leadership supported and in fact modeled innovation—as one member said, "He doesn't just *allow* us to think about things differently, he *requires* it"--it was difficult to for the Consortium to act on the commitment to innovation.

We have no specific recommendations for the current leadership. We address the issue of building leaders through partnership and strategic recruitment and succession policies, below.

### **B. Administration: Standardization**

Looking ahead to key milestones in the Consortium's work plan, we consider the value of being able to report, with certainty and with relative ease of data collection, the progress and achievements of the Consortium and its Committees. This suggests that a systematic way of developing and managing Consortium and Committee records would be useful. The Consortium staff currently supports the Committees by posting materials to the Consortium website, but, evidence suggests that committee documents are maintained in different formats and by individuals in different roles from committee to committee.

We recommend that standard documentation be maintained within each Committee, and across Committees. This documentation includes meeting agendas, meeting minutes and attendance records, as well as the manner in which supporting documentation is referenced and maintained for access.

Minutes and attendance records in particular are important to enabling the Consortium to assess its continuing progress, both on its priorities and in engaging communities of interest as partners. Many appropriate models exist, that can be adapted for the Consortium's needs.

Considering the typical schedule of meetings (see below), it is particularly recommended that a standardized system of communication to Committee members be established and maintained as part of the documentation for each Committee.

Clarity and standardization of reporting systems can only serve to support the high opinion members and others have of the work of the Consortium, and can certainly aid in the recruitment of new members, as well as facilitating the important public communication focus of the Consortium as it moves into the next four years.

### *C. Meetings and Attendance*

The overall plan of bimonthly meetings for Committees, alternating with Council meetings, has worked fairly well, according to those who took part in the interviews, and based on the meeting schedule data. Most Committees met between fifteen and nineteen times, out of the twenty anticipated if all Committees were meeting bi-monthly. Committees who met more frequently did not necessarily meet bimonthly; but rather met when the work of the Committee required intensive attention. This sense of flexibility and responsiveness is a characteristic of the Consortium structure in general, and can work well, provided that the Committee members who are not Advisory Council members are supported in their efforts to be involved in the work of the Committees between Committee meetings.

It will be useful for the Consortium to state specifically the minimum expected number of meetings that every Committee should hold, and refine the meeting schedule to encourage each Committee to hold a specific number of meetings. This is not merely for the sake of holding meetings themselves, but to enable the Committees to regularize their agendas; and the benefit for the Staff is the ability to plan more systematically to support the Committees. The Consortium may consider a reasonable number of meetings, based on the agenda at hand and the typical meeting patterns presented in this evaluation; and may leave the determination as to which meetings are cancelled in the hands of the Committee Chair, based on the work flow and availability of members. As they do now, Committee Chairs can use discretion as to the question of canceling a scheduled meeting or postponing, provided that the Committee is able to meet the standard that the Consortium will have defined. With a schedule of bi-monthly meetings, it is easy to lose momentum if a meeting is skipped, causing a four month lull between meetings. This is particularly relevant for Committee members who are not Chairpersons, and it is directly related to the emphasis that the Consortium has placed on building and maintaining partnerships.

Relatedly, the results suggest the need to review and adapt standards or expectations about the quorum required for decision-making. We describe above the number of meetings held; but we note that average meeting attendance is 44%, with the range being from 32% attendance to 60%. For some committees, the average meeting attendance is consistently below 40%. This may indicate that the schedule discussed above, which seems to permit the meetings to be held, is harder for participants to accommodate than the meeting numbers indicate. If the current level of active participation is acceptable to the Consortium, the current structure may continue to serve.

Attendance may be underestimated here due to inconsistencies in reporting. Nevertheless, the Advisory Council, with support from the Division staff, should discuss and determine

- if a quorum has been the expected norm thus far, and how that has been communicated;
- if a quorum is desired or necessary for each Committee and for the Advisory Council; and
- what the numeric determinant would be to establish the quorum.

Considering, again, the key theme of partnership development, and taking into account the value of retention and recruitment of desirable committee participants to longer-term partnership development, the combination of schedule issues and clarity regarding roles should be considered. We discuss these issues, below.

#### *D. Member Retention, Recruitment, and Succession*

It is notable that, while the Committees have been functioning over a number of years, there has not been an overall decline in attendance for most Committees, suggesting a good degree of sustainability. Many initiatives begin with high energy and enthusiasm, but wither over time as the work continues and easier goals are achieved, leaving more difficult challenges still remaining. Yet, this effort continues at a steady pace.

Congruent with the high commitment of key individuals associated with the initiative, there has been relatively little turnover for the Consortium leadership as a whole, with 15 of its original members still serving.

Committee membership has fluctuated somewhat in certain Committees; notably, to accommodate the change in focus of the Disparities Committee, the group membership was revised and expanded at least once during the period in question. The Information Committee also experienced turnover in membership.

Nevertheless, retention to the majority of Committees, and to the Advisory Council, is basically steady. The commitment of members both as professionals and as individuals has established the expectation of continued involvement. Such commitment, especially when coupled with the evidence of progress and organizationally appropriate systems, indicates that this approach has worked well for the Consortium.

However, the Consortium understands the need to establish recruitment, rotation and succession plans for members. As a permanent organization, the Consortium's future leadership will be found within the current membership in the short term. But in the long term, the need to encourage membership with the specific expectation of "raising" leaders is important. The current level of retention itself can be thought of as an indicator of lack of recruitment efforts, or planning for new membership and leader succession.

Recruitment to Committees to supplement or replace long-term members is an important element for planning, as it will affect the level of knowledge that members have; and may affect the priorities that Committees choose to address over time. Timing, overlap of committee members, and preparation to serve are all key issues here.

Succession planning for both formal and informal leadership is also necessary for the Council to consider. Recruitment and succession are important and useful tools when considered as part of a sustainable plan for an organization. In the case of the Consortium, whose stated approach is to ensure the development of strong partnerships and involvement of communities of interest in its work, these elements are critical.

To support both the recruitment of new members and the development of a common set of operational standards and procedures, we recommend the development of an orientation process, an informative set of materials, and a regular schedule for conducting the orientation. With low turnover, it has not

been a priority in the early years of the Consortium. This longevity of most members, though, may make the creation of an orientation even more important to give new members the necessary background as they join groups that have well-established norms and a substantial shared history.

The care with which new members are selected, and the support that individuals, senior or new, receive as Committee members, are critical hallmarks in the sustainability of the Consortium structure. Standardizing orientation is an important component. Equally important are the following:

- Deliberate and well-researched selection of individuals to serve on certain Committees
- Clarity regarding the roles of Committee members in relation to a Committee's charge[s]
- A system of communication that is both normalized and flexible, enabling the Chairs and staff of each Committee to communicate effectively with its members
- Work plans and agendas that take into account the qualities and potential contributions of the members
- Between-meeting communication or support for Committee members not involved with the Advisory Council

### *E. Staffing Support*

Staffing an endeavor like the Consortium poses unique challenges. With seven Committees addressing, at one time or another, a total of twenty-five high-level recommendations, the burden of management is fairly complex. The document review counted a total of one-hundred ninety-two activities launched by the Committees to address the range of recommendations. Each substantial effort of the Consortium requires data to support evidence-based decision-making. The scope of the Consortium's effort places heavy, steady demands on staff. The needs of the Advisory Council itself differ from those of each of the Committees, and Committees differ from one to another regarding the style and expectations of the leadership, planning and Committee management styles and processes, and so on.

Staff leadership must be continually and intimately connected to the Consortium, anticipating possible stumbling blocks and staying one step ahead of the Committees. Staff members interviewed related the staff perspective, that they have faced some challenges in helping Committees remain stable and productive. Recognizing the intense level of oversight required, we recommend that the Division and the Advisory Council conduct a workload analysis for two or three Committees, to assess the general burden, and, coupled with the experiential feedback that key staff such as Alisa Olshefsky, Amy Renninger and Jill Rogers can provide, develop an estimate of burden going forward. Looking ahead to the work plan described in the "Purple Book", which includes a certain degree of Committee reconfiguration, the Staff and the Advisory Council may develop staffing projections that will enable the appropriate level of internal staffing, and will enable the development and harmonization standard tools for Consortium management.

It is generally recognized that the staff support provided the Consortium at large, and certain Committees in particular, is very strong and consistently reliable. Thinking ahead to the next plan phase, we recommend that the Consortium support the staff in standardizing and harmonizing processes, communications and Committee infrastructure to the degree possible and useful. This would include standardizing the formats of Committee documentation, as above. It would also

include the development of a core set of information both for new member orientation and for support of the work of the Committees. In its early maturity, the organization is in a good position to do these tasks.

Reviewing the staffing feedback for each Committee leads us to recommend that, to the degree possible and useful, Committee staffing for routine meetings, document preparation and dissemination, and communication be managed directly through DPH rather than via outside contractors. A key value of staffing the Consortium internally within DPH is that the elements that are logically connected from Committee to Committee, or from time to time, are more easily linked and supported because they are in the hands of one office. Upon development of a standard for Committee activity and meetings documentation, managing from one locus will enable consistency and efficiency going forward. This recommendation may be affected by the sources or kinds of resources available to staff each Committee, so this will need to be taken into account. If outside contractors are used, they should be oriented to the standard processes, document templates and tools of the Consortium.

If the Division determines that engaging external support for staffing certain committees is necessary or useful, we recommend that a contractor orientation with clear formats, guidelines and reporting plan be put into place.

#### *F. Data Development and Use*

A key aspect of the culture of the Consortium is its emphasis on data to guide decision-making. Often the data doesn't exist and studies must be conducted, or approaches to collecting or measuring key decision-making elements must be created. As one interviewee put it, "One ground rule is: we were going to use data where it existed and put mechanisms in place to collect data to answer those questions for which we didn't have data. When we come to something that hasn't been solved or where data is not available, we get it."

Looking forward to the next work plan, one respondent commented that "...DPH needs to take it to another level of depth with the data, to peel another layer of the onion to get at the real context, and potential best data to support the implementation, as well as [have data to] evaluate to adjust the [Consortium's] programs. "

The Committees, by and large, took to heart the priority of using and developing data in their deliberations. An average of 25% of Committee-related efforts focused on developing and using data, although there was considerable variety in Committees' attention to this matter. This might be explained by the presence or quality of existing data. For instance, 40% of the attention to Environment Committee's charges focused on this aspect of process. This may mean that there was very little existing data about such issues as the presence of carcinogens in the ambient environment, or indoor air quality or even OSHA/workplace standards. As such, simply filling this gap and establishing surveillance on those topics would constitute a major accomplishment.

One discovery that emerged through this process is that while the theory of data-driven, evidence-based decision-making is admirable, it is much more difficult in practice. In general, the Consortium has done remarkably well on this focus, as suggested by both the attention paid to in their deliberations

and the ratings by interviewees. However, in many cases the data didn't exist in usable form. The Consortium has brought to the fore the need for consistent, high quality data that is usable for decision-making. We assume that the Committees will continue to identify needed data, and the Staff will either assist in providing it or support the Committees in developing it.

One key member of a data-centric Committee believes: "Data should come from staffers being thoughtful, analytic, and eager to set up additional data collection and analysis techniques." This seems to indicate that the development and translation of data should rest primarily in the hands of the Staff. It is not clear that this expectation is articulated or shared across all Committees. It will be useful for the Advisory Council to consider what its expectation will be in this regard, and articulate who is responsible for the development and availability of data for cancer control decision-making.

### *G. Partnerships*

In addition to the Consortium's commitment to use or develop data for its decision-making and to ensure that programs they develop are responsive to documented needs, the Consortium articulated a high expectation regarding partnerships and the engagement of non-traditional partners in the work of the Committees. We find that, by and large, the Consortium and its Committees have been successful in involving and getting commitment from parties in the medical community, other public sector entities and some key non-governmental organizations. Although the Disparities Committee, among others, actively recruited representation and involvement from community based organizations and programs whose focus is in the underserved communities of the State, involvement of non-traditional partners has not reached its expected level at this time. It is also noted that the university and academic community is under-represented for the purposes at hand, as is the public education system. Groups that would be considered traditional business community representatives--merchants or employers, or business community representatives—are not well represented in the Consortium. This is of particular interest in light of specific recommendations that involve those groups such as the Tobacco Committee's charge to ensure the adopting the CDC's model curriculum and the other charges related to provider education. Non-traditional partners have not been uniformly identified and included.

Another key dimension of the culture of the groups is that individual agencies must leave behind their own individual solutions to work together toward shared solutions; this is an artifact of the Consortium's articulated commitment to partnership development and use. Several interviewees commented on the need to fully engage members as partners in action. "When we established the Consortium, we told partners: you have to buy into the Green Book, AND tell us what you will do to help implement objectives. That piece of the mission has been lost. That speaks to the common level of commitment. As a result, the expectation is that the Division will carry out those responsibilities, not other [member or partner] organizations."

The roles and purposes of partners were not consistently articulated, it seems, and differed in practice across Committees. A Committee member who represents a community based organization observed, "We were not involved as "worker bees" and I consider this a shortcoming. The DPH staff did everything and we were not asked to use our skills or participate in projects. I think that the staff wanted it that way so that they could control the projects. But people want to do more than just attend



meetings.” Another interviewee tempered this criticism by noting the positions some members hold, which both argue for their continued involvement and point to the need for different roles to be recognized and taken into account: “We have not captured the idea of [balance]--of getting the full team engaged. It’s not possible to call a senator and ask where they were for a meeting.”

Although the Council did a good job of getting agreement of members to focus on the needs of the whole effort rather than their own, some member organizations are seen as more self-serving than others. To address this, “We have to look closely again at processes through which we encourage people to work together; [then] consider, and articulate, formalize [processes] as needed,” according to one respondent.

We recommend that the Consortium conduct a focused discussion involving the Advisory Council, staff and selected Committee members to discuss specifically the value of partnerships, the roles of partners and the logic of engaging partners from different interest group areas, in addition to those represented. The Advisory Council may develop a work plan with advisors and staff to target specific partners for certain areas where input would be most welcome and useful. Revisiting the strategy of partnership development, and developing tactics for engaging partners and using their capacities and contributions, would also enable the Consortium and staff to address the problem of partners advising, but not doing. This is in keeping with our recommendation to determine, for each Committee, what is actually expected of the Committee members based on Committee charges and associated activities, and create work plans accordingly. Members are eager to assist, and provide a wealth of knowledge, skill, connection and good will, that should be taken advantage of.

## ***H. Communication and Reporting***

Given the high quality and productivity of the Consortium’s work, it is surprising that we have a record of only nine press releases. Most Committees had developed one press release. The Consortium is clearly investing in marketing through AB&C, for public outreach, communication and education. Committees may be underutilizing the press in getting out the word on their many activities. We did not find significant indications that the Consortium has involved the media directly as a part of their partnership. Including a science writer from private media might be a way to take better advantage of relatively low-cost ways to keep the efforts of the Consortium in the public’s eye and awareness. One interviewee reflected that “the media outlets have not completely understood the efforts and results.”

Relatedly, the document review shows six articles or publications that have arisen from the work of the Consortium. Publication demonstrates leadership in innovation, evidence-based decision-making and dissemination, and, as the work of the Committees matures, may become a productive communication strategy.

The major tools for public communication have been the “Green Book” series, as well as the Consortium website. AB&C has been working with most, if not all, Committees to develop public-facing instruments and communiqués. An overview of the materials developed by each of the Committees, in the aggregate, may yield some insight regarding the value of coordinating key items, messages or timing of releases, to create a synergy of message that could work well for the Consortium. At the end of the first four years, it might also be an opportune time to conduct targeted public

feedback activities on each of the major priorities; assessing awareness, understanding, participation and support of the Committee's major efforts.

## **I. Consortium and Committee Structure**

At its inception, the Consortium structure was drafted by the input of those who took part in the framework development initiative. The Consortium has demonstrated a great deal of respect for the contributions of those early supporters. During the period of Committee charge development, the Consortium determined that some changes to the structure were necessary in order to fulfill the spirit of the work. At that time, the emphases of two Committees were changed slightly and the pervasive concept of disparities was captured to inform its own Committee.

Based upon the document review, observations and interview feedback, we recommend the following specific Committee structure changes:

*Data:* In order for the Committees to have access to, or guidance in the development of, data for the purposes of their programs, a separate data focus that is linked to each Committee would serve the purposes of the Consortium well. The combination of data as a focus with the Provide Information Committee has not been successful, for the several reasons mentioned above. In addition, the development and management of data is logically in the hands of the DPH staff, who, overseeing the work of the Committees, will be in an enhanced position to connect data needs and data sources for the benefit of more than one Committee at a time. The structure of a data work group, which connects to each Committee, might be a useful approach for the Consortium.

*Information and Knowledge:* The Committee has had a double focus over the course of the Green Book's life. It has not been able to meet the overall responsibility of data development and translation. We recommend that the charge of the Committee be amended to focus on the external facing efforts already underway, to enable greater progress to be made in the alliance development, work plan definition, and action; as well as the focus on the public education system cancer health council initiative. Clearly, using and coordinating data will be an important aspect of these activities. But the data workgroup will be able to serve the Information group in the same way it will be available to support the work of other Committees.

*Disparities:* The topic of disparities in cancer health was found to be pervasive across the conceptual framework that helped to structure the Committees. As a focused entity of its own, the Disparities Committee has a great deal of partner commitment and willingness to address the needs of the populations of the State. Its charge has, in essence, been fulfilled with the acceptance of the *Disparities in Cancer Incidence and Mortality Among Delaware Residents, 1998-2002* Report. At this time, the strength of the Disparities Committee would be put to great use by reconfiguring it as a Disparities Workgroup, similar to that of Data, as suggested above; and connecting it via its membership to each of the seated Committees. This will enable the critical issue of disparities to be always an active part of each Committee's agenda, and will encourage action and engagement of the Disparities Committee membership. The concept of harmonizing efforts related to disparities across Committees encourages cross-Committee innovation on initiatives that may have multiple potential benefits.



In general, it is recommended that the membership of Committees with multiple simultaneous project or research foci be increased to allow for critical mass to form subcommittees of such Committees. As an example, the Quality Committee may benefit from smaller work groups or subcommittees to tackle specific projects that relate to the goals of the Committee, as a Committee leader suggested during the interview process.

#### *J. The Decision Structure*

When the Council and Committee structure was developed, the process for final decision approval rested with the Advisory Council. Committees were to research, discuss, develop an approach, and recommend to the Council, who would then be responsible for the final decision. At this time, there is variation from Committee to Committee regarding decisions versus recommendations. The process has not been formalized along the way, and at this time habits of Committees and their leadership indicate differences of perception. This is particularly important as, coupled with more mature “products” and presence in the State, the Consortium becomes known for the work that the Committees produce. Clarity regarding the decision and approval is necessary as the programs and initiatives become more fully formed, and public information logically begins to be developed to inform and engage the appropriate audiences. One respondent indicated that the process of decision authority is not clearly formalized, and this should be discussed and determined by the Council.

## **XII. Conclusion**

The Delaware Cancer Consortium has established in its first four years a standard of engagement, productivity, and impact in which all who have participated rightly feel a great sense of pride. The commitment of individuals--whether volunteers, government officers or staff--is strong and steady. The support that the Governor's office has demonstrated has nurtured this effort at a critical time in the fight against cancer, enabling Delaware to change its own "face of cancer" for the better.

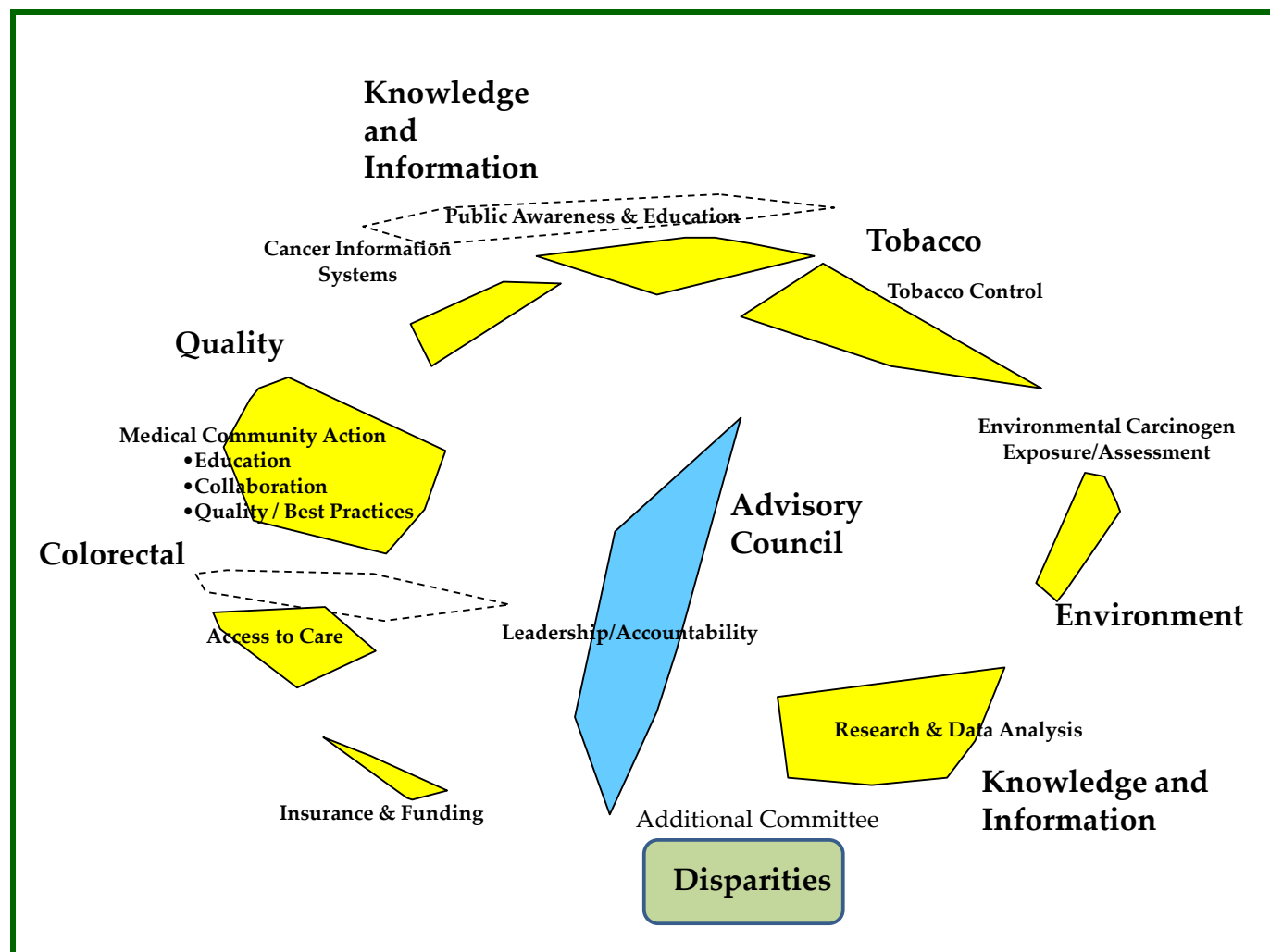
In this document, we report on the steps that the Consortium and its Committees have taken to achieve noticeable progress on each priority target established five years ago. Through the eyes of those most involved, we recognize the strengths of the structure and the individuals in it. We report opinions and aggregate findings to identify areas that would benefit from attention. We recommend specific ways in which the Consortium can strengthen its own position relative to its stated priorities.

The Consortium is in an early maturity organizational development stage; as one Committee member said, "I am seeing a positive shift and a new level of maturity and collaboration from the Committees and DCC." As the Consortium enters into the "Purple Book" phase, we share the Members' belief that the work of the Consortium will continue strongly and effectively, as they build upon this foundation.

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Appendix 1: Concept Map Structure



## Appendix 2: Advisory Council Members

**William W. Bowser, Esquire**  
Young Conaway Stargatt & Taylor

**John C. Carney, Jr.**  
Lt. Governor, State of DE

**Matt Denn**  
Insurance Commissioner, State of DE

**Christopher Frantz, MD**  
A.I. DuPont Hospital for Children

**Stephen Grubbs, MD**  
Medical Oncology Hematology Consultants, PA

**Bethany Hall-Long, RNC, PhD**  
University of DE  
State Representative, State of DE

**Patricia Hoge, PhD**  
American Cancer Society

**John Hughes**  
Secretary of DNREC, State of DE

**Meg Maley, RN, BSN**  
Oncology Care Home Health Specialists, Inc.

**David McBride**  
State Senator State of DE

**Julio Navarro, MD**  
Glasgow Family Practice

**Nicholas Petrelli, MD**  
Helen F. Graham Cancer Center

**Jaime H. Rivera, MD, FAAP**  
Director of Division of Public Health, State of DE

**Liane Sorenson**  
State Senator, State of DE

**James Spellman, MD, FACS, FSSO**  
Beebe Hospital - Tunnel Cancer Center

**Stephanie Ulbrich**  
State Representative, State of DE

### Appendix 3: List of Interviewees and their roles in the Delaware Cancer Consortium

**William W. Bowser, Esquire**

Advisory Council Chair

**The Honorable John C. Carney, Jr.**

Lieutenant Governor, State of DE

Disparities Committee Chair

Advisory Council Member

**Christopher Frantz, MD**

Quality Committee Chair

Advisory Council Member

**Robert Frelick, MD**

Disparities Committee Member

**Stephen Grubbs, MD**

Colorectal Committee Chair

Advisory Council Member

**Bethany Hall-Long, RNC, PhD**

Knowledge and Information Committee Chair

Advisory Council Member

**Patricia Hoge, PhD**

Tobacco Committee Chair

Advisory Council Member

**John Hughes**

Advisory Council Member

Environment Committee Member

**Surina Jordan**

Disparities Committee Member

Knowledge and Information Committee Member

**Meg Maley, RN, BSN**

Environment Committee Chair

Advisory Council Member

**The Honorable Ruth Ann Minner**

Governor, State of DE

**Alisa Olshefsky, MPH**

Division of Public Health, State of DE,

Chronic Disease Bureau Chief

**Nicholas Petrelli, MD**

Quality Committee Chair

Advisory Council Member

Disparities Committee Member

**Anthony Policastro, MD**

Colorectal Committee Member

Quality Committee Member

**Jaime H. Rivera, MD, FAAP**

Division of Public Health, State of DE, Director

Advisory Council Member

Disparities Committee Member

Insurance Committee Member

**Jill Rogers, MSN**

Division of Public Health, State of DE, Health

Promotion and Disease Prevention Chief

**Paul Silverman, DrPH**

Division of Public Health, State of DE

**Kathleen Wall**

Disparities Committee Member

## Appendix 4: Interview Protocol Section Examples

### SECTION A: Background and Expectations of the Consortium

<b>Interviewee:</b>	<b>Title:</b>	<b>Date:</b>
<b>Interviewer:</b>	<b>Start Time:</b>	<b>End Time:</b>

#### Introductions and Background

Thank you for making time in your schedule to talk with me. I am (name), and I am a research project manager/consultant at Concept Systems. Concept Systems is working with Alisa Olshefsky and Jill Rogers at the Division of Public Health to develop a comprehensive evaluation of the work and structure of the Delaware Cancer Consortium in its first four years. We hope to ask you your views on the Consortium (DCC) and Committee work.

You have been asked to take part in this part of the evaluation because of your role in the Consortium or one or more of its committees thus far. You are one of a small group of people taking part in this interview process. The results will be aggregated and no particular statement will be attributed to any specific person. Concept Systems Inc. will keep confidential the source of each statement.

The responses of those who take part in this will be reported back in the evaluation of the DCC in writing and at a follow-up meeting as part of the overall evaluation.

We have asked for about 60 minutes of your time, and we hope to use it well. So we have provided you with the interview survey in advance of this call, so you might have had a chance to provide us with some of your responses already. If not, we hope you've had a chance to look over the interview plan and survey, so that we can make good use of your time, and pace the questions accordingly.

Before we begin, I'd like to ask if you have any questions about the purposes of the interviews, and about the evaluation in general. PAUSE HERE. NOTE questions below:

Purposes of Interviews:

Questions about the Evaluation:

#### About the respondent

1. I'd like to ask you a few questions about your involvement with DCC and the \_\_\_\_\_ Committee.
2. How and when did you initially become involved with the DCC?
3. Did you take part in the ad hoc advisory council that preceded the consortium? Y N
4. Were you involved in that advisory council from the beginning? Y N
5. If you were not an original member of the Council, were you provided orientation when you joined the consortium or any committee? Y N
6. What roles have you taken on or performed with the DCC in the first four years? (LIST)

## About the Respondent's Expectations

In order to help us link our review of committee and consortium processes and progress to expected progress and results, we'd like to learn more about your expectations of the Consortium's first four years. When you first became involved in the Consortium or on a Committee, what were your expectations that

	High	Neutral	Low
1. The Consortium/Committee's mandate and recommendations (the Green Book) would be used to plan and carry out the work of the organization?			
2. The Consortium's work would be conducted responsibly?			
3. The Consortium and committees would be innovative in their approaches?			
4. The Consortium's progress would be communicated effectively?			
5. The Consortium would actively involve a range of communities and resources?			
6. Your committee(s) would be able to make progress on recommendations			
7. Your committee(s) would receive the staffing support and management needed			
8. Your committee(s) would be able to involve key communities of interest in its work			



## INTERVIEW SECTION B

### Consortium Leadership

When you think about the people who provide either formal or informal leadership in the **Consortium**, whom do you think of—either by name or by position? Are these people formal leaders or informal leaders?

Name or Position	Formal/Informal

Now, thinking about this group of leaders in the aggregate,

Please rate the total effectiveness of the Consortium's leadership in each of the following areas:

1. Acting responsibly for the Consortium

☐ Excellent  
☐ Very good  
☐ Good  
☐ Fair  
☐ Poor  
☐ Don't know

Comment:

2. Inspiring or motivating people involved in the Consortium

☐ Excellent  
☐ Very good  
☐ Good  
☐ Fair  
☐ Poor  
☐ Don't know

Comment:

3. Communicating the vision of the Consortium

☐ Excellent  
☐ Very good  
☐ Good  
☐ Fair  
☐ Poor  
☐ Don't know

Comment:

4. Working to develop a common level of commitment to the Consortium's responsibilities

☐ Excellent  
☐ Very good  
☐ Good  
☐ Fair  
☐ Poor  
☐ Don't know

Comment:

Please rate the total effectiveness of the Consortium's leadership in:

5. Fostering respect, trust, inclusiveness, and openness in the Consortium

☐ Excellent  
☐ Very good  
☐ Good  
☐ Fair  
☐ Poor  
☐ Don't know

Comment:

6. Resolving conflict among Consortium members

☐ Excellent  
☐ Very good  
☐ Good  
☐ Fair  
☐ Poor  
☐ Don't know

Comment:

7. Combining the perspectives, resources, and skills of Consortium members

☐ Excellent  
☐ Very good  
☐ Good  
☐ Fair  
☐ Poor  
☐ Don't know

Comment:

8. Helping the Consortium to innovate and look at the issues differently

☐ Excellent  
☐ Very good  
☐ Good  
☐ Fair  
☐ Poor  
☐ Don't know

Comment:

## INTERVIEW SECTION C

### Administration and Management

The Division of Public Health serves as Staff to the Consortium and its Committees. They are or have been supported by external contractors in some cases. We would like you to think about the administrative and management activities in the Consortium.

Please rate the level of effectiveness that DPH, working with the Consortium, has achieved in :

1. Coordinating communication among members

☐ Excellent  
☐ Very good  
☐ Good  
☐ Fair  
☐ Poor  
☐ Don't know

Comment:

2. Coordinating communication with people and organizations outside the Consortium

☐ Excellent  
☐ Very good  
☐ Good  
☐ Fair  
☐ Poor  
☐ Don't know

Comment:

3. Organizing Consortium activities, including meetings and projects

☐ Excellent  
☐ Very good  
☐ Good  
☐ Fair  
☐ Poor  
☐ Don't know

Comment:

4. Preparing materials that inform Consortium members and help them make timely decisions

☐ Excellent  
☐ Very good  
☐ Good  
☐ Fair  
☐ Poor  
☐ Don't know

Comment:

5. Providing orientation to new members as they join the Consortium

☐ Excellent  
☐ Very good  
☐ Good  
☐ Fair  
☐ Poor  
☐ Don't know

Comment:

6. Making good use of members' time

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor
- ☐ Don't know

Comment:

Please respond to the following questions about decision making:

7. How comfortable are you with the way decisions are made in the Consortium?

- ☐ Extremely comfortable
- ☐ Very comfortable
- ☐ Somewhat comfortable
- ☐ A little comfortable
- ☐ Not at all comfortable

Comment:

8. How often do you support the decisions made by the Consortium?

- ☐ All of the time
- ☐ Most of the time
- ☐ Some of the time
- ☐ Almost none of the time
- ☐ None of the time

Comment:

9. How effectively does the Consortium use data and evidence in its decision-making?

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor
- ☐ Don't know

Comment:

## INTERVIEW SECTION D

### PARTICIPATION AND PARTNERSHIP

Please respond to the following questions about participation:

1. How satisfied are you with the way people and organizations in the Consortium work together?

- ☐ Completely satisfied  
☐ Mostly satisfied  
☐ Somewhat satisfied  
☐ A little satisfied  
☐ Not at all satisfied

Comment:

2. How satisfied are you with your influence in the Consortium?

- ☐ Completely satisfied  
☐ Mostly satisfied  
☐ Somewhat satisfied  
☐ A little satisfied  
☐ Not at all satisfied

Comment:

3. How satisfied are you with the Consortium's progress toward achieving its goals?

- ☐ Completely satisfied  
☐ Mostly satisfied  
☐ Somewhat satisfied  
☐ A little satisfied  
☐ Not at all satisfied

Comment:

Please rate the total effectiveness of the Consortium's relationship efforts in

4. Recruiting diverse people and organizations into the Consortium

- ☐ Excellent  
☐ Very good  
☐ Good  
☐ Fair  
☐ Poor  
☐ Don't know

Comment:

5. Creating linkages with the medical community

- ☐ Excellent  
☐ Very good  
☐ Good  
☐ Fair  
☐ Poor  
☐ Don't know

Comment:

6. Creating linkages with educational institutions

- ☐ Excellent  
☐ Very good  
☐ Good  
☐ Fair  
☐ Poor  
☐ Don't know

Comment:

7. Creating linkages with community based organizations and advocates

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor
- ☐ Don't know

Comment:

8. Being recognized as a respected entity that can speak to cancer control issues in Delaware?

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor
- ☐ Don't know

Comment:

## INTERVIEW SECTION E

### COMMITTEE FEEDBACK EXAMPLE

To the Committee Chair: This worksheet asks your assistance in completing the record of your Committee's meetings and progress. Please provide feedback as requested, to the degree that you have further information. Thank you.

#### Meeting Records

Consortium files include meeting minutes, notes or other indication that a meeting took place for the dates marked below. Can you provide information about

- ☐ whether other meetings took place?
- ☐ whether notes exist for each additional meeting? If notes are available, please include information regarding their location.

Date	Meeting took place?	Agenda available?	Notes available?
10/8/01	Yes	Y	Yes
10/25/01	Yes	Y	Yes
9/22/03	Yes	Y	Yes
11/7/03	Yes	Y	Yes
1/20/04	Yes	Y	Yes
3/15/04	Yes	Y	Yes
5/17/04	Yes	Y	Yes

#### Chair comments, observations regarding

- ☐ Meeting schedule- meetings are held every other month and summit meetings are also held.
- ☐ Availability of meeting documentation

The Committee was charged with several recommendations for action. Documents provide information about some of these recommendations. We haven't successfully linked some of the recommendations to the documents we have. Can you provide additional information about the recommendation(s) listed here? Were they adopted or acted upon by the Committee?

Recommendation/Charge	Question	Response
<p>Form a statewide, permanent alliance to coordinate and promote public education on cancer.</p> <ol style="list-style-type: none"> <li>1. Develop a unified mission to provide consumer information and education on prevention, screening, detection and treatment, best practices for care and available resources</li> <li>2. Investigate methods to reach populations at higher risk for cancer with screening, early detection and prevention messages</li> <li>3. Collect and integrate data on public education in cancer</li> </ol>	<p>Our records indicate that in January 2004 a timeline was created for the development of a Statewide Public Education Alliance. Could you please update us on the status of the this Alliance? Is there is a mission statement for this Alliance you could share with us?</p> <p>What methods have been investigated thus far to reach populations at higher risk for cancer to inform them?</p> <p>What data has been collected and integrated on public education in cancer?</p>	
<p>Estimate the number of cancers that can be prevented and the number of deaths that can be avoided by primary prevention and early detection. Prioritize our common and preventable cancers.</p> <ol style="list-style-type: none"> <li>1. Collect data on known/suspected risk factors, and calculate the number of preventable cancer cases and deaths by gender, race, and age group, for each risk factor.</li> <li>2. Collect data on cancer diagnosis by stage, and calculate the number of preventable cancer deaths by gender, race, and age group with earlier detection.</li> <li>3. Summarize and distribute results to improve program planning and healthy lifestyle choices.</li> </ol>	<p>Our records indicate that there is on-going data collection. Could you provide us with an update on the efforts around data collection and dissemination of results?</p>	



<p>Improve the collection and reporting of cancer incidence and mortality data.</p> <ol style="list-style-type: none"> <li>1. Enforce reporting requirement; impose fines for non-reporting</li> <li>2. Increase information collected by the cancer registry, including demographics, occupational history, and exposures to certain risks.</li> <li>3. On death certificates, improve reporting of cause of death, by educating physicians on proper procedure.</li> <li>4. Introduce and pass legislation requiring hospitals to staff their registries with a certified tumor registrar.</li> <li>5. Provide certification training and annual continuing education for tumor registrars.</li> <li>6. Publish report annually that integrates most recent cancer incidents, mortality, and risk behavior data.</li> <li>7. Fully staff the Delaware Cancer Registry and ensure appropriate continuing education.</li> <li>8. Develop a public education campaign on cancer rates and their age adjustment to the 2000 US standard population.</li> <li>9. Evaluate the ability to a standardized race and ethnicity data collection across cancer-related data sets.</li> <li>10. Evaluate the ability to match cancer incidence and mortality records, including special software, and develop matching capabilities.</li> </ol>	<p>Our records indicate efforts in improving the cancer registry data collection and reporting. Could you update us of the current status of these items?</p>	
<p>Conduct a survey to examine the importance of past exposure to today's cancer rates.</p> <ol style="list-style-type: none"> <li>1. Analyze results and develop appropriate control strategies.</li> </ol>	<p>Our records indicate that in January 2004 the Retrospective survey was distributed to committee members. We have few records after that point. Since then, have the results been analyzed and control strategies been developed?</p>	