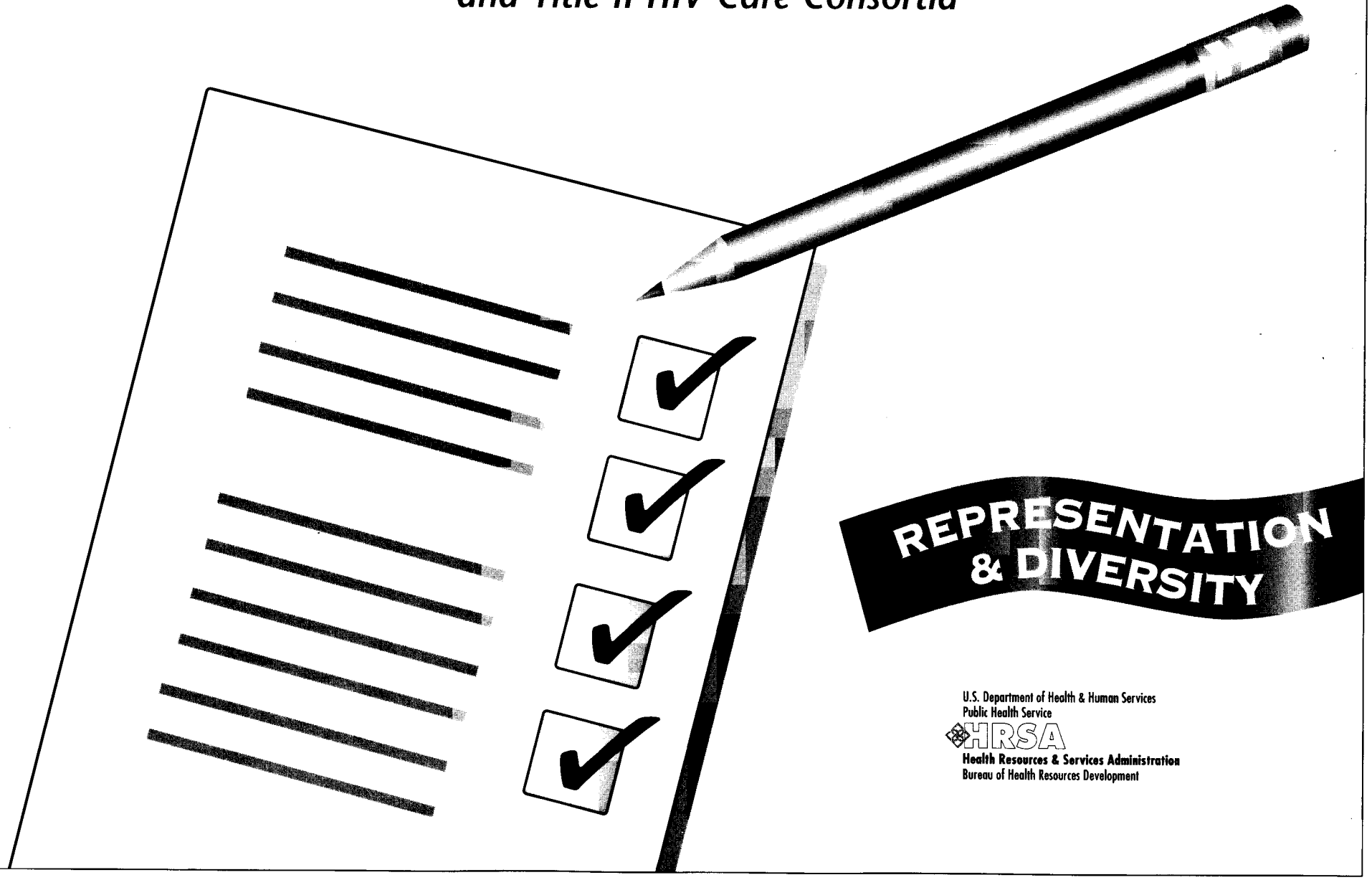
SELF-ASSESSMENT MODULE

for Ryan White CARE Act Title I HIV Health Services Planning Councils and Title II HIV Care Consortia



U.S. Department of Health & Human Services
Public Health Service
HRSA
Health Resources & Services Administration
Bureau of Health Resources Development

ACKNOWLEDGEMENTS

Author

Stewart Landers, John Snow, Inc.

Editor

Frances Marshman, John Snow, Inc.

Pilot Test Sites

Ryan White CARE Consortium, Kansas City, Missouri
South Central Pennsylvania AIDS Planning Coalition, Camp Hill, PA

Special appreciation is extended to the Kansas City Ryan White CARE Consortium and the South Central Pennsylvania AIDS Planning Coalition in Camp Hill, PA for serving as sites to pilot test this module. Their comments and insights contributed greatly to this final version of the Representation and Diversity module.

CONTENTS

Introduction 2

Self-Assessment Questions 12

Defining and Supporting Representation 12

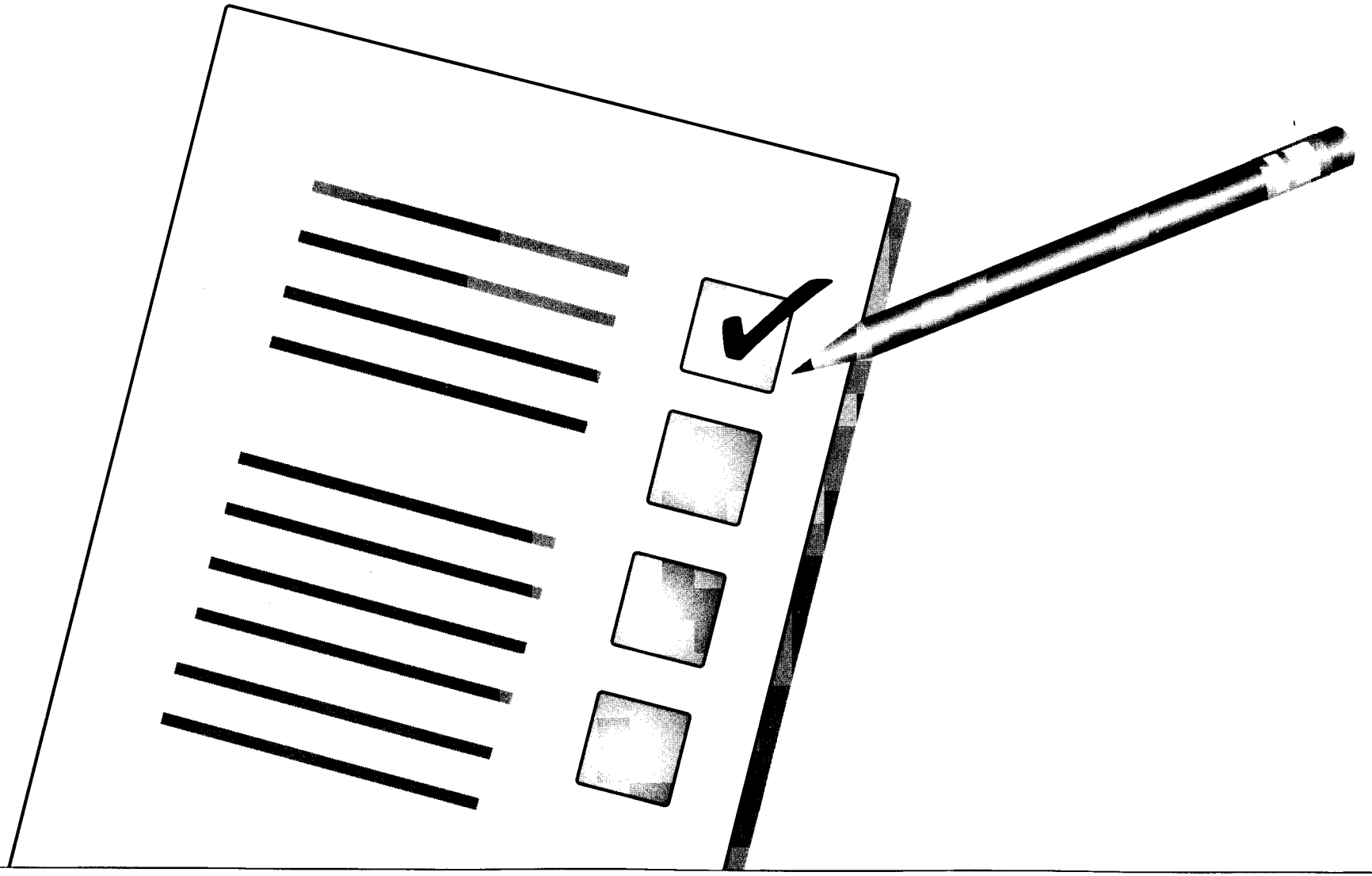
Planning for a Representative and Diverse Membership 20

Recruitment, Orientation, and Retention of Membership 29

Representation and Diversity on the Council or Consortium 42

Resources 64

Introduction



The Self-Assessment Module Series

The Division of HIV Services (DHS) and the Office of Science and Epidemiology (OSE) at the Health Resources and Services Administration (HRSA) have developed a series of tools to help HIV planning councils and consortia assess their effectiveness in critical areas of responsibility defined by the Ryan White CARE Act. The areas covered in the series are: Comprehensive HIV Services Planning, Continuum of Care, Developing and Pursuing the Mission, Needs Assessment, Priority Setting and Resource Allocation, and Representation and Diversity.

Each area is covered in a separate module. At the same time, information is complementary across the modules and cross-referenced when appropriate. The modules can be used independently of each other or as a full series.

The tools have been designed to facilitate **self-assessment** by planning councils and consortia. **Use of any and all modules in the series is completely voluntary. Councils and consortia are free to determine which area(s) they want to assess, when to conduct the self-assessment, how extensive the scope of the assessment will be, and with whom they will share results.**

DHS staff and the Technical Assistance Contractor are available to introduce the modules or to respond to any concerns raised through the self-assessment process. Please contact your DHS project officer if you have any questions about the self-assessment modules or would like assistance.

Purpose of the Representation and Diversity Module

A cornerstone of the Ryan White CARE Act is the requirement of an inclusive planning process to guide all aspects of health services delivery. The CARE Act presumes that Title I HIV Health Services Planning Councils and Title II HIV Care Consortia work best when they represent a broad range of constituencies. This module will enable members of councils and consortia to assess how well their planning bodies reflect these constituencies. Specifically, this module is designed to help councils and consortia assess their representativeness in four areas:

- First, the module assesses the extent of planning activities used to create a representative and diverse membership.
- Second, the module assesses activities used to recruit and retain a diverse membership.
- Third, it evaluates the composition of membership with respect to local and federal policies.
- Fourth, it examines the impact of membership composition on the accomplishment of specific goals.

Diversity of the council or consortium will emphasize representation and participation of:

- historically underserved groups and sub-populations;
- affected racial and ethnic groups;
- people living with HIV (PLWH), including at-risk population groups such as gay men, injection drug users, and women;
- the geographic breadth of the planning council or consortium; and
- a broad range of service provider types and disciplines involved in the delivery of HIV services.

Conducting the Self-Assessment

This section discusses how to conduct the self-assessment. It provides tips to make the self-assessment process efficient, productive, and positive. While the recommendations are based on experience and pilot tests of the modules, each planning council and consortium should adapt these processes to fit local constraints and issues. The discussion covers the following questions.

- Who should use this module?
- Who conducts the self-assessment?
- What activities should be part of the self-assessment?
- How much time and money are required?

Who Should Use This Module?

All councils and consortia should consider using this module to assess the representativeness and diversity of their memberships. It may assist a council or consortium that feels uncertain about whether it has represented the variety of stakeholders in its eligible metropolitan area (EMA) or service area adequately. This includes representation of service providers, community leaders, organizations, and sub-populations affected by the local epidemic. The results of this module should lead to improvement in the operation of a council or consortium.

Councils and consortia are free to determine when to conduct the self-assessment and how large or small its scope will be. The questions presented in this module may be used in their entirety or may be tailored to reflect the concerns and issues of the group intending to use them. The action plan sections of the module are designed to help apply self-assessment results to strengthen future membership efforts. Councils and consortia may have specific concerns or questions about an area, such as retention of PLWH or recruitment, of this module. Therefore, councils and consortia are encouraged to adapt the module to accommodate local circumstances.

A standing committee, such as an evaluation, planning, or executive committee may consider and recommend the use of this module. Alternatively, an *ad hoc* group of five to ten individuals may be convened to make recommendations about whether to use the module. This same group should also decide at the outset whether, how, and with whom the results of the assessment will be shared.

Use of this module is completely voluntary. The decision to conduct the self-assessment belongs to the membership of the council or consortium and to no one else. Councils and consortia are free to determine when to conduct the self-assessment and how large or small the scope will be.

Who Conducts the Self-Assessment?

A committee or workgroup should oversee the implementation of the self-assessment. This could be the same group that made the recommendation to do the self-assessment or a newly convened group. A group of five to ten is suggested and should include representatives of the infected community. Attention to racial, ethnic, and gender diversity is also critical. Geographic representation should be considered, especially when the service area is diverse. Some of the group should be drawn from existing council or consortium membership, but it is also possible to go outside the membership for specific expertise. In general, it is desirable to include a grantee representative in order to promote a cooperative and collaborative relationship. Including representatives from the grantee or others outside the planning council or consortium membership (such as from colleges or universities) may facilitate access to information and/or provide additional resources for completing the module.

It may not be advisable to have the person(s) directly responsible for membership lead this self-assessment effort because it may be difficult for him or her to be objective. On the other hand, his or her participation in the self-assessment will provide an important perspective and may help ensure that improvements are implemented. The self-assessment workgroup should receive a written charge from the council or consortium authorizing the self-assessment.

This and all the other self-assessment modules have been designed to be completed by groups of volunteers—members of councils and consortia and others. However, council or consortium staff may also be involved, depending on local circumstances and availability. For instance, council or consortium

staff may be needed to assist in the gathering of documents and in ensuring effective communication among members during the process. Consultants should not be used to conduct the self-assessment. They may, however, be helpful in modifying this module for the local environment, or in facilitating the self-assessment process. DHS staff are also available to assist in the application of the module.

What Activities Should Be Part of the Self-Assessment?

There are five major activities that must occur to complete the self-assessment:

1. Review and adapt the module to the local environment.
2. Collect information and documents needed to answer the questions in the module.
3. Answer and score the questions in the module.
4. Develop an action plan to guide future activities.
5. Apply results of the self-assessment.

Tips are offered for each of these activities.

1. **Review and adapt module.** After the decision is made to proceed with the self-assessment, the first step is to review the module and adapt it as necessary. For example, questions that are irrelevant should be eliminated, and lists of stakeholders should be augmented or reduced as appropriate. Careful review of all the module's sections at the outset will facilitate its implementation and minimize frustration among workgroup members.

   The module should be distributed to all members of the self-assessment workgroup approximately one week before the first workgroup meeting. This meeting, in person if possible, should be used to determine the specific scope and content of the self-assessment to be implemented, clarify the purpose of the self-assessment, define the process and time line by which the self-assessment will be conducted, assign roles and responsibilities of workgroup members, and clarify specific questions for all members. If a chairperson has not been appointed, one should be elected at this meeting.

2. **Collect information and documents, conduct interviews.** Once the workgroup has agreed on the scope of the self-assessment, members should proceed with collecting and reviewing related documents and information. Interviews with key people involved in the recruitment and orientation of new members should also be scheduled.

Documents could include the current list of members, documents used to recruit and retain members, such as application forms, recruitment plans, mentoring programs, and orientation materials; and minutes and attendance logs from meetings of committees or advisory boards that work on membership issues, as well as council or consortium meetings where membership was discussed.

Interviews could be conducted with members of the council or consortium committee who oversee membership; council or consortium staff who work on membership; consultants who worked on membership issues; and people representing service organizations and affected populations.

3. **Answer and score the questions.** After collecting relevant information and conducting key interviews, the workgroup should convene to discuss the questions in the module. Depending on the number of questions being addressed, the discussion could take four to six hours. The discussion may occur in a single meeting, in a series of meetings, or by telephone conference calls. The questions have been subdivided into sections to facilitate a segmented discussion.

   Many questions will require significant discussion and coming to consensus. It is important to choose an individual who can focus and facilitate discussion.

   There are two important parts to answering the questions. First, and most important, is a qualitative discussion of the question, what the council or consortium did well, and what it could do better. Second is assignment of a score when scoring is indicated. Numerical scoring is provided on several questions to help the council or consortium identify areas of strength and weakness. The scores can also provide a baseline for future self-assessments.

   A question-by-question overview and discussion of scoring is provided at the end of each section. The overview elaborates on each question and how to interpret your score and answers. It may be helpful to refer to this overview while answering the questions.

   The points in each section are added up then divided by the number of scored questions (and subquestions) in the section. By dividing the total points by the number of scored questions, you will have a single score of 0 to 3 for each section. That score can be compared to the score in other sections. Combined with a qualitative assessment of strengths and weaknesses in each section, the scores can be helpful in highlighting areas where a planning council or consortium has done very well (high scores, e.g., 2 to 3), as well as areas in which changes or enhancements should be considered (low scores, e.g., 0 to 1).

   Assigning scores is not the ultimate goal of the self-assessment. It is much more important that the group engage in substantive discussion of the questions. If you get stuck on scoring, move on. All scores are confidential and are not compared across planning councils and consortia or shared with DHS.

4. **Develop action plans.** Each section of questions concludes with the development of an action plan for that section. The self-assessment will be most successful if it improves the representation on a council or consortium by keeping what works well, modifying what doesn't, and adding important aspects that are missing. The action plans are intended to lead a planning council or consortium forward. Particular attention should be paid to questions that were scored 0 to 1, because these may be problem areas. You should not, however, lose sight of areas of strength when planning future activities.

   A format is provided for developing the action plan for each section, but it may be modified to meet the needs of a particular planning council or consortium. For each section you are asked to list objectives, time line, resources needed, and lead person responsible for completing the objective. Once the section-specific action plans are done, an overall plan with priorities should be developed.

5. **Apply results.** The results of the self-assessment, including answers to questions, scores, and action plans, belong to the planning council or consortium and to no one else. However, a planning council or consortium may decide to share part or all of its results with the grantee, with DHS, or with the community.

   The overarching purpose for conducting a self-assessment is to improve the functioning of the council or consortium. There may be other reasons for conducting the self-assessment, such as responding to local questions or concerns, but the self-assessment modules have been designed primarily to give councils and consortia tools to help them improve the quality of their operations. The action plan component of the module is intended to lead to such improvements. Viewing the module as a quality improvement tool supports the premise that results of the self-assessment are for internal use and do not need to be shared, except at the discretion of the council or consortium.

   At the conclusion of the self-assessment, the planning council or consortium may want to develop a brief report summarizing the process. The report could address the charge to the workgroup or committee, workgroup membership, and processes used to complete the module (e.g., number of meetings, time lines, people interviewed, documents reviewed).

How Much Time and Money are Required?

The self-assessment process has been designed to be very low cost. Time is the principal investment required of those who help complete the module.

Once a planning council or consortium has decided to proceed with the self-assessment, the process should take between eight and twelve weeks, beginning with tailoring the module to the local environment and ending with an action plan and reporting of results to the council or consortium.

A prototype time line for the self-assessment follows. ➔

Phase I — Deciding to do Self-assessment

Week 1: Convene evaluation committee to consider the self-assessment process, recommendations to planning council or consortium.

Week 2: Planning council or consortium decides to proceed with self-assessment, identifies *ad hoc* workgroup to conduct assessment, writes charge to the workgroup, decides who will get results.

Phase II — Preparatory Work

Week 3: Self-assessment module distributed to workgroup members for review, first meeting of workgroup scheduled.

Week 4: Workgroup meets, elects chair, reviews and modifies questions, assigns responsibilities.

Weeks 5-8: Documents reviewed, interviews conducted.

Phase III — Answering Questions

Week 9: Workgroup meets to discuss and to score questions, develops action plans for completed sections.

Week 10: Workgroup meets to complete discussion of action plans.

Phase IV — Reporting and Implementing

Week 11: Present results to planning council or consortium, report on process and final decision.

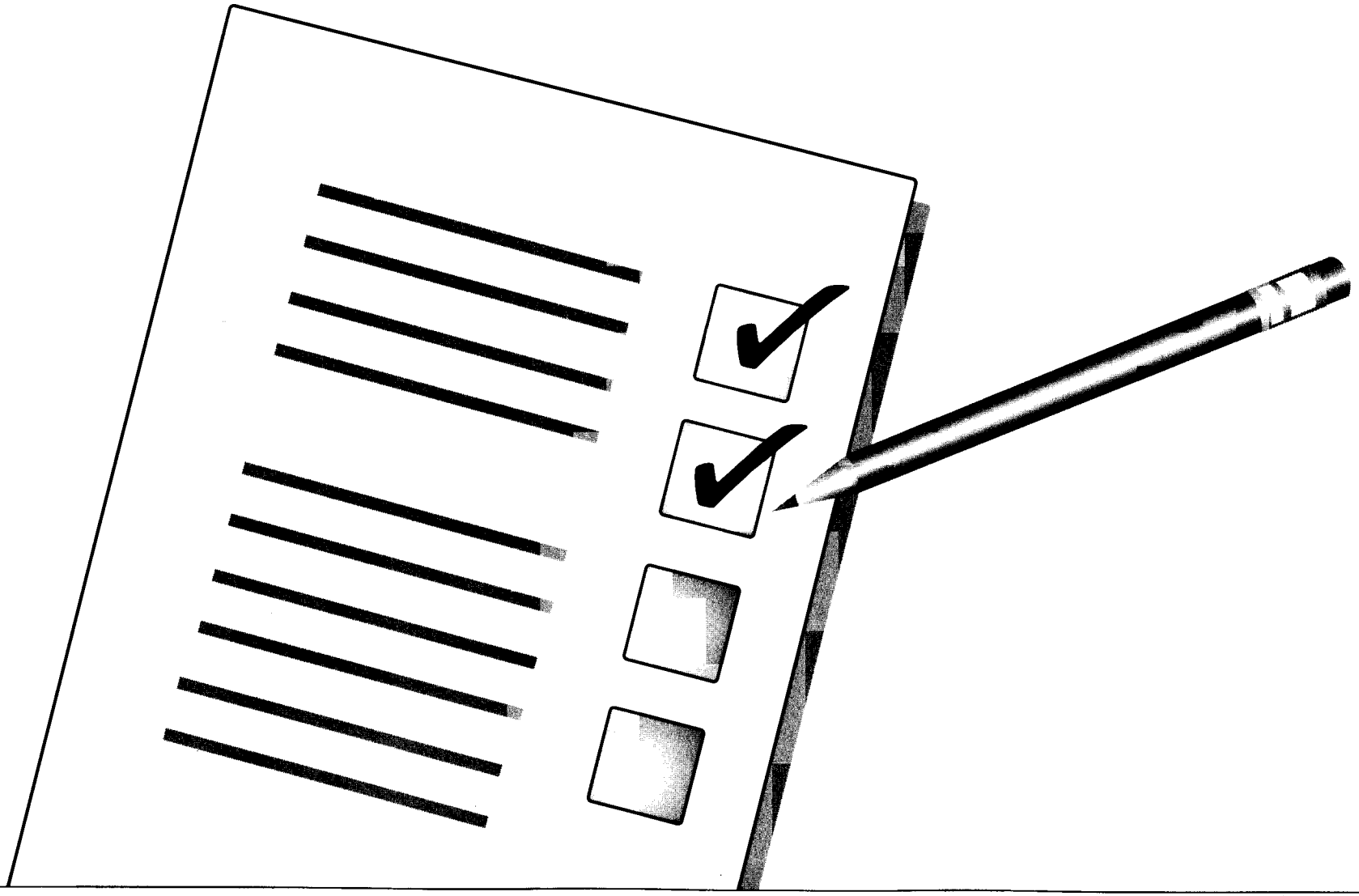
Weeks 12-14: Decide on overall plan and implementation, request technical assistance, if needed.

Information Sources

To complete the Representation and Diversity module, you will need:

- planning council or consortium bylaws, goals and objectives, mission statement, operating guidelines
- membership lists of the planning council or consortium, its major committees, and relevant demographics of members
- Ryan White legislation
- meeting minutes of the council or consortium and relevant committees
- information related to membership recruitment and retention, including application forms, recruitment plans, mentoring programs
- For planning councils, the most recent Title I application guidances (formula and supplemental)
- For consortia, the most recent Title II application guidance
- policy documents from federal, state, and local governments relevant to the issue of conflict of interest, and
- local surveillance data.

Self-Assessment Questions



DEFINING AND SUPPORTING REPRESENTATION

1 To what extent has your planning council or consortium discussed and defined the criteria that members must meet to be considered "representative" of a given group or target population?

no discussion of criteria — complete discussion of criteria

0 pts | 1 pt | 2 pts | 3 pts

2 Please describe the extent to which each of the following criteria is used to assess the representativeness of members or potential members with respect to a specific population group targeted for membership:

never used — always used

a Member is part of the target population to be represented.

0 pts | 1 pt | 2 pts | 3 pts

b Member is a service provider with extensive and recent experience working with the target population.

0 pts | 1 pt | 2 pts | 3 pts

c Member is a community leader (not necessarily an HIV/AIDS service provider) of the target population.

0 pts | 1 pt | 2 pts | 3 pts

d Member actively seeks input from and provides feedback to the affected population he or she represents.

0 pts | 1 pt | 2 pts | 3 pts

never used — always used

e Member is selected to serve on the council/ consortium by the target population he or she represents.

0 pts 1 pt 2 pts 3 pts

f Other _____

0 pts 1 pt 2 pts 3 pts

Total Points for Question 2 ☐

The CARE Act, as amended, requires Title I Planning Councils to have representatives from the following groups. These are the groups, as listed in the CARE Act, that should be considered when answering questions 1-6:

A) health care providers, including federally qualified health centers;

B) community-based organizations serving affected populations and AIDS service organizations;

C) social service providers;

D) mental health and substance abuse providers;

E) local public health agencies;

F) hospital planning agencies or health care planning agencies;

G) affected communities, including people with HIV disease or AIDS, and historically underserved groups and sub-populations;

H) non-elected community leaders;

I) State government, including the state Medicaid agency and the agency administering the Title II program;

J) CARE Act grantees under Title III (b);

K) CARE Act grantees under Title IV; and

L) grantees under other federal HIV programs.

The composition of a Title II consortium has more general requirements (see page 60). Therefore, a consortium may decide which groups, if any, it wants to have represented as members. Some consortia may not have chosen a representational model for their group.

3 Has the council or consortium used the following methods to encourage members to seek input from and share information with their stakeholder group(s)?

		no	yes
a	Constituent meetings	0 pts	3 pts
b	One-on-one discussions	0 pts	3 pts
c	Distribution of meeting minutes	0 pts	3 pts
d	News articles	0 pts	3 pts
e	Other _____	0 pts	3 pts

Total Points for Question 3 ☐

4 Has the council or consortium discussed use of the following activities to assist members in their efforts to obtain input from and share information with stakeholders?

		no	yes
a	Organizing of meetings for affected populations	0 pts	3 pts
b	Organizing of public hearings	0 pts	3 pts
c	Reimbursing of costs for members who meet with the affected population	0 pts	3 pts
d	Other _____	0 pts	3 pts

Total Points for Question 4 ☐

5 Are council or consortium members **required** to seek input or share information with their constituencies on any of the following issues?

		no	yes
a	Assessment of needs	0 pts	3 pts
b	Development of comprehensive plan	0 pts	3 pts
c	Priority setting and resource allocation	0 pts	3 pts
d	Evaluation of CARE Act-funded services	0 pts	3 pts
e	Other _____	0 pts	3 pts

Total Points for Question 5 ☐

6 What barriers, if any, exist to having members seek input from or share information with the stakeholder group(s) he or she represents?

_____ _____

_____ _____

_____ _____

Summary: Defining and Supporting Representation

Scoring

To score, follow these steps:

STEP 1 Add up the points for questions 1 through 6 and put that amount in the TOTAL POINTS box.

STEP 2 Add up the number of scored questions (and subquestions) answered and put it in the TOTAL NUMBER OF SCORED QUESTIONS ANSWERED box.

STEP 3 Calculate your final score: TOTAL POINTS divided by TOTAL NUMBER OF SCORED QUESTIONS ANSWERED.

STEP 4 Record your final score in the SCORE box.*

TOTAL POINTS ☐

divided by

TOTAL NUMBER OF SCORED QUESTIONS ANSWERED ☐

equals

SCORE ☐

**If your score equals more than 3, double-check your addition of points and counting of subquestions answered.*

Strengths And Weaknesses

What aspect(s) of defining and supporting a representative membership has worked well?

_____

_____

_____

_____

What needs to be improved?

_____

_____

_____

_____

Action Steps

Based on your responses to questions 1 through 6, list the key areas where action should be taken to help councils and consortia ensure that their members represent stakeholder groups. →

Action Steps for Questions 1–6

OBJECTIVE:	RESOURCES:
TIME LINE:	PERSON RESPONSIBLE:
OBJECTIVE:	RESOURCES:
TIME LINE:	PERSON RESPONSIBLE:
OBJECTIVE:	RESOURCES:
TIME LINE:	PERSON RESPONSIBLE:

DEFINING AND SUPPORTING REPRESENTATION: DISCUSSION OF SCORING AND QUESTIONS 1–6

Following is a discussion of **questions 1-6.** It is intended to help interpret the questions and assign scores. This section looks at how the council or consortium defines representation. The CARE Act, as amended, requires that Title I Planning Councils include **representatives** of 12 different groups. These questions look at how these members **represent** their constituency.

The CARE Act, as amended, does not address the issue of **representation** on Title II Care Consortia. If a consortium does not use a representative model, it may choose not to answer or score these questions.

Question 1: A zero score means that your council or consortium has not discussed to what extent its members should represent the groups listed in the box on page 13. The choices in **question 2** are helpful ways to think about how an individual represents a constituency. These definitions are not mutually exclusive. In other words, it is possible to have all of these choices as part of a definition of representation. Zero points indicate members are not assessed with respect to the particular criterion. Three points on each criterion means that members must demonstrate several ways they represent a constituency.

Question 3: Members of the planning council or consortium are encouraged to communicate with community residents about the planning and implementation of HIV/AIDS services in their EMA or catchment area. **Question 3** suggests some ways members may be encouraged to seek input and share information. The more points you scored, the better the communication will be between council or consortium members and the groups they represent.

Question 4: This question encourages the council or consortium to assist members to seek input from and share information with their constituency. The more points you scored in this section, the more support members are receiving from the council or consortium for interacting with the community.

Question 5 indicates that there may be specific issues which require input or sharing of information. Again, the more points you scored in this section, the more responsive your council or consortium is to its constituents. Note: Do the answers to this question differ with respect to members with HIV? If so, why is their relationship to their stakeholder group different than other members?

Question 6 allows the council or consortium the opportunity to discuss barriers to communication between members and their respective stakeholder groups.

7 Does the council or consortium have a written policy or plan to include the following groups in its membership? ➔

KEY STAKEHOLDER GROUPS	no	yes	IN WHICH DOCUMENT(S) IS THIS ISSUE RAISED?
a. People living with HIV (PLWH).	❑ 0 pts	❑ 3 pts	❑ Bylaws ❑ Mission Statement ❑ Goals/Objectives ❑ Operating Guidelines/Procedures ❑ Other _____
b. Racial/ethnic populations affected by HIV in the community.	❑ 0 pts	❑ 3 pts	❑ Bylaws ❑ Mission Statement ❑ Goals/Objectives ❑ Operating Guidelines/Procedures ❑ Other _____
c. Diverse service provider types/organizations.	❑ 0 pts	❑ 3 pts	❑ Bylaws ❑ Mission Statement ❑ Goals/Objectives ❑ Operating Guidelines/Procedures ❑ Other _____

KEY STAKEHOLDER GROUPS	no — yes	IN WHICH DOCUMENT(S) IS THIS ISSUE RAISED?
d. State and local public agencies (e.g., state Medicaid agency).	0 pts — 3 pts	❑ Bylaws ❑ Mission Statement ❑ Goals/Objectives ❑ Operating Guidelines/Procedures ❑ Other _____
e. At-risk populations (e.g., injection drug users, men who have sex with men, women)	0 pts — 3 pts	❑ Bylaws ❑ Mission Statement ❑ Goals/Objectives ❑ Operating Guidelines/Procedures ❑ Other _____
f. Representatives from all geographic areas (e.g., counties or sections of the service area)	0 pts — 3 pts	❑ Bylaws ❑ Mission Statement ❑ Goals/Objectives ❑ Operating Guidelines/Procedures ❑ Other _____

Total Points for Question 7 ☐

8 What objectives have been established regarding membership composition?

OBJECTIVE 1

OBJECTIVE 2

OBJECTIVE 3

OBJECTIVE 4

❑ No objectives (Skip to Question 11)

9 Is there a plan to reach the objectives listed in question 8?

	no	yes
Objective 1	0 pts	3 pts
Objective 2	0 pts	3 pts
Objective 3	0 pts	3 pts
Objective 4	0 pts	3 pts

Total Points for Question 9 ☐

10 Does the plan:

a Identify specific individuals who are responsible for implementation?

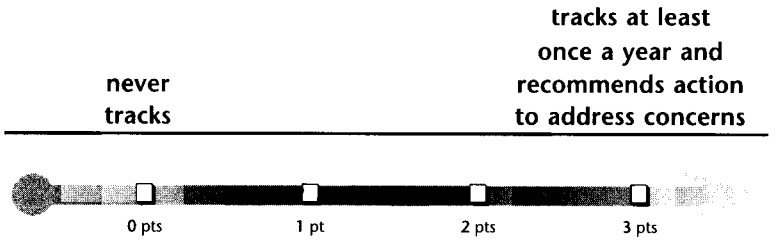
	no	yes
Objective 1	0 pts	3 pts
Objective 2	0 pts	3 pts
Objective 3	0 pts	3 pts
Objective 4	0 pts	3 pts

b Contain a time line for achieving membership goals?

Objective 1	0 pts	3 pts
Objective 2	0 pts	3 pts
Objective 3	0 pts	3 pts
Objective 4	0 pts	3 pts

Total Points for Question 10 ☐

11 To what extent does the council or consortium track the representativeness and diversity of its membership over time?



12 What issues, if any, have arisen with respect to planning for an inclusive and diverse membership?

Summary: Planning for a Representative and Diverse Membership

Scoring

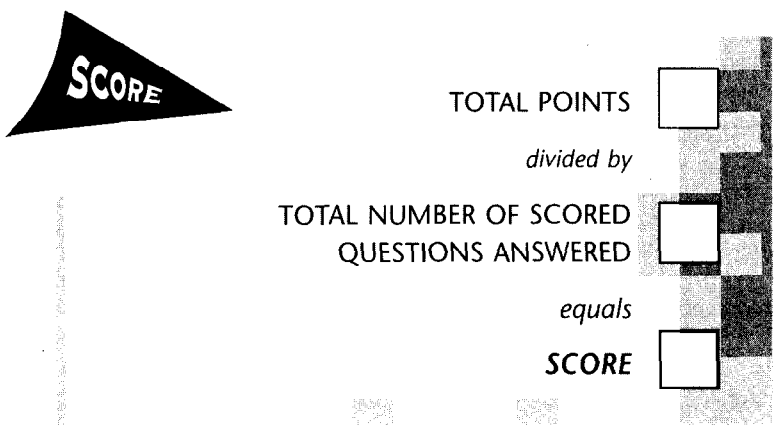
To score, follow these steps:

STEP 1 Add up the points for questions 7 through 12 and put that amount in the TOTAL POINTS box.

STEP 2 Add up the number of scored questions (and subquestions) answered and put it in the TOTAL NUMBER OF SCORED QUESTIONS ANSWERED box.

STEP 3 Calculate your final score: TOTAL POINTS divided by TOTAL NUMBER OF SCORED QUESTIONS ANSWERED.

STEP 4 Record your final score in the SCORE box.*



If your score equals more than 3, double-check your addition of points and counting of subquestions answered.

Strengths And Weaknesses

What aspect(s) of planning for a representative and diverse membership worked well?

_____

_____

_____

_____

What needs to be improved?

_____

_____

_____

_____

Action Steps

Based on your responses to questions 7 through 12, list the key areas where action should be taken to improve planning for a representative and diverse membership. ➔

Action Steps for Questions 7–12

OBJECTIVE:	RESOURCES:
TIME LINE:	PERSON RESPONSIBLE:
OBJECTIVE:	RESOURCES:
TIME LINE:	PERSON RESPONSIBLE:
OBJECTIVE:	RESOURCES:
TIME LINE:	PERSON RESPONSIBLE:

PLANNING FOR A REPRESENTATIVE AND DIVERSE MEMBERSHIP: DISCUSSION OF SCORING AND QUESTIONS 7–12

The following is a discussion of **questions 7-12.**

Question 7: While many planning councils and consortia are aware of the requirements for a representative and diverse membership, it is helpful to incorporate these requirements into key documents such as bylaws, mission statement, goals and objectives, and operating guidelines and procedures. Each council or consortium should have written plans, if needed, to attain a representative and diverse membership.

Question 8: Objectives are not scored. However, if you do not have any explicit objectives around membership, it is difficult to plan effectively in this area.

Questions 9 and 10: Planning is an effective method to select members. Each objective listed in **question 8** should have a plan accompanying it. It is important to have a plan that identifies who is responsible for implementation of the objective and a time line for reaching that objective.

A good reference for effective membership selection is *"Who Should Be On Your Board?"* by Cyril O. Houle, Nonprofit World, Vol. 8, No. 1, January/February, 1990.

Question 11: A plan is most effective if it is monitored. Give yourself credit if you scored points for tracking the progress you are making in the implementation of your plan. However, even councils and consortia without a plan should monitor the representation and diversity of their members.

Question 12 asks the council or consortium to discuss any issues related to planning for a representative and diverse membership.

13A Does the council or consortium have written recruitment policies and procedures that include any of the following?

		no	yes
a	Criteria for membership	0 pts	3 pts
b	Job description for planning council or consortium members	0 pts	3 pts
c	Open nomination process	0 pts	3 pts
d	Timetable for application process	0 pts	3 pts
e	How membership decisions are publicized	0 pts	3 pts
f	How membership decisions may be appealed	0 pts	3 pts
g	Conflict-of-interest standard	0 pts	3 pts

Total Points for Question 13A ☐

13B Does the council or consortium publicize its recruitment policies and procedures?

		n/a	no	yes
a	Criteria for membership	❑	0 pts	3 pts
b	Job description for planning council or consortium members	❑	0 pts	3 pts
c	Open nomination process	❑	0 pts	3 pts
d	Timetable for application process	❑	0 pts	3 pts
e	How membership decisions are publicized	❑	0 pts	3 pts
f	How membership decisions may be appealed	❑	0 pts	3 pts
g	Conflict-of-interest standard	❑	0 pts	3 pts

Total Points for Question 13B ☐

14 To what extent has the council or consortium considered using the following outreach methods for recruiting membership?

not at all considered — **considered thoroughly**

a Recruitment procedures mailed to community-based organizations

0 pts 1 pt 2 pts 3 pts

b Written, telephone, or face-to-face contact with AIDS services providers

0 pts 1 pt 2 pts 3 pts

c Direct contacts with PLWH by HIV service providers

0 pts 1 pt 2 pts 3 pts

d Recruitment procedures described in appropriate newsletter(s)

0 pts 1 pt 2 pts 3 pts

e Use of media (e.g., television or radio public service announcements, newspaper stories)

0 pts 1 pt 2 pts 3 pts

f Contacts with PLWH organizations

0 pts 1 pt 2 pts 3 pts

g One-on-one recruitment of community leaders not currently working on HIV/AIDS

0 pts 1 pt 2 pts 3 pts

h Other _____

0 pts 1 pt 2 pts 3 pts

Total Points for Question 14 ☐

15 Does the council or consortium have written policies regarding recruitment of PLWH?

		no	yes
a	Council or consortium states explicitly in recruitment materials that it is looking for members who are PLWH.	0 pts	3 pts
b	Council or consortium describes to whom a PLWH member, representing a PLWH stakeholder group, is required to disclose his or her HIV status.	0 pts	3 pts
c	Council or consortium describes whether it is recruiting members with HIV who are (i) unaffiliated with any AIDS service organizations (ASO) (except as clients), (ii) volunteers at ASO, or (iii) paid staff at ASO.	0 pts	3 pts
d	Council or consortium describes supports (child care, stipends, etc.) offered to PLWH.	0 pts	3 pts
e	Council or consortium describes to what extent PLWH groups or organizations assist in recruitment and nomination of PLWH.	0 pts	3 pts
f	Council or consortium allows PLWH groups or organizations to select representatives to the council or consortium.	0 pts	3 pts
g	Council or consortium specifies a minimum percentage of members who must be PLWH.	0 pts	3 pts

Total Points for Question 15 ☐

16 To what extent has the council or consortium considered the following methods to orient new members?

		not at all considered			considered thoroughly
a	Mentoring programs	0 pts	1 pt	2 pts	3 pts
b	Formal orientation sessions for new members	0 pts	1 pt	2 pts	3 pts
c	Handbooks with information about procedures and operations	0 pts	1 pt	2 pts	3 pts
d	Instructions on how to read budgets	0 pts	1 pt	2 pts	3 pts
e	Committee to oversee orientation process	0 pts	1 pt	2 pts	3 pts
f	Social reception to welcome new members and to create sense of involvement	0 pts	1 pt	2 pts	3 pts
g	Specific opportunities for new members to speak at meetings	0 pts	1 pt	2 pts	3 pts
h	Use of outside trainers to teach needed skills	0 pts	1 pt	2 pts	3 pts
i	Other _____	0 pts	1 pt	2 pts	3 pts

Total Points for Question 16 ☐

17 To what extent has the council or consortium considered the following methods to support and retain members? (Note: Some of these may be implemented for all members, while some may be used for PLWH, indigent members, rural residents, etc.)

not at all considered — **considered thoroughly**

a Transportation assistance

b Child care or reimbursement for babysitting

c Handicapped accessible meeting space

d Interpretation services

e Staff assistance for committees

f Reimbursement for incidental expenses

g Rotation of meeting sites

h Flexible meeting times

i Healthy refreshments

	not at all considered			considered thoroughly
j Mentoring programs	0 pts	1 pt	2 pts	3 pts
k Alternate members (if unable to attend) or proxy voting	0 pts	1 pt	2 pts	3 pts
l Appreciation dinners	0 pts	1 pt	2 pts	3 pts
m Flexibility in expectations regarding meeting attendance and work assignments	0 pts	1 pt	2 pts	3 pts
n Participation by conference call	0 pts	1 pt	2 pts	3 pts
o Other _____	0 pts	1 pt	2 pts	3 pts

Total Points for Question 17 ☐

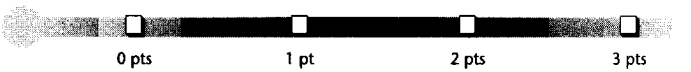
18 To what extent has there been turnover on the planning council or consortium?

substantial number (>25%) of voting members leave before completion of term			no turnover between terms
0 pts	1 pt	2 pts	3 pts

19 In localities where it has been difficult to recruit PLWH members, to what extent has the council or consortium considered using the following methods to obtain input from PLWH:

not at all considered — **considered thoroughly**

a Allow individuals to testify anonymously at public meetings.



b Solicit input through meetings run by and for PLWH only.

c Set up suggestion boxes or call-in lines.

d Conduct a survey of clients.

e Establish a consumer committee.

f Other _____

Total Points for Question 19 ☐

20 What issues, if any, have arisen with respect to recruitment, orientation, and retention of council or consortium membership?

Summary: Recruitment, Orientation, and Retention of Membership

Scoring

To score, follow these steps:

STEP 1 Add up the points for questions 13 through 20 and put that amount in the TOTAL POINTS box.

STEP 2 Add up the number of scored questions (and subquestions) answered and put it in the TOTAL NUMBER OF SCORED QUESTIONS ANSWERED box.

STEP 3 Calculate your final score: TOTAL POINTS divided by TOTAL NUMBER OF SCORED QUESTIONS ANSWERED.

STEP 4 Record your final score in the SCORE box.*

TOTAL POINTS ☐

divided by

TOTAL NUMBER OF SCORED QUESTIONS ANSWERED ☐

equals

SCORE ☐

**If your score equals more than 3, double-check your addition of points and counting of subquestions answered.*

Strengths And Weaknesses

What aspect(s) of recruitment, orientation, and retention of members worked well?

_____

_____

_____

_____

What needs to be improved?

_____

_____

_____

_____

Action Steps

Based on your responses to questions 13 through 20, list the key areas where action should be taken to recruit, orient, and retain your membership. ➔

Action Steps for Questions 13–20

OBJECTIVE:	RESOURCES:
TIME LINE:	PERSON RESPONSIBLE:
OBJECTIVE:	RESOURCES:
TIME LINE:	PERSON RESPONSIBLE:
OBJECTIVE:	RESOURCES:
TIME LINE:	PERSON RESPONSIBLE:

RECRUITMENT, ORIENTATION, AND RETENTION OF MEMBERSHIP: DISCUSSION OF SCORING AND QUESTIONS 13–20

Following is a discussion of **questions 13-20.** This section looks at various methods that councils and consortia can use to recruit and retain membership.

Questions 13A and 13B: In order to recruit membership successfully, it is important that there be a clear application process. Every planning council and consortium should have specific written policies and procedures addressing each of these points. **Question 13A** recommends seven recruitment policies that should be written. In addition, **question 13B** encourages a council or consortium to publicize recruitment policies, so this information is available to prospective members.

Benchmark: The CARE Act, as amended, requires that nominations for membership on a Title I Planning Council be identified through an open process (Section 2602 (b) (1)).

See *"Final Report: The Participation of People with HIV in Title I HIV Health Services Planning Councils"* and the PLWH Sourcebook for recommendations about member recruitment policy for PLWH.

Question 14: Outreach is a major component of the successful recruitment of members. The choices suggested in **question 14** are not meant to be exclusive. Higher scores show that more thought has gone into considering outreach methods.

Question 15: Special efforts are frequently required to recruit members with HIV. The choices suggested in **question 17** can help recruit members with HIV. Note: While DHS requires that 25 percent of authorized Title I Planning Council members are PLWH, a council may set a higher percentage. Consortia are encouraged to follow the 25 percent rule.

Question 16: Another aspect of successful recruitment is to orient new members to the activities of the planning council or consortium. Thorough consideration of the suggested mechanisms for orienting new members will maximize their ability and willingness to participate in council or consortium activities fully.

Question 17: This question lists several mechanisms frequently used by councils and consortia to help support and retain their membership. Some of these activities may help retain and support a diverse membership.

Benchmark: One paper, *"Report on Communities of Color: A Preliminary Progress Report from the Division of HIV Services"* suggests that mentoring programs and social events are helpful in recruitment and retention of members from communities of color who may find the planning council or consortium environment uncomfortable.

There is no single correct score, but if it is difficult to retain members or the membership seems reluctant or "burned out," it may be helpful to explore whether these methods are being used well or can be improved.

Question 18: A score of three points means that there is little or no turnover of members other than the normal expiration of membership terms. If you scored zero points, it is suggested that you review **question 17** to examine whether there are adequate supports given to members.

Question 19: This question provides additional suggestions on how to obtain input from PLWH who are not members of the council or consortium. This can be particularly helpful for rural consortia having difficulty recruiting PLWH.

Benchmark: Policy #1 suggests that "planning councils... establish a formal program of support to facilitate the participation of HIV-positive members. This support may include flexibility in membership expectations regarding factors that are affected by health status..., and reimbursement of incidental expenses related to transportation, parking, and child care incurred... All meetings should take place in handicapped accessible facilities...."

Question 20 is intended to stimulate discussion based on issues related to recruitment, orientation, and retention of members.

Representation and Diversity on the Council or Consortium

A planning council or consortium should include a wide range of community stakeholders.

Representation refers to the 12 categories of membership defined in the CARE Act for Title I Planning Councils.

Reflectiveness refers to the degree to which a council or consortium reflects the demographics of the epidemic in its composition.

21 To what extent do the following types of stakeholders participate in the council or consortium?

A score of 0 means that there is no participation from this type of individual or group. A 3 means that a member of this category is an active voting member of the planning council or consortium. A score of 1 or 2 may be used to indicate the participation of non-voting members or non-members who participate on a committee or task force.

TYPE OF ORGANIZATION | **LEVEL OF PARTICIPATION**

Service Organizations

	no participation from this type of organization			voting member on council or consortium
	0 pts	1 pt	2 pts	3 pts
a Health care providers, including federally qualified health centers (community, migrant, and homeless health centers)*				
b AIDS service organizations and community-based organizations serving affected populations*				
c Local public health agencies*				
d Hospital planning agencies or health care planning agencies*				
e Home care agencies				

**The Ryan White CARE Act of 1990, amended in 1996, requires that these groups be represented on the Title I HIV Health Services Planning Council.*

21 To what extent do the following types of stakeholders participate in the council or consortium?

A score of 0 means that there is no participation from this type of individual or group. A 3 means that a member of this category is an active voting member of the planning council or consortium. A score of 1 or 2 may be used to indicate the participation of non-voting members or non-members who participate on a committee or task force.

TYPE OF ORGANIZATION	LEVEL OF PARTICIPATION
Service Organizations	

		no participation from this type of organization			voting member on council or consortium
a	Health care providers, including federally qualified health centers (community, migrant, and homeless health centers)*	0 pts	1 pt	2 pts	3 pts
b	AIDS service organizations and community-based organizations serving affected populations*	0 pts	1 pt	2 pts	3 pts
c	Local public health agencies*	0 pts	1 pt	2 pts	3 pts
d	Hospital planning agencies or health care planning agencies*	0 pts	1 pt	2 pts	3 pts
e	Home care agencies	0 pts	1 pt	2 pts	3 pts

**The Ryan White CARE Act of 1990, amended in 1996, requires that these groups be represented on the Title I HIV Health Services Planning Council.*

		no participation from this type of organization			voting member on council or consortium
f	Social service providers*	0 pts	1 pt	2 pts	3 pts
g	Mental health centers*	0 pts	1 pt	2 pts	3 pts
h	Dental clinics	0 pts	1 pt	2 pts	3 pts
i	Substance abuse treatment centers*	0 pts	1 pt	2 pts	3 pts
j	Homeless shelters	0 pts	1 pt	2 pts	3 pts
k	Prisons	0 pts	1 pt	2 pts	3 pts
l	Meals on wheels and food pantries	0 pts	1 pt	2 pts	3 pts
m	Hospices	0 pts	1 pt	2 pts	3 pts
n	Housing programs	0 pts	1 pt	2 pts	3 pts

		no participation from this type of community leader			voting member on council or consortium
o	Religious communities	0 pts	1 pt	2 pts	3 pts
p	Business communities	0 pts	1 pt	2 pts	3 pts
q	Women's groups	0 pts	1 pt	2 pts	3 pts
r	Gay/lesbian groups	0 pts	1 pt	2 pts	3 pts
s	Racial/ethnic groups	0 pts	1 pt	2 pts	3 pts
t	HIV activist groups	0 pts	1 pt	2 pts	3 pts
u	Neighborhood/community coalitions	0 pts	1 pt	2 pts	3 pts
v	PLWH groups	0 pts	1 pt	2 pts	3 pts
w	Title I grantee	0 pts	1 pt	2 pts	3 pts

		no participation from this type of funder/collaborator			voting member on council or consortium
x	Title II grantee*	0 pts	1 pt	2 pts	3 pts
y	CDC HIV Prevention Community Planning Groups	0 pts	1 pt	2 pts	3 pts
z	Statewide Coordinated Statement of Need (SCSN) working group	0 pts	1 pt	2 pts	3 pts
aa	Title IIIb grantees*	0 pts	1 pt	2 pts	3 pts
bb	Title IV grantees*	0 pts	1 pt	2 pts	3 pts
cc	Planning council or consortium with overlapping service areas	0 pts	1 pt	2 pts	3 pts
dd	AIDS Education and Training Center (AETC) programs	0 pts	1 pt	2 pts	3 pts
ee	Special Projects of National Significance (SPNS)	0 pts	1 pt	2 pts	3 pts

	no participation from this type of funder/collaborator			voting member on council or consortium
ff Substance Abuse and Mental Health Services Administration (SAMHSA) programs	0 pts	1 pt	2 pts	3 pts
gg Housing Opportunity for People with AIDS (HOPWA) programs	0 pts	1 pt	2 pts	3 pts
hh Maternal and Child Health programs	0 pts	1 pt	2 pts	3 pts
ii TB programs	0 pts	1 pt	2 pts	3 pts
jj STD programs	0 pts	1 pt	2 pts	3 pts
kk State Medicaid program*	0 pts	1 pt	2 pts	3 pts
ll Community funders	0 pts	1 pt	2 pts	3 pts
mm Other _____	0 pts	1 pt	2 pts	3 pts

Total Points for Question 21 ☐

Questions 22–25 and 29 compare how the composition of council or consortium membership reflects the demographics of the local epidemic. To answer these questions, you will need to obtain surveillance data for AIDS cases reported over the most recent two-year time period. (Note: In areas where HIV reporting is mandatory, you may choose to use HIV case reports.)

Here is an example of how this works:

If African-Americans comprise 45% of the AIDS cases reported from 1991 through 1995, write ".45" in Column 1. If African-Americans comprise 36% of the current voting membership of the council or consortium, write ".36" in column 2. The ratio used to measure the adequacy of the representation is:

$$\frac{\text{Percent of Voting Membership}}{\text{Percent of AIDS Cases}} = \text{Ratio of Representativeness}$$

In this case the formula would look as follows:

$$\frac{\text{.36 (Percent of Voting Membership)}}{\text{.45 (Percent of AIDS Cases)}} = \text{.80}$$

Based on the scoring scale, this result would be scored a "2."

22 How diverse is your planning council or consortium with respect to race and ethnicity?

Race/Ethnicity

		Column 1 % of AIDS or HIV Cases Reported in Most Recent 2-Year Period	Column 2 % of Voting Members of Council/Consortium	Column 3 Ratio (Column 2÷ Column 1)	0–.30 0 pts	.31–.60 1 pt	.61–.90 2 pts	>.90 3 pts
a	African-American				0 pts	1 pt	2 pts	3 pts
b	White/Caucasian				0 pts	1 pt	2 pts	3 pts
c	Latino/Hispanic				0 pts	1 pt	2 pts	3 pts
d	Asian or Pacific Islander				0 pts	1 pt	2 pts	3 pts
e	American Indian/Alaska Native				0 pts	1 pt	2 pts	3 pts

Total Points for Question 22

23 How diverse is your planning council or consortium with respect to gender?

Gender

	Column 1 % of AIDS or HIV Cases Reported in Most Recent 2-Year Period	Column 2 % of Voting Members of Council/Consortium	Column 3 Ratio (Column 2÷ Column 1)	0–.30 0 pts	.31–.60 1 pt	.61–.90 2 pts	>.90 3 pts
a Female				0 pts	1 pt	2 pts	3 pts
b Male				0 pts	1 pt	2 pts	3 pts

Total Points for Question 23

24 How diverse is your planning council or consortium with respect to geography? *

		Column 1 % of AIDS or HIV Cases Reported in Most Recent 2-Year Period	Column 2 % of Voting Members of Council/Consortium	Column 3 Ratio (Column 2÷ Column 1)	0–.30 0 pts	.31–.60 1 pt	.61–.90 2 pts	>.90 3 pts
a	Area 1 _____				0 pts	1 pt	2 pts	3 pts
b	Area 2 _____				0 pts	1 pt	2 pts	3 pts
c	Area 3 _____				0 pts	1 pt	2 pts	3 pts
d	Area 4 _____				0 pts	1 pt	2 pts	3 pts
e	Area 5 _____				0 pts	1 pt	2 pts	3 pts
f	Area 6 _____				0 pts	1 pt	2 pts	3 pts
g	Area 7 _____				0 pts	1 pt	2 pts	3 pts

Total Points for Question 24 ☐

* *Planning councils/consortia must decide how to identify key geographic areas. In general, an area may consist of one or more counties or part of a county (a list of cities, towns, or other incorporated or unincorporated areas).*

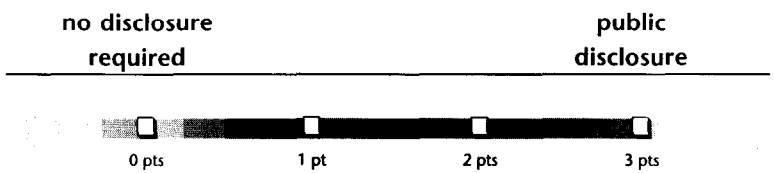
25 How diverse is your planning council or consortium with respect to other population groups significantly affected by the local HIV epidemic?

		Column 1 % of AIDS or HIV Cases Reported in Most Recent 2-Year Period	Column 2 % of Voting Members of Council/Consortium	Column 3 Ratio (Column 2÷ Column 1)	0–.30 0 pts	.31–.60 1 pt	.61–.90 2 pts	>.90 3 pts
a	Gay and bisexual men/ men who have sex with men				0 pts	1 pt	2 pts	3 pts
b	Injecting drug users				0 pts	1 pt	2 pts	3 pts
c	Gay men of color (Specify: _____)				0 pts	1 pt	2 pts	3 pts
d	Other * _____				0 pts	1 pt	2 pts	3 pts
e	Other * _____				0 pts	1 pt	2 pts	3 pts

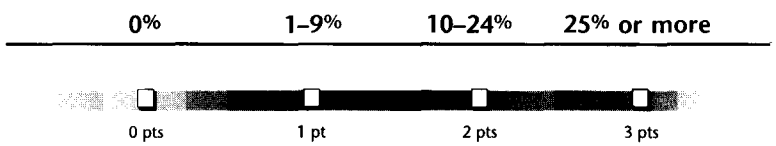
Total Points for Question 25 ☐

** Note: The planning council or consortium must decide which other groups should be reflected within their voting membership based on the local epidemic. The CARE Act Amendments of 1996 state that particular consideration should be given to the inclusion of disproportionately affected and historically underserved groups and sub-populations. Groups such as homeless or dually diagnosed individuals should be considered here.*

26 Has your council or consortium defined the level of disclosure required of PLWH members?



27 What percentage of your authorized (voting) membership consists of PLWH?



28 What percentage of the following committee memberships consists of PLWH?

COMMITTEE	DOES IT EXIST?	0%	1–9%	10–24%	25% or more
a Steering or Executive	☐	0 pts	1 pt	2 pts	3 pts
b Priority Setting and Resource Allocation	☐	0 pts	1 pt	2 pts	3 pts
c Needs Assessment	☐	0 pts	1 pt	2 pts	3 pts
d Planning	☐	0 pts	1 pt	2 pts	3 pts
e Membership	☐	0 pts	1 pt	2 pts	3 pts
f Service Monitoring or Program	☐	0 pts	1 pt	2 pts	3 pts
g Other _____	☐	0 pts	1 pt	2 pts	3 pts

Total Points for Question 28 ☐

29 How diverse is the representation of **people living with HIV** with respect to the following groups?

	Column 1 % of AIDS or HIV Cases Reported in Most Recent 2-Year Period	Column 2 % of Voting PLWH Members of Council/Consortium	Column 3 Ratio (Column 2÷ Column 1)	0–.30 0 pts	.31–.60 1 pt	.61–.90 2 pts	>.90 3 pts
a Caucasian/white gay or bisexual men/men who have sex with men				0 pts	1 pt	2 pts	3 pts
b Injecting drug users				0 pts	1 pt	2 pts	3 pts
c Recipients of blood products				0 pts	1 pt	2 pts	3 pts
d Persons infected through heterosexual contact				0 pts	1 pt	2 pts	3 pts
e Gay/bisexual men of color/men of color who have sex with men				0 pts	1 pt	2 pts	3 pts

		Column 1 % of AIDS or HIV Cases Reported in Most Recent 2-Year Period	Column 2 % of Voting PLWH Members of Council/Consortium	Column 3 Ratio (Column 2÷ Column 1)	0–.30 0 pts	.31–.60 1 pt	.61–.90 2 pts	>.90 3 pts
f	Latino/Hispanic				0 pts	1 pt	2 pts	3 pts
g	African-American/Black				0 pts	1 pt	2 pts	3 pts
h	American Indian/ Alaska Native				0 pts	1 pt	2 pts	3 pts
i	Asian or Pacific Islander				0 pts	1 pt	2 pts	3 pts
j	Women				0 pts	1 pt	2 pts	3 pts

Total Points for Question 29

30 What barriers, if any, have arisen with respect to achieving a representative and diverse planning council or consortium?

	not at all			to a very large extent
31 Has the diversity of the membership helped to increase the diversity of clients receiving services?	0 pts	1 pt	2 pts	3 pts
32 Has the diversity of the membership supported the development of HIV service programs by provider agencies serving diverse communities?	0 pts	1 pt	2 pts	3 pts
33 Has the participation of PLWH provided key information about the needs of affected target populations?	0 pts	1 pt	2 pts	3 pts
34 Has the participation of PLWH influenced service priorities?	0 pts	1 pt	2 pts	3 pts
35 Has the participation of PLWH influenced the allocation of CARE Act funds?	0 pts	1 pt	2 pts	3 pts
36 Are the voting members of the council or consortium satisfied with the representation and diversity of its membership?	0 pts	1 pt	2 pts	3 pts

Summary: Representation and Diversity on the Council or Consortium

Scoring

To score, follow these steps:

STEP 1 Add up the points for questions 21 through 36 and put that amount in the TOTAL POINTS box.

STEP 2 Add up the number of scored questions (and subquestions) answered and put it in the TOTAL NUMBER OF SCORED QUESTIONS ANSWERED box.

STEP 3 Calculate your final score: TOTAL POINTS divided by TOTAL NUMBER OF SCORED QUESTIONS ANSWERED.

STEP 4 Record your final score in the SCORE box.*

TOTAL POINTS ☐

divided by

TOTAL NUMBER OF SCORED QUESTIONS ANSWERED ☐

equals

SCORE ☐

**If your score equals more than 3, double-check your addition of points and counting of subquestions answered.*

Strengths And Weaknesses

Among what groups has the council or consortium done well in terms of representation or reflectiveness?

_____

_____

_____

_____

Among what groups is improvement needed?

_____

_____

_____

_____

Action Steps

Based on your responses to questions 21 through 36, list the key areas where action should be taken to accomplish the planning council or consortium's overall objectives for a representative and diverse membership. ➔

Action Steps for Questions 21–36

OBJECTIVE:	RESOURCES:
TIME LINE:	PERSON RESPONSIBLE:
OBJECTIVE:	RESOURCES:
TIME LINE:	PERSON RESPONSIBLE:
OBJECTIVE:	RESOURCES:
TIME LINE:	PERSON RESPONSIBLE:

REPRESENTATION ON THE COUNCIL OR CONSORTIUM: DISCUSSION OF SCORING AND QUESTIONS 21–36

Following is a discussion of **questions 21-36.**

Question 21: This question scores the number of active voting, non-voting, and committee/task force members (non-active members should not be counted). An asterisk indicates required types of participants for Title I HIV Health Services Planning Councils. Each planning council should have at least one representative from each of these groups as a member of the council. Note: The CARE Act lists mental health and substance abuse providers together, so only one representative is required from those groups.

Benchmark: See Ryan White CARE Act of 1990, as amended, Section 2602(b)(2).

Benchmark: A consortium is defined as an association of one or more public and one or more nonprofit private health care and support service providers. Private for-profit providers may substitute for nonprofits in areas where for-profits are the only available providers of quality HIV care, Ryan White CARE Act of 1990, as amended, Section 2613 (a) (1).

There is no ideal size for planning councils or consortia. This question provides a large list of potential members. In general, the overall size of membership should be sufficient to accomplish the work of the council or consortium. Too few members may create an inability to staff committees adequately, to develop and rotate leadership, and to minimize burnout. A relatively large and inclusive membership can provide a wide variety of skills, perspectives, and community connections.

It is also useful to look at types of members who may or may not be represented adequately. The absence of members with ties to the business, law enforcement, or religious communities may limit the ability of a council or consortium to broaden community ownership and acceptance of efforts to improve local HIV services. A lack of representation from organizations serving women, gay men and lesbians, and communities of color may be associated with difficulty reaching key populations. An open discussion of the results of this question may help members think more about who should be part of the council or consortium and why.

Questions 22, 23, 24, and 25: These questions compare the percentage of voting council or consortium members with the percentage of AIDS or HIV cases reported in the most recent two-year period in the EMA/consortium service area for a range of specific affected population groups. The module uses a threshold of .90 as a "3," because it is not always possible to have a one-to-one correspondence between these two percentages.

Benchmark: The Title I FY 1997 Formula Grant Application Guidance states that "To reflect does not necessarily mean to identically mirror the epidemic..., but to reasonably reflect it."

Consortia, in general, are required to demonstrate that "the consortium includes agencies and community-based organizations that are representative of populations and subpopulations reflecting the local incidence of HIV..." (CARE Act Section 2613(c)(1)(A)(ii))

Use of .90 as a threshold will let members know which groups reasonably reflect the local case rate. In categories where the ratio falls below .90, it will be important for members to discuss which groups are not reflected at that level, and whether this is something that needs to be addressed with an action plan.

Question 26 asks what level of disclosure is required by people living with HIV to be counted as part of this category of membership. The FY 1996 Supplemental Grant Application Guidance asks planning councils how many of its authorized members are "**self-identified** persons with HIV/AIDS?" However, there is no definition of self-identification. It is generally construed to be public disclosure, since many state or local "sunshine" laws require that council and consortium meetings are public, and privacy cannot be assured. However, some councils and consortia have defined self-identification more narrowly, requiring disclosure only to council or consortium members. A good discussion of disclosure issues can be found in the PLWH Sourcebook.

Question 27: While points are awarded to acknowledge inclusion of a lesser percentage of membership, planning councils with less than 25 percent are out of compliance with HRSA policy. An action plan should be instituted immediately to recruit PLWH until the 25 percent level of membership is attained. In Policy #1, DHS requires that councils out of compliance "must develop and implement within six months... a plan with related activities and time lines, acceptable to DHS, to achieve the requisite recruitment and sustained participation of people with HIV disease in planning council processes." Title II HIV Care Consortia are not required by the DHS policy to have PLWH constitute 25 percent of membership; however, they are strongly encouraged to do so.

Benchmark: DHS Policy #1 (Participation of People with HIV Disease on Title I HIV Health Services Planning Councils—referred to as Policy #1) requires that people living with HIV constitute 25 percent of the authorized (voting/specified) membership of planning councils.

Benchmark: In Policy #1, the section on "Suggestions for Policy Implementation and Attaining Compliance" states that PLWH should be encouraged to participate through "specific committee work." Specific mention is made of encouraging PLWH participation in "the needs assessment and comprehensive planning process."

Question 28: While particular percentages are proposed, the list in this question is meant to encourage participation by PLWH on committees that have decision making and other important functions. It is also intended to encourage a level of participation similar to that of the overall planning council or consortium. In other words, if PLWH constitute 25 percent of your membership but 0 percent of your executive or steering committee, a problem may need to be addressed.

Question 29: The method used to determine whether members of the various target populations are represented adequately is the same as the method used in **questions 22–25** to measure overall diversity. Using this method will allow the council or consortium to see where their diversity reflects that of the local epidemic and where it does not.

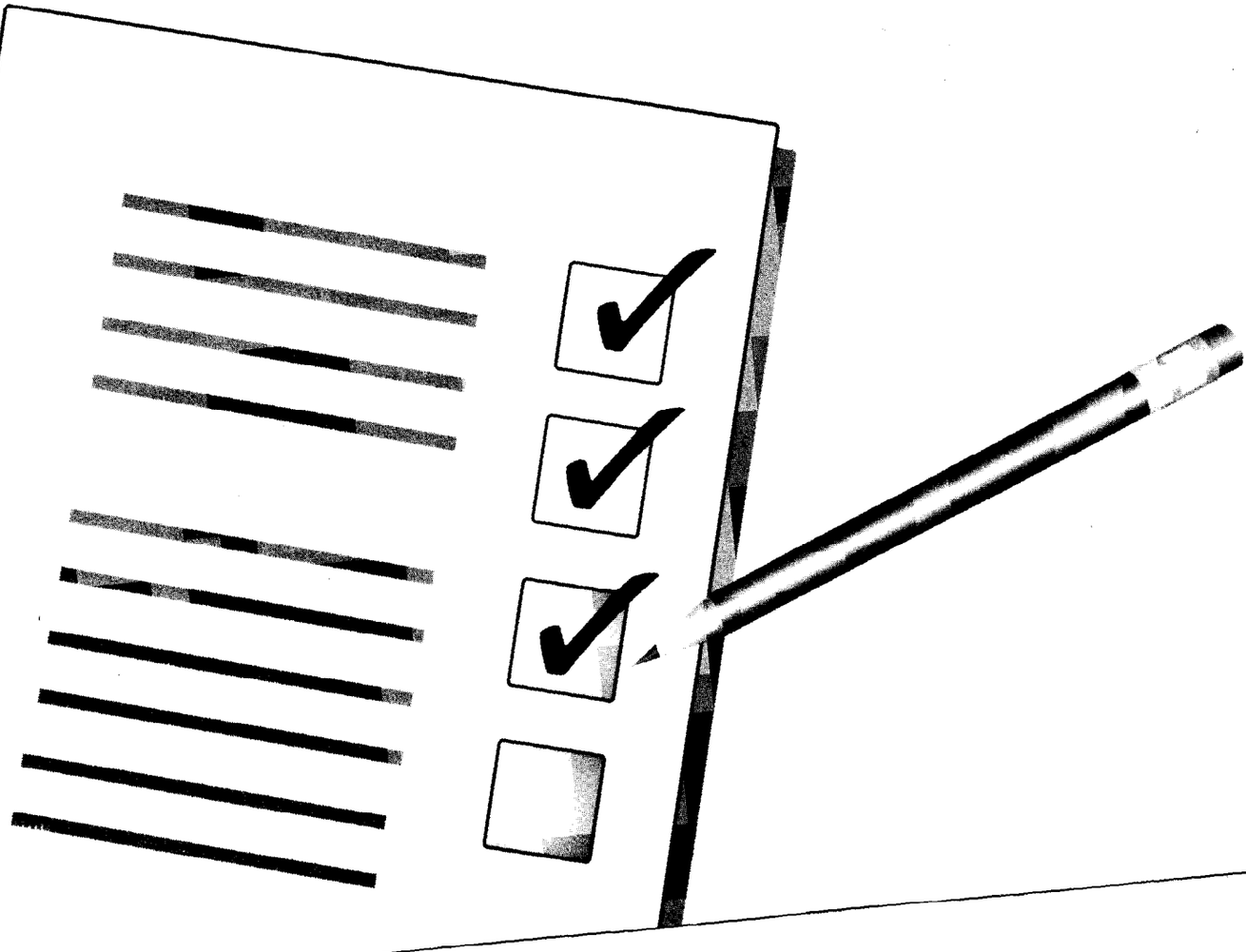
Benchmark: Policy #1 states with reference to PLWH members of planning councils, "These members must reflect the demography and epidemiology of HIV in the EMA..."

Question 30 asks the council or consortium to identify barriers to achieving a representative membership.

Questions 31–36 measure to what extent council or consortium members perceive the diversity of membership has benefitted its planning council or consortium. Answers can be used to stimulate discussion among membership about the impact of diversity on operations.

These questions connect a diverse and representative membership to an improvement in council or consortium operations. Membership must represent and reflect a broad range of stakeholders to improve the quality of services received by PLWH.

RESOURCES



Below is a list of legislation, HRSA documents, articles, and books related to this topic.

LEGISLATION

- CARE Act of 1990 as amended by the Ryan White CARE Act Amendments of 1996.

HRSA DOCUMENTS

- Division of HIV Services Policies:

  Policy #1: The Participation of People with HIV in Title I HIV Health Services Planning Councils.

  Draft Policy #2: Demographic Diversity of Membership on Title I HIV Health Services Planning Councils (working draft).

  Draft Policy #3: Planning Council Duties, Responsibilities, Bylaws, and Operating Procedures (working draft).

- Final Report: The Participation of People with HIV in Title I HIV Health Services Planning Councils, Academy of Educational Development. September, 1994.
- FY 1997 Title I Formula Grant Application Guidance.
- FY 1997 Title I Supplemental Grant Application Guidance.
- FY 1997 Title II Application Guidance.
- HIV/AIDS Workgroup on Health Care Access Issues for African-Americans.
- HIV/AIDS Workgroup on Health Care Access Issues for American Indians and Alaska Natives.
- HIV/AIDS Workgroup on Health Care Access Issues for Gay and Bisexual Men of Color.
- HIV/AIDS Workgroup on Health Care Access Issues for Hispanic-Americans.
- HIV/AIDS Workgroup on Health Care Access Issues for Women.
- Involvement of Persons With HIV/AIDS in Title I and Title II Programs, Technical Assistance Conference Call (held December 14, 1994). Final draft report, MOSAICA. August, 1995.
- PLWH Sourcebook: Involving People Living with HIV Disease in Titles I and II of the Ryan White CARE Act. May, 1996.
- Report on Communities of Color: A Preliminary Progress Report from the Division of HIV Services.
- Report on Women and Title I and II of the CARE Act.
- Working Draft WHITE PAPER: Issues for Consideration by HIV Health Services Planning Councils.

ABSTRACTS, ARTICLES, AND REPORTS

- Board Members Tell How To Get — and Keep — Them Motivated. *Common Ground* #3 (1994): 1, 13.
- Freeman, F. Expanding the Minority Pipeline: A Guide for Board Members. *Association of Governing Boards of Universities and Colleges.* 1992.
- Gantz McKay, E. Do's and Don'ts for An Inclusive HIV Prevention Community Planning Process: A Self-Help Guide. *National Council of La Raza, Center for Health Promotion and MOSAICA.* 1994.
- Houle, C.O. Who Should Be on Your Board? *Nonprofit World* 8. 1 (1990): January/February.
- Houston-Hamilton, A., Pounds, M., Marconi, K. Barriers to Health Care for People of Color Living with HIV *(paper under review).*
- John Snow, Inc. *Formation and Operation of Coalitions to Provide Health Care Services to People with HIV Illness: Analytic Synopsis.* 1993.
- Marmor and Marone. Representing Consumer Interests. *Milbank Memorial Fund Quarterly* 58.1 (1980): 125–165.
- McKinney, M., and Bragg, K. Building an HIV Care Network in Central Iowa. *AIDS and Public Policy Journal* 9.3 (1994): 114–122.
- McKinney, M. Consortium Approaches to the Delivery of HIV Services Under the Ryan White CARE Act. *AIDS and Public Policy Journal* 8.3 (1993):115–125.
- National Association of People With AIDS. *Development Models for PWA Coalitions: A Training Booklet.*
- Nelson, J.G. Six Keys to Recruiting, Orienting, and Involving Nonprofit Board Members. *National Center for Nonprofit Boards.* 1991.
- Robinson, M.K. Developing the Nonprofit Board: Strategies for Orienting, Educating, and Motivating Board Members. *National Center for Nonprofit Boards.* 1994.
- Weisfeld, V.D. AIDS Health Services at the Crossroads: Lessons for Community Care. *Robert Wood Johnson Foundation.* 1991.

BOOKS

- Mor, Fleishman, Allen, and Piette. *Networking AIDS Services.* Ann Arbor: Health Administration Press, 1994.