Concept Paper

Developing a National Quality Improvement Campaign

This concept paper discusses the implementation of the Health Resources and Services Administration (HRSA) HIV/AIDS Bureau (HAB)-funded National Quality Improvement Campaign to advance HIV care and treatment in the United States. The purpose of the Campaign is to improve outcomes on a critical quality topic in HIV care by engaging Ryan White Program-funded grantees and other stakeholders, such as consumers or funders.

This Campaign is a project managed by the National Quality Center (NQC). NQC provides no-cost, state-of-the-art technical assistance for grantees of all Parts funded by HRSA through the Ryan White HIV/AIDS Treatment Extension Act of 2009. Ryan White serves people living with HIV/AIDS who have no health insurance, have insufficient health care coverage, or lack financial resources to get the care they need for their HIV disease. As such, the Ryan White HIV/AIDS Program fills gaps in care not covered by other funding sources.

Background

At the 2009 NQC Steering Committee and Consumer Advisory Committee Meetings, Ryan White stakeholders gathered together to discuss formative concepts for an HAB/NQC-sponsored National Quality Improvement Campaign in HIV care. These groups generated ideas regarding topic selection criteria, involvement of stakeholders, strategies for the Campaign, and support for Campaign participants.

In March 2010, NQC received approval from HRSA HAB to proceed with development of this project. A consultant team¹ assisted NQC to gather information on campaign best practices, to review other quality improvement (QI) campaign models, and to further organize input from the HIV community.

In August 2010, a national survey was conducted with Ryan White Program grantees across all funding streams to inform the development of this Campaign. Additionally, several focus groups were held during the HAB 2010 All Grantee Meeting in Washington, DC.

Throughout the fall of 2010, additional Focus Group Conference Calls were held to gather more input about grantee preference toward the logistics of the Campaign.

In February 2011, a background report and discussion of the pros and cons of two proposed topics (Viral Load Suppression and Patient Retention in Care) was submitted to HAB for consideration. HAB selected Retention as the topic of the 2011/2012 Campaign.

¹ Matthew McClain and Steve Holman, McClain and Associates, Inc.
The balance of this paper summarizes the outputs of these inquiries with the intention of informing the decision-making process on the Campaign’s scope, duration, cost, support structure, and resources needed.

Several quality campaigns in other settings have been looked at as models for the implementation of the NQC Campaign: Data Quality Campaign, Home Health Quality Improvement Campaign, HRSA Health Disparities Collaboratives, and Institute for Healthcare Improvement 100,000 Lives Campaign. Reports are available on each of these campaigns, including an overview, website address, sponsor, approach, duration, participants, motivation/rationale for participating, incentives, launch, implementation, and support provided (website, meetings, documents/guidelines/checklists, conference calls/webinars, videos, and other data).

Overview of NQC Quality Improvement Campaign

This National HIV Campaign is designed to facilitate local, regional, or even state-level efforts on a specific HIV topic while building and sustaining a community of learners among Ryan White providers.

The following basic structure is suggested:

- the Campaign will focus on one aspect of HIV care that is critical to HIV providers across the country and aligned with national HIV policies and strategies
- participation in the Campaign is voluntary and Ryan White grantees and subgrantees across all funding streams are invited to join
- participating grantees enroll for a 12 month commitment
- reporting up to 4 uniform campaign-related measures via an online database every other month
- routine submission of a simple 1-page progress report is expected to highlight improvement strategies and challenges
- monthly conference calls/webinars are held to provide content expertise and promote peer sharing/learning
- participating grantees have access to coaches for support and technical assistance
- where possible, regional/local meetings of NQC Campaign participants are held
- Consumers will be involved in this Campaign wherever possible
- a Technical Working Group is formed to provide content expertise on the Campaign topic
- the Planning Committee is comprised of HAB and NQC representatives, Ryan White grantees, recipients of Ryan White services and other stakeholders to provide guidance to the Campaign.
Recommended Campaign Elements

Drawing from a study of other campaign models and input from hundreds of QI experts, practitioners, and recipients of HIV services, a set of core elements that should define the National Quality Improvement Campaign can be described:

- The Campaign should provide improvement-seekers with a vehicle for mobilizing HIV providers for focused and sustained action on a specific health care topic, critical to HIV care and of national significance.
- While information dissemination/sharing and collaboration is a part of the Campaign, participation in it will require local action that results in documented improvements in patient outcomes based on comparison between the baseline and the endpoint of the Campaign cycle.
- While the submission of topic-related data is required, the process for monthly data reporting should be automated, analyzed, aggregated, and reported; the development of a secure, online portal is suggested.
- While performance measurement plays a critical role, the main focus of upcoming Campaigns is on improving health outcomes on critical aspects of HIV care.
- A Campaign coaching team of diverse quality improvement experts comprised of grantees, consumers, and stakeholders, should be mobilized to lead monthly content presentations and provide assistance, online and face-to-face, to participating grantees.
- The Campaign Coaches should routinely review monthly submissions, provide feedback and conduct periodic check-ins; it was suggested to ‘assign’ specific Coaches to individual grantees or groups of grantees.
- Campaign data collected every other month should be aggregated into a national/regional benchmark report and instantly made available to participating grantees; stratification by Part, region, or other programmatic factors are suggested.
- There will be routine sharing of updates to highlight improvement strategies and challenges.
- Ryan White Program grantees should understand before enrollment that participation is for the full period of the Campaign (e.g., 12-month commitment).
- At the online registration, applicants should provide detailed information about the grantee organization, its quality management infrastructure, quality-related accomplishments and challenges, and other questions related to the Campaign topic.
- As soon a grantee has registered to participate in the Campaign, the grantee should be encouraged to initiate pre-Campaign assignments, such as baseline data collection.
- The Campaign should facilitate building and sustaining key quality improvement competencies while a community of learners and improvers among the participants is strengthened; participation in the Campaign should strengthen the grantee-specific quality management program.
- A Campaign toolkit of key resources, information, tools, and promotional materials should be available to participants.
- Promotional and other ancillary marketing materials and activities will be needed to launch and initiate the Campaign and to creatively engage HIV providers.
- The Campaign will rely on virtual technologies, including teleconferences, webinar events, listservs, etc., to promote quality improvement activities.
Working across individual grantee agencies and across regions is strongly encouraged.
The Campaign should identify options for establishing and supporting regional/local support systems of participating grantees; individual grantees are asked to serve as local hosts for a group of grantees; expectations for local hosts are to ‘sponsor’ regional meetings (provide a meeting room, send out invitations, and facilitate the meetings).
Regional HIVQUAL groups should be utilized to the extent possible.
HAB/NQC should provide some form of recognition to participants who successfully complete a full cycle of the Campaign, with special categories awarded to those that document improvements in outcomes.
Prior NQC Collaborative participants should be recruited in advance of the launch of the campaign.
The impact of the campaign should be measured in health outcomes.

Input from the HIV Quality Community

Through interviews, focus groups, and an online survey taken by respondents in 136 Ryan White programs representing all Parts, potential participants from the community of HIV quality managers, administrators, consultants, and consumers show strong support for a formal, national, evaluated, HIV quality improvement campaign. For example, when asked to describe their level of interest in participating in the Campaign, 75% of respondents to the question say they are either “very interested” or “somewhat interested.” Other input from the HIV community includes:

- Grantees from all Parts of the Ryan White Program are interested in participating.
- The Campaign has the potential to impact a significant number of people living with HIV/AIDS receiving Ryan White Program services.
- A robust quality improvement environment exists among Ryan White grantees, as evidenced in the number and type of quality improvement projects by Ryan White grantees.
- Despite interest in and willingness to participate, grantees face many demands for their time and resources.
- The selection of the Campaign topic is a key determining factor for participating in this Campaign.
- Assume that participants have intermediate or better levels of QI experience.
- NQC should collaborate with HAB and the Office of National AIDS Policy to link the Campaign with the implementation of the National AIDS Strategy.
- Assume that the capacity exists for participants to report up to four uniform measures (preferably from among the HAB core clinical performance measures for adults/adolescents), to attend conference calls/webinars, to make use of dedicated coaches, and to host/attend local/regional Campaign meetings.
- Unblinded data reports should be shared while individual data should not be shared beyond the collaboration without the grantee’s consent.

Two Focus Group Conference Calls were held during the fall of 2010. In both Focus Groups, initial reactions to the Campaign were positive. The findings of the Focus Groups were in line
with those from the survey and other interviews. All participants expressed their support of the Campaign. Those participants directly involved with a grantee indicated that their organizations would be interested in participating in the Campaign and that they expected others in their State would join as well. The general consensus during both Focus Group calls was that a 12-month Campaign would be preferable because grantees would be more willing to fully commit for this amount of time rather than a longer one.

As indicated by the Focus Groups and August 2010 NQC Survey, the topic of the Campaign will play a pivotal role in recruiting grantees to the Campaign. Because participation in the Campaign is voluntary, it is important that the topic appeals to grantees so that they are committed to joining and enthusiastic about participating in the Campaign. Without this buy-in, it would be difficult to recruit the necessary number of participating organizations and reach the most people living with HIV/AIDS. There was some consensus between the Focus Groups that the topic should be chosen to match the following criteria:

- HAB gives a preference for the topic
- Topic involves little to no new costs to the participant
- Topics should be one the participants should already be tracking
- Participants have accessible data for this topic
- Topic can be measurably improved in the course of 12 months

When asked to pick the 3 quality-related topics in a 2010 survey, that are of most interest to them from a list of 10 pre-selected options, more than two-thirds of survey respondents chose “Retaining HIV-positive patients in HIV primary care.” Survey responses are shown below.

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Percent</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Retaining HIV-positive patients in HIV primary care</td>
<td>67.40%</td>
<td>58</td>
</tr>
<tr>
<td>Increasing the number of HIV-positive persons not in care linked to HIV care</td>
<td>45.30%</td>
<td>39</td>
</tr>
<tr>
<td>Increasing the rate of cervical cancer (PAP) screening for women with HIV</td>
<td>45.30%</td>
<td>39</td>
</tr>
<tr>
<td>Improving health literacy among HIV-positive persons in care</td>
<td>26.70%</td>
<td>23</td>
</tr>
<tr>
<td>Increasing the rate of annual mental health screening</td>
<td>24.40%</td>
<td>21</td>
</tr>
<tr>
<td>Increasing the proportion of HIV-positive persons in care who receive an annual oral health screening</td>
<td>24.40%</td>
<td>21</td>
</tr>
<tr>
<td>Increasing the rate of syphilis screening for HIV-positive patients</td>
<td>19.80%</td>
<td>17</td>
</tr>
</tbody>
</table>
Retention in HIV Care

Two topics were initially identified to meet the above criteria and submitted to HRSA HAB. The topic of Retention in HIV Care was selected for the first Campaign.

Across the U.S., 1,106,400 adults and adolescents were living with the HIV at the end of 2006 according to the U.S. Centers for Disease Control and Prevention (CDC). Access to antiretroviral therapy has increased over the last decade; furthermore, antiretroviral therapy has become more potent, better tolerated, and less complex. In fact, most people living with HIV receiving combination antiretroviral therapy achieve an undetectable plasma HIV-RNA level. Nevertheless, deficits in the spectrum of engagement in HIV care including late HIV diagnosis, suboptimal linkage to and retention in HIV care, insufficient use of antiretroviral therapy, and suboptimal adherence to therapy, pose significant barriers to achieving optimal treatment outcomes.

HAB conducted an expert consultation meeting in 2005 focusing on outreach efforts to engage HIV-infected persons in care. This meeting produced an engagement in care continuum model intended to assist service providers and policymakers design programs to meet variable client needs, see Figure below. At one end of the continuum are those who are completely unaware of their HIV status and thus not in care, while those fully engaged in continuous HIV care are at the other end. In between are various degrees of engagement.

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Ideally, HIV-infected persons would progress from learning they are HIV positive to immediate linkage to HIV care to maintaining full engagement in high quality HIV care. However, the reality is quite different. Research has shown that clients may move through different stages along the continuum at various times in their lives. Successful HIV treatment requires sustained engagement in HIV care.\textsuperscript{7} \textsuperscript{8} Population-based studies have found that 45\%–55\% of known HIV-infected individuals fail to receive HIV care during any given year.\textsuperscript{9} \textsuperscript{10} Over longer periods, approximately one-third of HIV-infected individuals fail to access care for 3 consecutive years in some communities.\textsuperscript{11} Continuous retention in care has benefits similar to those of timely entry, and a number of strategies have been developed to promote retention such as intensive case management, patient navigation, peer support groups, and mobile outreach to find clients who were lost to follow-up.\textsuperscript{12}

Patient retention in care measures the ability of a provider to maintain a continuous relationship with a patient through regular medical appointments; this is most often represented as “appointments missed, medical visits at regularly defined intervals, [or…] a combination of those methods focusing on use of the health care system.”\textsuperscript{13} After a positive diagnosis, it is important to retain HIV-infected patients in care for the rest of their lives. HIV/AIDS has shifted into the realm of chronic disease and with this shift, retention of patients in HIV and primary

\textsuperscript{13} Horstmann, E., J. Brown, F. Islam, J. Buck, & B. Agins. “Retaining HIV-Infected Patients in Care: Where Are We? Where Do We Go from Here?” Clinical Infectious Diseases (2010); 50: 752-761
care becomes increasingly important. Improved retention is linked to the main public health goals of reduced morbidity and prevention of chronic disease.

Despite the fact that retention in care is commonly understood as an important indicator for HIV health and is linked in many studies to lower mortality, many HIV-infected patients each year are lost to follow-up, or not retained in care for one reason or another. Studies have found certain characteristics in patients who missed appointments: “a history of or current injection drug use, lower perceived social support, less engagement with the health care provider, and shorter duration of follow-up since baseline.” Many patients who missed appointments have cited reasons such as conflicts with work schedules, lack of child care or transportation, family illness, and hospitalization… forgetting appointments, conflicting appointments, or feeling too sick to attend, and… unexpected social reasons.” These reasons were consistent with patients not retained in care who were not HIV-infected.

A continuous relationship between provider and patient is commonly understood as having important implications for public health. Studies have shown that retaining patients in care results in better health outcomes and lower costs for the patient as regular appointments with a provider are shown to result in improved CD4 count, suppressed viral load, and fewer hospital admissions/emergency room visits. Not only is retention in care linked to better health outcomes for the individual, but retaining a patient in care is also shown to better “prevent […] HIV transmission by promoting safer sex behavior.” However, some argue that the linkage between retention in care (especially in the first year of care) and better health outcomes should not be treated as causal, but rather may be used to “identify a subset of patients whose health behaviors portent mortality.” In this way, retention is an important measure to identify those patients who should be addressed early for future poor health outcomes.

Despite the data available on the importance of retention in care and its linkage to important health outcomes, “little is known about how to retain patients in care.” Several non-treatment factors have been shown in randomized trials to increase retention to care: access to case-management at the time of diagnosis, social services, and flexible clinic and appointment hours.

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15 See Horstmann
16 See Horstmann
17 See Horstmann
20 See Giordano
In summary, 50% of known HIV-infected individuals are not engaged in regular HIV care. As a result, these individuals do not have sustained access to antiretroviral therapy, prophylactic medications, or other medical services. Those who receive antiretroviral therapy intermittently are at increased risk of viral resistance. For these reasons, poor engagement in care is associated with poor health outcomes, including increased mortality. In addition, these individuals contribute to ongoing HIV transmission in the community.

There is much documented support for the use of retention in care as the topic of a National Campaign in HIV care. In the August 2010 survey, 60% respondents indicated that retention in care was the topic of choice for a National HIV Campaign. Both focus groups also indicated that they believed retention in care would be a sound choice for the campaign. According to the August 2010 survey, 18% of respondents are already running interventions focused on Retention in Care, which shows that it is a topic of priority already among participants and that stronger focus on this topic may be of interest to many organizations. Also, this indicates that these respondents are likely already collecting data for retention in care so the data would be readily accessible to the organizations for the campaign.

The Focus Groups indicated that retention in care is a complex topic which would require a multi-faceted campaign allowing participants to get involved in a variety of ways, and the Focus Groups believed this would be beneficial in recruiting participants. There is also strong support for retention in care in the business case for health, and this makes the topic particularly appealing to organizations given the current economic environment.

Lastly, increasing the percentage of patients retained in HIV care (particularly in Ryan White care) is named as a goal in President Obama’s 2010 National HIV/AIDS Strategy. Selection of a topic which is in line with the goals outlined in this National Strategy is an important criterion to ensure the universal relevance to all Ryan White Program grantees.
Planning Committee
The Planning Committee provides the general direction for the National Campaign along with refining its structure and the collateral materials needed to support these activities. The Planning Committee assumes the following responsibilities:

- **Review the progress of the Campaign and suggests potential changes:** the Committee will routinely discuss the progression of the Campaign and suggest any necessary adjustments; routinely review aggregated data reports and provide feedback; review the timetable of the Campaign and ensure critical milestones are met; suggest potential content areas to be covered on upcoming conference calls; present at webinars/conference calls.

- **Defines the elements that are needed to conduct a successful Campaign and to provide input into its development:** a list of collateral materials necessary to conduct a successful campaign has been developed, including marketing brochures to engage grantees in the Campaign, a toolkit that will detail the steps in participation in the campaign, a video that will succinctly illustrate why grantees should participate and other supportive materials as specified by the Committee.

- **Oversee the development of the website and database for the campaign:** a Campaign-specific website will be developed to allow of posting of specific materials and an online database to allow individual agencies to enter and report performance data collected on the Campaign’s performance measures; the Planning Committee will advise the development of these resources.

- **Communicate with key internal and external stakeholders:** the Planning Committee will key key constituencies informed about the progress of the Campaign.

- **Coordinate and guide the various activities of the Technical Working Group, Coaches and Consumer Advisory Committee for National Campaign:** review the activities of these committees and ensure that their work is in line with the overall direction of the Collaborative.
The Planning Committee should meet weekly, particularly during the initial planning stages of the Campaign to maintain a routine communication flow. All calls will be facilitated by a designated facilitator. This approach will provide an opportunity to keep the planning cycle moving forward and able to react to inputs from stakeholders. Potentially, a subgroup of the Planning Committee could be formed to address specific issues, such as a detailed analyses of individual data reports.

**Campaign Coaches**

It is vital that participating grantees have access to expert quality improvement consultants after the launch of the Campaign. Grantees might encounter problems in implementation including how to collecting data, reengaging clients lost to care, reporting on their activities within their organization to name but a few.

The Coaches consist of NQC Consultants and provide individual support to participating grantees. The Coaches, which will participate on the Planning Committee, represents an opportunity to gauge the level of grantee participation, understand any local problems that arise in the grantees ability to execute the Campaign and also provide a forum to talk through issues to continuously make improvements to the Campaign.

The Coaches assume the following responsibilities:

- Support participating grantees: provide technical assistance to grantees, including data reporting and issues related to retention; each coach will be assigned a number of grantees/a region of grantees; support regional meetings of grantees where held.
- Review individual data submissions: routinely review data collection submissions of assigned grantees and provide feedback in writing.
- Identify successes and challenges: assist the Planning Committee in identifying best practices and quality champions as well as common challenges across grantees; identify peer presenters for webinars/conference calls.

The Coaches provide a valuable source of information to NQC as the Campaign proceeds. Consultants will be a valuable communication link between the Planning Committee and the grantees enabling NQC to extend its reach to virtually every grantee involved in the Campaign.

**Consumer Advisory Committee for National Campaign (CAC-NC)**

The members for this Consumer Committee will be chosen from among the NQC CAC Committee. The 4 members chosen for this Committee will advise NQC on all matters related to the Campaign and provide guidance on the Campaign’s design and implementation from the consumers’ perspective. The role of the CAC-NC would be distinct from that of the Planning Committee – it would focus on issues of the National Campaign which affect consumers. One of the individuals from the CAC-NC should also be included on the overall Planning Committee for the Campaign. This individual would be responsible for reporting to the Planning Committee the opinions of the CAC-NC and in bringing back the direction and intentions of the Planning Committee to the CAC-NC.
Technical Working Group
A Technical Working Group comprised of distinguished experts in the field of retention will be created to advise the Planning Committee on content issues for the Campaign. This Committee would meet during the start-up phase of the Campaign to provide suggestions on retention measures and other content areas and conduct some content webinars throughout the Campaign. Some potential members of this Technical Working Group include clinical experts, researchers, national stakeholders, and other strategic thinkers from the Ryan White and other health care communities. Dr. Bruce Agins will chair the Panel and Dr. Laura Cheever should be the co-chair.

Local Sponsor
A local sponsor organization for the National Campaign would be a participating organization in the Campaign which would a) help “sponsor” two regional meetings during the course of the year and b) would hold the position of “peer coaches” on the planning committee of the National Campaign. In hosting the two regional meetings, the local sponsor would facilitate the meetings as well as provide a meeting room and invitations. The benefit in acting as the local sponsor organization would be the opportunity to act as “peer coaches;” the local sponsor would be involved in the planning stages of the Campaign and would have more direct access to the National Quality Center resources. “Peer coaches” refers to the title of the position they would hold on the planning committee of the National Campaign. These local sponsors would be volunteers from the group of participating organizations. They would be chosen on the basis of their ability to produce the necessary rooms and services as well as the location of their organization – they would need to be located in an area which was accessible by car to several other participating organizations. Some possible regions for local sponsors are: California, Chicago, New York, and Florida.

Marketing

There were several approaches to marketing the Campaign. The Campaign should be framed in a way that emphasizes its benefit to participants. Some of these benefits include: feedback during monthly calls (grantees can learn from each other), connecting with high performers in their field, reducing costs by utilizing free resources to improve quality, cleaning up their RSR data, assistance to meet HAB quality expectations, and extra support on QI projects that they would be running separately from the Campaign. To engage grantees once already enrolled in the Campaign, a marketing toolkit will be created and distributed to raise morale in the organization through promotional materials.

Toolkit
A marketing toolkit will be distributed to increase awareness for the Campaign upon enrolling in the Campaign. The marketing toolkit may include the following pieces: pamphlets to be distributed to providers and consumers on the topic chosen, a video to excite grantees, providers, and consumers about participation in the Campaign, and posters or other promotional materials for the grantee organization, etc. to publicize participation in this Campaign and thus the
commitment to improvement in the chosen topic. The toolkit also includes explicit, step-by-step information on how to begin the activities of the Campaign – specific information on data submission, conference calls, monthly reports, etc.

**Stakeholder Engagement**
In order to recruit participants to enroll in the Campaign, Project Officers should be used to reach out to individual grantees. All grantees which participated in the Cross-Part Collaboratives should be directly targeted prior to the announcement of the Campaign so that upon the opening of publicity and recruitment, a large number of grantees will already be signed on. The goal for enrollment is to recruit Ryan White grantees that serve 1 in 5 individuals with AIDS in the U.S.