



New York State Department of Health AIDS Institute

Healthcare Stories Project

Instructional Guide



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Poster and Activity One: Developing Word Clouds

Welcome to the Healthcare Stories Project! This quality care campaign kicks off now, and runs through March 2015 across New York State. It consists of three posters and accompanying activities to encourage people living with HIV/AIDS (healthcare users) to share their experiences and ideas about healthcare. The campaign uses innovative strategies to guide healthcare programs like yours to gather a range of insights from healthcare users, and to use the information to improve the quality of healthcare.

This instructional guide explains Poster and Activity One, called Developing Word Clouds. The guide will assist your program in making a word cloud similar to the poster you received, and, through this process, gain insights into your patient population's perspectives about the quality of care you provide.

The guide walks you through six steps to implement the word cloud activity, beginning with hanging the poster in a prominent space for everyone in the clinic to see. It provides instructions on how to form a Healthcare Stories planning team, collect and map information about quality care, and develop and share the word cloud with healthcare users and staff in your clinic.

Step One (week 1): Identify Space to Display Poster One

Before you go any further, please designate space to display the word cloud poster. You can hang it in a clinic waiting room, or anywhere easily seen by healthcare users and clinic staff.

Why? What does Poster One show? Poster One's word cloud was developed based on responses to the question, "What does quality care mean to you?" asked of healthcare users in New York State during a qualitative study called *Through a Consumer's Lens: Examining Ideas and Experiences of Quality in New York State HIV Healthcare Programs*. The study was conducted between 2010-2011 with 45 healthcare users and their providers in three HIV outpatient hospital-based programs in New York State. The study was ethnographic, meaning that it used open-ended, qualitative research methods to gather descriptive information from users' perspectives. Interviews and observations were some of the primary methods. Poster One visually represents the words of healthcare users who participated in the study. Like any word cloud, the BIGGER the word, the more times it was used to define quality care.

What was learned from healthcare users about *quality care*?

- Relationships matter: 90% of the words describe interpersonal dynamics. As you can see, the number one term was *care*. The poster also includes other relationship-oriented words like *compassion*, *respect*, and *friendly*.
- Other key terms were technical and organizational, such as the importance of *treatment success*, *coordination*, and *informative care*.
- Study participants also used the words to tell their personal stories. These stories illustrated how they made sense of, felt, and acted within their healthcare settings. Quality discussions became very animated and offered insights into the many ways quality care is shaped by healthcare users.

Step Two (week 2): Establish a Word Cloud Team and Hold Initial Meeting to Develop a Clinic-Based Word Cloud

Assemble a Word Cloud Team that includes healthcare users and clinic staff from various disciplines who can successfully carry out the word cloud activity. Consumer Lens findings showed that many healthcare users are interested in participating in program-related activities, so engaging them capitalizes on and strengthens their involvement capacities. The team will need to identify a Word Cloud Team Leader. This individual should be enthusiastic about the project, and have experience managing and championing tasks and timelines in the clinic.

The first task is to set up an introductory Word Cloud Team Meeting. The Team Leader should choose a meeting format that fits the clinic's on-going quality related activities. Team meetings might ideally occur as spin-offs of regularly scheduled QI, PI or CAB forums.

During the initial meeting, the Team Leader should convey to the team the importance of capturing healthcare users' terminology and stories through the word cloud activity. The team can discuss how open-ended and collaborative learning methods such as those used in Consumer Lens offer insights about quality care. The information can be collected in a similar manner to help the clinic learn about:

- Healthcare users' points of view about how clinic services are perceived;
- Whether healthcare users interpret services differently from clinic staff;
- New insights about services, which may broaden and strengthen the quality improvement program.

The Team Leader should assign specific roles and responsibilities to members of the team to carry out project activities, including:

- Project timeline development;
- Plans to capture quality care terms and stories from healthcare users using the provided or self-designed forms (*See Steps Three and Four*);
- Systems to collect and input completed forms (*See Step Four*);
- Data analysis processes to summarize and map terms and stories (*See Step Five*);
- Methods to create and share the program's word cloud (*See Steps Five and Six*).

Step Three (weeks 3-11): Distribute Blurb Cards and Collect Quality Care Information

Use the Blurb Cards Template (*Attachment 1*) to collect information. For approximately 8 weeks, assigned team members should capture healthcare users' stories and terminology using the blurb cards. Healthcare users should be given the card with instructions to complete it during clinic visits or at other times that work for your program.

On side one of the blurb card: healthcare users should be asked to list the three most important words to describe what quality care means to them, or what they want their care to be like.

On side two of the blurb card: ask users to share their most important story that comes to mind (positive or negative) using the words they have listed on side one.

Please inform healthcare users that the story can be about anything related to their healthcare as long as it took place in the clinic. Tell them that their responses will be anonymous. Stories can be short, long, written, and/or captured through drawings. Team members and other clinic staff should be available to assist healthcare users in sharing their stories, especially individuals with low literacy skills. The blurb card should be collected from the healthcare user once it is completed.

Step Four (weeks 3-11): Display Blurb Cards

Designate space near the initial word cloud poster and put the blurb cards up for viewing by healthcare users and clinic staff. The cards should be put up with the words facing out and the stories on the back. Post the blurb cards for approximately eight weeks so they accumulate as an active collage representing everyone's ideas. Clinic staff can support the activity by encouraging as many healthcare users as possible to contribute to the collage.

After 8 weeks, assigned staff should take pictures to memorialize the collage, take down the blurb cards, and prepare to work with them. The AIDS Institute is interested in seeing your collage, so please consider posting photos to the Healthcare Stories Project website improvementexchange.org/hcsp.

Please note: the blurb card template can certainly be adapted to fit your program. The team can also consider other ways of collecting information that may be more appropriate to your clinical setting.

Step Five (weeks 12-13): Mapping and Discussion

Convene the Word Cloud Team to map and discuss the blurb cards. A minimum of 3-4 hours will be needed for this process and may require two or more meetings.

Before this meeting, the team point person should put up the photos taken of the blurb collage and distribute the Bucket Exercise Worksheet (*Attachment 2*), which guides the mapping process.

The filled-out blurb cards should be available to team members. Spend time reviewing the cards during the meeting and begin a mapping process using the following guidelines to assist your team:

1. Establish three subgroups responsible for identifying **Key Terms, Positive Stories, and Negative Stories**. Each group should be comprised of at least one healthcare user and a staff member. Each group should use the Bucket Exercise Worksheet in paper and/or digital form.
2. **Key Terms Subgroup:** Review side one of the blurb cards to identify and list the key terms provided by healthcare users. All terms should be typed into a program such as Microsoft Word. Once all of the terms are listed, cut and paste the words into Wordle, a software word cloud-generating program that can be accessed at www.wordle.net. Then, begin having discussions about the words healthcare users have written on blurb cards guided by the questions provided on the back of the Bucket Exercise Worksheet.
3. **Positive Stories Subgroup:** Read through all the stories on side two of the blurb cards and make notes about healthcare users' positive experiences. Positive stories should be placed into buckets based on common themes. Use a notation to distinguish between positive aspects that are specific (to a particular provider, service, or unique visit) versus more general aspects of care. Once all the positive stories have been accounted for and bucketed, begin to discuss the questions on the back of the Bucket Exercise Worksheet.
4. **Negative Stories Subgroup:** Read through the stories on side two of the blurb cards and make notes about healthcare users' negative experiences. Stories should be placed into buckets based on common themes. Use a notation to distinguish between positive aspects that are specific (to a particular provider, service, or unique visit) versus more general aspects of care. Once all the negative stories have been accounted for and bucketed, begin to discuss the questions on the back of the Bucket Exercise Worksheet.
5. All subgroups should reconvene and report back to one another on key terms and themes. The team should then discuss the questions on the Bucket Exercise Worksheet as a group, and move to filling out the Action Steps Worksheet for each theme based on a discussion of all the responses (*Attachment 3*).

Step Six (weeks 14-16): Creating and Sharing Clinic Word Cloud

Upon completion of the mapping and interpretation, the team should be ready to make the word cloud poster at www.wordle.net. Then, print and affix this new clinic-specific word cloud poster to the wall for everyone to see. It may take the place of the original poster, or the original and yours may be displayed side by side.

If the team wants to go beyond the poster concept, consider creative ways to show off the material you have collected; you might want to make a quilt, an art installation, video, or audio recording.

All clinics that have participated in the Healthcare Stories Project should plan an event such as a ribbon-cutting ceremony to unveil the clinic-specific word cloud poster. This event is an opportunity to present the findings to clinic staff from all disciplines, healthcare users, and key stakeholders who visit the healthcare program. During the event, a discussion should take place about the work that went into the word cloud, the findings, and action steps. This is a way to sustain momentum, encourage integration of findings into program activities, and continue involving healthcare users in clinic activities.

It is important to recognize team members for their contributions and hard work on the Healthcare Stories Project. All activities should be documented for evaluation and replication. Word Clouds and other similar open-ended activities can be used to explore topics in addition to quality care, to inform a range of policy and service delivery issues.

Healthcare Stories Series: Word Cloud Activity Checklist

- Display Poster One in Visible Public Space
- Create a Word Cloud Team comprised of:
Point Person, Healthcare Users and Staff Representing Diversity of Disciplines
- Schedule First Word Cloud Team Planning Meeting
- Assign Team Member Roles/Responsibilities
- Collect Blurb Cards and Create Blurb Card Collage
- Take Pictures of Collage and Send to Cubes
- Hold Second/Third Team Meetings to Map and Discuss Data
- Use Tools to Map Terms and Create Word Cloud
- Use Tools to Find Patterns
- Use Tools to Create Next Action Steps
- Print Word Cloud and Display in Healthcare Program
- Host Word Cloud Unveiling Event to Share Findings and Gather Momentum for Next Steps

The AIDS Institute will be hosting instructional webinars to assist providers across New York State to implement the activities. If you need guidance, technical assistance or on-site coaching, please contact Daniel Tietz, Consumer Affairs Manager, New York State Department of Health AIDS Institute at 877.874.0776 or email at det01@health.state.ny.us, or for additional information visit improvementexchange.org/hcsp.

Stay tuned for upcoming posters two and three with instructional guides for the Healthcare Stories Project. Poster Two will be released in Spring 2014. It will focus on healthcare users' quality journeys!

For inspiration on activity design, thanks to: *The Natural History Museum of Chicago, Center for Cultural Understanding and Change; Always Action Events, Picker Institute and Institute for Healthcare Improvement; and John Bate and Glenn Robert, Bringing User Experience to Healthcare Improvement (Oxford: Radcliffe Publishing, 2007).*

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www.hivguidelines.org/hcsp