How to Evaluate Activities to Increase Colorectal Cancer Screening and Awareness

Version 4

Evaluation Toolkit

NATIONAL
Colorectal
Cancer
ROUNDTABLE

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How to Evaluate Activities to Increase Colorectal Cancer and Awareness
Version 4

Evaluation Toolkit

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INTRODUCTION

The National Colorectal Cancer Roundtable (NCCRT) has partnered with Wilder Research to create this evaluation toolkit. The NCCRT is a national coalition of public, private, and voluntary organizations whose mission is to advance colorectal cancer control efforts by improving communication, coordination, and collaboration among health agencies, medical-professional organizations, and the public. The ultimate goal of the Roundtable is to increase the use of proven colorectal cancer screening tests among the entire population for whom screening is appropriate. The NCCRT has launched the shared goal of regularly screening 80 percent of adults ages 50 and older for cancer by 2018. Hundreds of organizations have signed a pledge committing to this goal, each of which develops and implements a wide range of interventions intended to increase screening.

This latest version of the toolkit is intended to help organizations and communities evaluate a wide variety of interventions [1] designed to increase awareness and use of colorectal cancer screening. The toolkit will help you learn the seven basic steps to evaluation, whether you are working to increase community demand for colorectal cancer screening, encouraging health care providers to recommend screenings, or trying to implement policy, systems, or environmental (PSE) changes. This toolkit will provide you with:

- A basic understanding of evaluation strategies.

- Tools that you can use and adapt to assess baseline screening rates, or the effectiveness or impact of the intervention.

- Basic skills to collect outcome data to inform and improve decision-making.

- Tips for incorporating evaluation results into grant proposals, reports, and other dissemination activities.

- Practical yet comprehensive evaluation references and resources.

This toolkit includes an overall introduction to the concepts and steps involved in evaluating colorectal cancer screening awareness interventions. Throughout this toolkit, you will find examples that highlight what organizations need to do during each phase of an evaluation process. In addition, the Appendix includes case studies focusing on the evaluation of a patient reminder program (Appendix 1.1), a group education program (Appendix 1.2), a provider education program (Appendix 1.3), an initiative designed to increase clinic screening rates

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[1]   Throughout the toolkit, these activities may be referred to as programs, initiatives, interventions, or efforts.

([Appendix 1.4](#)), a day off policy effort ([Appendix 1.5](#)), and a reimbursement policy change ([Appendix 1.6](#)).

FOCUS OF THE TOOLKIT

There are many ways organizations work to increase colorectal cancer screening. Some activities are aimed at health care systems, such as informing providers if their patients are due for screening services. Other approaches seek to remove barriers to screening, such as interventions that reduce out-of-pocket costs or provide transportation to screening services.

The original NCCRT toolkit focused on evaluating programs that seek to increase community demand for colorectal cancer screening, based on interventions reviewed in the Community Guide, http://www.thecommunityguide.org/cancer/index.html. These include:

- **Client reminders** – printed or telephone messages advising people that they are due or late for screening. Screening navigators or health professionals may help provide these reminders to patients.

- **Client incentives** – small, non-coercive rewards (e.g., cash or coupons) to motivate people to seek cancer screening for themselves or encourage others (e.g., family members or close friends) to seek screening.

- **Small media** – videos or printed materials (e.g., letters, brochures, pamphlets, flyers, or newsletters) distributed from health care systems or other community settings that convey educational or motivational information to promote colorectal cancer screening.

- **Group education** – information on screening, including the benefits of getting screened and ways to overcome barriers to screening with the goal of informing, encouraging, and motivating participants to be screened for colorectal cancer. Group education is usually conducted by health professionals or by trained laypeople, including screening navigators.

- **One-on-one education** – information conveyed by telephone or in-person about screening procedures, including benefits and ways to overcome barriers to screening with the goal of informing, encouraging, and motivating people to seek colorectal cancer screening. These messages are delivered by health professionals or by trained laypeople, including screening navigators.

In this new version of the toolkit, we have expanded the number of interventions discussed, to take a wider look at how evaluation works. These interventions include:

■ **Provider assessment and feedback interventions** – interventions that both evaluate provider performance in recommending or delivering screening to clients (assessment) and present providers with information about their performance in providing screening services (feedback). Feedback may describe the performance of a group of providers (e.g., mean performance for a practice) or an individual provider, and may be compared with a goal or standard.

■ **Provider reminder and recall systems** – provider reminders inform health care providers it is time for a client's cancer screening test (called a "reminder") or that the client is overdue for screening (called a "recall"). The reminders can be provided in different ways, such as in client charts or through electronic medical records (EMR).

■ **PSE changes** – organizations can also direct their work to policy, system, and environmental (PSE) changes to support increased screening. While people's health is affected by their individual behavior, other factors such as rules, laws, the physical environment, and access to jobs, education, and health care also play a key role. The PSE approach attempts to address these factors in an effort to create sustainable changes that could have a broader impact on people's choices and health.

  o **Policy change** – a change in laws, ordinances, and regulations, or smaller scale change to an organization's rules, mandates, or practices. Examples include: required coverage of colorectal cancer screening under the Affordable Care Act or a workplace policy that allows employees to get screened for colorectal cancer during work hours.

  o **System change** – a change that impacts all aspects of an organization, institution, or system. System change can work in tandem with policy change. Examples include: a statewide program that trains health care providers on how to change their policies and practices to increase the number of patients who are referred for colorectal cancer screening, or a clinic that trains its staff on how to create a new system to standardize reminders for patients about receiving colorectal cancer screening. [2] System change is being emphasized by the CDC in its Colorectal Cancer Control Program, which is a grant program in 24 state health departments,

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[2] The NCCRT has several resources to assist with system changes, including: (1) How to Increase Colorectal Cancer Screening Rates in Practice: A Primary Care Clinician's Evidenced-Based Toolbox and Guide; (2) Steps for Increasing Colorectal Cancer Screening Rates: A Manual for Community Health Centers and (3) EHR Best Practice Workflow and Documentation Guide to Support Colorectal Cancer Screening Improvement with eClinicalWorks.

six universities, and one American Indian tribe. CDC also has <u>a guide for measuring colorectal cancer screening rates in health system clinics</u>.

- **Environmental change –** simple or complex changes to the physical environment. Environmental changes often provide greater access to resources that promote health, such as sidewalks, bike lanes, or a farmers market. An example of an environmental change related to colorectal cancer screening is a mobile health unit that, in concert with a local community health center, provides a variety of health services, including initial consultations on colorectal cancer screening. This intervention is a short-term environmental change because it temporarily impacts the opportunities for screening consultation available to residents in a geographic area.

The evidence showing the effectiveness of different interventions varies. There is strong evidence supporting small media, sufficient evidence supporting client reminders and one-on-one education, and insufficient evidence showing the effectiveness of client incentives and group education. Provider assessments and feedback and provider reminders have also been effective and are recommended interventions. PSE interventions can vary tremendously in intent, implementation, and impact. However, there is general support for the role PSE change efforts can play in improving public health. Despite the variety of strategies presented, the approach to evaluation is similar across the interventions. Whatever type of colorectal cancer screening awareness activity you are implementing, there is a way to evaluate it.

The toolkit is not designed to evaluate mass media campaigns, as evaluating a mass media campaign requires specific skills, knowledge, and resources that are not comprehensively covered here. Evaluating mass media campaigns most often requires the assistance of experienced professionals. However, in recent years, there has also been increased use of social media to promote colorectal cancer screening. Evaluating social media campaigns can be done for low or no cost, and can require less technical expertise to implement. Some general information about evaluating mass media and social media campaigns can be found in <u>Appendix 2.1</u>, along with a case study highlighting the evaluation of a social media initiative.

Finally, it is important to note that while this toolkit was developed specifically for programs working to increase colorectal cancer screening, the concepts can transfer to the evaluation of any number of health- or non-health related interventions. These concepts can be successfully applied to evaluate health and human services programs and activities in a wide variety of settings, including clinics, schools, nonprofit organizations, and government agencies.

THE IMPORTANCE OF EVALUATION

Chapter overview

By the end of this chapter, you will be able to:

- **Understand the importance of conducting a program evaluation.**

- **Begin identifying your evaluation questions.**

Are your efforts a worthwhile use of time and resources? Are you making the difference you want to make? How can you do your work even better?

At its most basic level, evaluation gathers the information necessary to help answer these questions.

We know that screening for colorectal cancer helps prevent and detect the disease early, thus increasing the likelihood of survival. Colorectal cancer incidence rates have dropped by over 30 percent in the U.S. among adults age 50 and older in the last fifteen years, with a substantial portion of these declines due to screening. For these reasons, many organizations have joined the 80% by 2018 effort, focusing resources on raising awareness about colorectal cancer, increasing individuals' commitment to undergo screening, or reducing barriers to screening.

Evaluation, collecting information about how your intervention [3] operates and its impact, helps you demonstrate the success of your activities. A good evaluation can also help you monitor service delivery or implementation, assess participant or community needs, and identify ways to improve.

Evaluation can also support your efforts to secure funding—funders are more willing to provide resources if you can show that your intervention is making a difference. Evaluation can help you enhance funding requests by demonstrating an intervention's strengths, identifying a need to improve, or justifying a need to expand. The information you collect can also build other types of support, including recruiting staff or volunteers, engaging potential collaborators, attracting participants, or influencing decision-makers. By sharing your evaluation results with others, you expand the knowledge base of effective colorectal cancer screening awareness interventions, essentially multiplying the reach of your work.

When it comes to evaluation, there is no "one-size-fits-all." To make the best use of your time and resources, your evaluation should be tailored to your organization. Understanding what your organization hopes to learn through the evaluation will help you determine the information you need to collect and the tools you will use to do so.

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[3]   Throughout the toolkit, these activities may be referred to as programs, initiatives, interventions, or efforts.

TYPICAL EVALUATION QUESTIONS

Evaluation can help you learn useful information about your intervention. This toolkit focuses on the following types of questions related to activities to increase colorectal cancer screening awareness and use.

> ▶ Are we communicating accurate information about colorectal cancer and colorectal cancer screening options?

> ▶ Did we reach our target group?

> ▶ Did we increase participants' knowledge of colorectal cancer and the importance of screening?

> ▶ Did we increase intention, motivation, or pledges to screen for colorectal cancer?

> ▶ Did we increase the number of people who talked to their doctor or health care provider about screening?

> ▶ Did we increase discussions about colorectal cancer screening among family and friends?

> ▶ Did risk-appropriate individuals get screened for colorectal cancer as a result of our activities?

> ▶ Did we increase overall screening rates among the age-appropriate population?

> ▶ How did one intervention compare to another in terms of benefit? In terms of cost?

> ▶ How satisfied are people with the program activities and materials? What suggestions do they have for improvement?

> ▶ Did we reduce barriers to screening, making it easier for people to obtain recommended screening tests?

> ▶ Did we influence or change the processes or practices of key systems such as public health departments, physicians' offices, clinics, or hospitals?

During an evaluation, you will not generally focus on all of these issues at a single time. Instead, it is important to select the most relevant evaluation questions. Below are descriptions of three sample organizations that are embarking on the evaluation process, including their initial evaluation concerns. In subsequent sections of the toolkit, we will follow these organizations to see how their questions were used to guide their evaluation process and how they used what they learned to enhance the interventions.

SAMPLE PROGRAMS

Example 1: Northside Medical Clinic

The Northside Medical Clinic is a community-based clinic with 15 practicing physicians. They have joined a nationwide effort to increase the rates at which they screen adults for colorectal cancer. The clinic is not currently tracking who is eligible for screening, how often physicians discuss screening with patients, or how often people actually get screened.

Some physicians are confident that most of their patients are being screened as appropriate. Others are uncertain of how many patients are following through with screening. A review of a small number of patient records shows that many patients age 50 and older are not up to date with screening recommendations.

The team would like to select an intervention to help them increase screening, but without accurate information about their current rates, they are finding it hard to set realistic goals and choose the right approach. They decide to use an external reporting tool to extract data from the Electronic Health Record (EHR) and use the data for quality improvement. The tool extracts the data from the EHR and loads it into a reporting database, so each physician can receive a summary of his or her own screening rates each quarter.

Example 2: Metropolitan Colon Cancer Collaborative

The Metropolitan Colon Cancer Collaborative, an advocacy group, develops and distributes brochures and other written information to promote colorectal cancer screening. Their target audience is the African American community.

Every five years, the Collaborative engages in a strategic planning process to identify community needs, assess the impact of their materials, and establish future priorities.

As part of this process, Collaborative members consult with core stake-holders including leaders within the African American community and local public health professionals. Their discussions yield a number of questions: Are they successfully reaching their target group? Do people read and understand their materials? Do their materials provide accurate information about colorectal cancer and screening options? Does it change the way recipients think or feel about screening? Do the materials increase knowledge of colorectal cancer and the importance of screening? Do more people ultimately get screened?

Example 3: The Wellness Clinic

The Wellness Clinic, a hospital-based medical clinic, has been identifying individuals who should begin screening for colorectal cancer (based on their age or other risk factors) and conducting one-on-one educational sessions during other types of appointments. Their goal is to increase the percentage of patients who get screened.

The staff already know that one-on-one education should help increase knowledge and awareness. However, their clinic manager and board of directors are not convinced. They want to see data on their own patients to justify the cost and staff time dedicated to these one-on-one conversations.

Because the education is happening one-to-one, clinic staff are also interested in patient satisfaction. It is important to them that people are comfortable with the discussion, and view staff as knowledgeable and helpful.

ENGAGING STAKEHOLDERS IN EVALUATION ACTIVITIES

Evaluation can also be an effective strategy for helping build and strengthen relationships with critical stakeholders, such as project staff, organizational partners, and participants. Involving these partners in the process also helps ensure evaluation activities meet the needs of all stakeholders. Throughout the toolkit, we will offer suggestions for engaging stakeholders in your evaluation project. For example, you could consider:

- Including key stakeholders at all stages of the evaluation process (e.g., formulation of questions, development of design, collection of data, analysis of results).

- Establishing credibility of the evaluation by demonstrating local relevance and the usefulness of the results.

- Fostering trust by stressing the importance of the evaluation work and building relationships between public health professionals and people targeted by the intervention.

- Developing collaborations and relationships with the target population (e.g., community leaders and organizations).

- Recruiting team members from the various communities targeted by the intervention—this can increase the visibility of the project and enhance the credibility of the evaluation.

- Providing outreach and education to inform potential participants of the purpose and benefit of the evaluation.

WHAT IS EVALUATION?

Chapter overview

By the end of this chapter, you will be able to:

- **Understand the steps involved in program evaluation and the importance of addressing ethical and cultural considerations throughout the process.**

- **Understand the purpose of measuring outcomes and how the results can show a change in knowledge, attitude, or screening behavior of a targeted population.**

- **Know how process and satisfaction measures can be helpful for improving program implementation.**

- **Be ready to get started with your own evaluation.**

Evaluation is a technical process that encourages careful planning of what you want to know and how you are going to gather the data to answer your questions. However, evaluation does not need to be overly complicated, time-consuming, or expensive. In fact, the best evaluations are often those that are simple and targeted to answering key program[4] questions. Many organizations conduct evaluations to help them improve programming, using limited resources and internal staff who are not formally trained evaluators.

That being said, evaluation does require some knowledge and skill to do well. Rushing into an evaluation without a basic understanding of the process often yields information that is difficult to use. This toolkit provides a step-by-step guide to help staff with limited experience build their knowledge of and capacity to do evaluation. Anyone with the time and interest can become a competent evaluator. However, it can also be helpful to remember that you do not need to tackle this on your own. If you feel confused or overwhelmed as you move through the process, you may want to seek support or advice from a professional evaluator.

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[4] Throughout the toolkit, these activities may be referred to as programs, initiatives, interventions, or efforts.

A STEP-BY-STEP APPROACH

Evaluation is best thought of as a series of steps designed to help you identify and prioritize your evaluation needs, collect the right information to answer your questions, interpret your findings, and use the results to enhance your intervention. It is not uncommon for novice evaluators to want to skip some of the early planning steps and move quickly into the information gathering stage. However, by following the steps outlined below, your evaluation is likely to run more smoothly and produce better data. Each of these steps is further described in subsequent chapters of the toolkit. The same steps apply, regardless of the type of intervention being offered. They can be used to evaluate a targeted intervention, such as client reminders, a small media effort, a policy change within an organization, or broader system-wide initiatives.

Rather than being a one-time linear process, it is helpful to think of evaluation as cyclical. Once an evaluation cycle is complete (that is, you've moved through all seven steps outlined below), you will typically find yourself back at the beginning. At this point, you may want to revise your evaluation to explore additional questions not given priority in the first cycle, or those questions which emerged from the initial evaluation. If the initial evaluation findings resulted in a change to services or approach, you may want to continue the evaluation to determine whether the changes had the desired impact on your intervention's success.
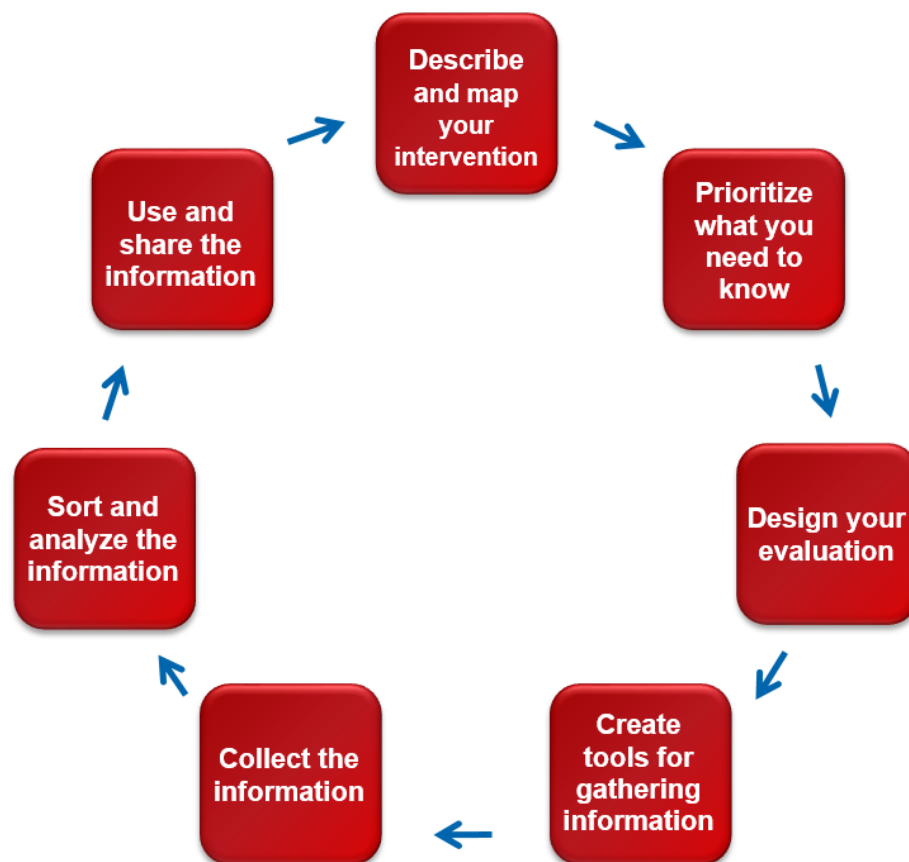
Step 1: Describe and map your intervention. Whenever you design an intervention to increase colorectal cancer screening, consider factors such as who the intervention should target and how the intervention should be delivered. A necessary part of the evaluation process is being able to clearly articulate why you provide each specific intervention and how these activities will benefit the people targeted by the intervention. The why and how is often referred to as a **program theory**. Concisely describing your program theory can help build a shared understanding of the effort among stakeholders, identify the right outcomes to measure, and guide program or policy improvements.

In addition to articulating what your intervention does, it is also helpful to "map" the intervention. Program maps or **logic models**, present a clear picture of the links between program activities and what you expect to happen as a result, your "outcomes." Logic models represent an easy way to show stakeholders, such as funders, staff, and participants, what should happen in your intervention.

Step 2: Prioritize what you need to know. Once you have developed your logic model, you are ready to prioritize the evaluation issues you *specifically* want to address. Use your logic model and other program materials, as well as feedback from people interested in your intervention, to decide which evaluation questions are the most important to answer.

Step 3: Design your evaluation. Before embarking on an evaluation, save time and energy by assessing your organization's evaluation capacity. By knowing what resources are available, you can design a process that will answer your evaluation questions and be completed within the available budget, staff, and time. Once you have selected your key evaluation issues or questions and assessed your capacity, the next step is to develop a plan for gathering the right information. For example, you might want to identify potential data collection strategies, such as using a survey to collect data from participants at events, conducting a phone interview with patients, or gathering information from program records or community databases, and then select the best option and number of data collection points. All strategies for gathering information have strengths and weaknesses; considering the strengths and weaknesses of each method helps you choose the most appropriate and reasonable options for your situation.

Step 4: Create tools for gathering information. The tools you use to collect information will vary for each evaluation. You could design your own data collection tools or use existing tools. Either way, your data collection materials should align with your prioritized evaluation questions and be tailored to your audience to make it easy for them to understand what you are asking.

Step 5: Collect the information. The next step is to implement the evaluation by gathering the necessary information. Depending on your evaluation plan, you may need to conduct surveys, interview project partners, document service delivery, or collect information another way.

Step 6: Sort and analyze the information. Whether you have collected verbal information such as transcribed responses from a key informant interview, or numerical data such as responses to a survey question, the next step is to organize the data in a way that can be easily understood and used to identify your key findings.

Step 7: Use and share the information. Once you have gone through the effort of conducting an evaluation, it is important to put the information to use. You can use the information to help improve your programming, target your efforts, solicit funding, or communicate your successes. It is important to share what you learn with those who care about your intervention such as participants, program staff, medical practitioners, funders, and decision-makers. Likewise, sharing evaluation information with a broader professional audience, through journals or presentations, can further the field of colorectal cancer awareness and screening.

IMPORTANT CONSIDERATIONS

Across all of these steps, it is important to ensure that the evaluation is appropriate and sensitive to your target population. Making sure that your evaluation is ethically sound and culturally appropriate will require some consideration throughout each step of the process.

Identify ethical implications. Whenever you start an evaluation, ethics should be addressed up front. It is important to think about how the data will be used, what data privacy laws apply, and how data will be kept confidential. It is also important to ask yourself how the evaluation protects the rights and dignity of intervention and evaluation participants.

> *Key Ethical Questions*
> *Are you allowing participants the opportunity to opt out of the evaluation?*
> *Are you explaining how you will keep their information private?*
> *Are you explaining how the information will be used?*
> *Are you giving clients opportunities to ask questions and learn the results of the evaluation?*

These questions should be a continuous part of the evaluation process. More information about ethical issues can be found in Appendix 2.2, including advice for protecting individuals' rights, addressing ethical issues, and information on Institutional Review Boards (IRBs). The Appendix also includes a sample consent form, in both English (Appendix 3.1) and Spanish (Appendix 3.2).

Address cultural considerations. Throughout the evaluation process, you should consider differences among stakeholders, participants, and communities based on characteristics such as race, ethnicity, language, literacy level, available resources, age, and gender. People react differently to interventions and evaluation depending on their background and experiences, and you want your evaluation to be sensitive to the needs of the community with which you are

working. Take care to approach any evaluation activities, as with any program activities, with sensitivity to cultural considerations.

There may be reluctance among some communities to participate in evaluation efforts, given historical concerns and the perception of the process as intrusive and potentially exploitative. Build relationships with community leaders, and know that it may take time and open communication to develop trust. Work with the community to co-create projects of interest or importance, and allow authentic opportunities to provide input regarding the proposed evaluation.

WHAT EVALUATIONS MEASURE

When conducting an evaluation, it is important to decide what you want to know. Your organization may want to understand what screening resources people are using or what prevents people from getting screened. You may be interested in how well your intervention is being implemented, or whether or not you are meeting your objectives. You may also want to know if program participants are satisfied with your materials or the new systems you have put in place. These evaluation questions often fall into three broad categories: outcomes, process, and satisfaction.

When you design an evaluation, it is a good idea to consider all three of these categories. For example, your organization may be interested in knowing whether your reminder postcards result in more people speaking with their health care providers about getting screened. It may also be beneficial to learn whether you are reaching the people originally intended, and if they are satisfied with the information they received about screening options.

> *Combining questions about outcomes, process, and satisfaction will help your organization make more informed programming decisions, as you will better understand not only the outcomes that resulted, but where changes should be made to enhance success and increase satisfaction.*

Outcomes

Outcomes are any changes that can be reasonably expected as a result of your intervention. Measuring outcomes documents the intervention's actual impact and can identify promising strategies for strengthening or refocusing services.

Benefits of an outcome evaluation include:

- **Understanding how well your intervention reached its goals.** An outcome evaluation can provide evidence of change as a result of the intervention, which is helpful in proving intervention effectiveness to funders or other stakeholders. These results can also help you devise solutions to improve outcomes.

■ **Identifying promising practices.** If your intervention has been shown to produce positive outcomes, you would most likely want to replicate the activities in order to increase your potential impact and others may want to learn from your "promising practices." An outcome evaluation can help pinpoint these promising practice strategies.

■ **Sustaining current funding or securing future funding.** Funders may be more likely to continue supporting your intervention if there is evidence of increased awareness, knowledge, or behavior among the people targeted by the intervention.

■ **Recognizing a job well done among staff.** Positive outcomes can indicate staff effectiveness and dedication. Evaluation can offer practical evidence that the intervention is making a difference, which can help boost morale of staff and support continued investment and buy-in from program managers.

Although increased screening rates are typically a long-term goal of colorectal cancer screening awareness interventions and provider or system-level interventions, your organization may choose to focus on an earlier outcome, such as changes in awareness, knowledge, or intention to be screened. In a small media campaign, for example, a desired outcome may be to increase the number of people who speak with their health care providers about colorectal cancer screening. The following are sample questions colorectal cancer screening interventions could address through an outcome evaluation:

▶ Do people show increased knowledge of colorectal cancer screening?

▶ Did the intervention increase community members' intention or commitment to get screened?

▶ Did more people speak with their health care provider about getting screened?

▶ Did age-appropriate participants receive a screening recommendation?

▶ Did screening rates improve compared to rates prior to the intervention?

▶ Did providers' screening rates increase compared to their baseline?

▶ Did regular updates for health care providers on their screening rates lead to an overall increase in rates as compared to their other providers?

▶ How did a lower cost intervention compare to a more expensive intervention in increasing screening rates?

▶ Do people show increased knowledge of insurance coverage for colorectal cancer screening?

Process

Process evaluation can help you understand how your intervention works and whether it is working the way you expect. It can help you identify any implementation concerns, determine whether the program is communicating the right messages about colorectal cancer screening, or determine whether participants understand the information they receive. Benefits of a process evaluation include:

- **Explaining how your intervention is put into practice and identifying room for improvement.** A process evaluation provides an in-depth look at how your intervention operates— the reach of your campaign or activities, whether participants understand your materials, the adequacy of funding to meet your objectives, and the strength of your organization's partnership with other entities. This information will help determine whether your intervention is doing what it intended and can help pinpoint where changes could be made in order to reach your goals.

- **Understanding potential for impact.** Although a process evaluation does not assess actual outcomes, it can help you see whether the intervention is on the right course to accomplish its goals. Should any challenges present themselves (e.g., patients cannot understand the materials or clinicians are having difficulty making reminder calls consistently) you will be able to devise a plan for dealing with them.

- **Describing interventions to stakeholders.** Program stakeholders, may be interested in understanding how your intervention functions, the activities you offer, and how many people you reach. Funders may use process evaluation results to decide whether an intervention should be continued or expanded. Should others be interested in replicating your intervention, the results can help with understanding how your program runs, any challenges that have emerged, and how they were addressed.

A process evaluation can help your organization answer questions relating to **your program message**, **service delivery and reach**, **and how the implementation of the intervention relates to outcomes**:

- ▶ Are the messages you are sending out about colorectal cancer and screening appropriate (e.g., culturally appropriate or consistent with guidelines)?

- ▶ How many people are you reaching through your colorectal cancer screening efforts? Are you reaching your intended target groups?

- ▶ Does the intervention have a defined point of completion, such as attending a number of colorectal cancer education sessions or regularly informing all providers of their screening

rates a set number of times annually? If so, did you meet the goal? What factors influence completion or implementation rates?

▶ How well are your activities meeting your participants' needs?

▶ Is the intervention being implemented according to plan (e.g., timeline, budget, staffing, and the number of participants)?

▶ Does everyone on staff understand the workflow for a new office policy to support screening?

▶ Are there certain aspects of the intervention that make people more or less likely to benefit from it?

▶ What questions or concerns do staff members, participants, or other key stakeholders have about the intervention?

▶ What challenges and barriers have been encountered? How have you addressed those, and with what degree of success?

▶ If you are working in collaboration with other health-related agencies or organizations, how are those partnerships working?

▶ To what extent was a policy supported by organizational, administrative, or political leaders?

▶ What resources are needed to sustain the efforts?

Satisfaction

Evaluating satisfaction helps you understand whether the individuals who received services or participated in an activity were pleased with the services, felt they received the right type or amount of services, or have suggestions for change. In some cases, this assessment may include other stakeholders, such as health care providers, family members, and collaborators. This type of evaluation often addresses issues such as satisfaction with staff and the quality of facilities or materials. While having satisfied participants is not necessarily the same as having successful outcomes, it can be a useful source of feedback. The following are benefits of evaluating stakeholder satisfaction:

■ **Understanding your intervention's strengths and where there is potential room for improvement.** Key stakeholders can let you know what they enjoyed or disliked about your intervention and how helpful they found staff, materials, or services. Participants

should be given the opportunity to offer specific feedback about activities in order to uncover suggestions for improvement.

- ■ **Determining what aspects of your intervention should continue, what could be improved, and what should be discarded.** This feedback is crucial for your colorectal cancer screening intervention, as it can determine whether participants will continue with the effort or staff will remain committed.

Here are some evaluation questions that address satisfaction:

▶ Did clinical staff find the new policy easy to implement? If so, how? If not, why not?

▶ How satisfied are key stakeholders with our intervention?

▶ Did participants find the educational or screening materials useful? If so, how? If not, why not?

▶ Did participants find program staff helpful? If so, why? If not, why not?

▶ Would participants or clinic staff recommend the program to others?

▶ Is there additional information that participants or clinic staff would have liked to have received?

An understanding of community needs

Evaluations of outcomes, process, and satisfaction encompass the most common types of program evaluation. Prior to conducting any of these types of evaluation, however, it may be in your organization's best interest to assess your community's needs. These assessments are not only helpful while planning your intervention, but can also be beneficial for understanding whether you are still meeting the needs of your target population as the program progresses. Further information on evaluating community needs can be found in Appendix 2.3.

SAMPLE INTERVENTIONS

As described in the previous chapter, the three sample organizations have all identified a number of initial evaluation questions of interest to them.

Example 1: Northside Medical Clinic

Northside Medical Clinic is interested in outcomes, primarily an increased rate of colorectal cancer screening for each provider and across their clinic as a whole.

Example 2: Metropolitan Colon Cancer Collaborative

The Metropolitan Colon Cancer Collaborative is interested in outcomes such as impact of their educational materials on recipients' knowledge and subsequent likelihood of being screened. They also identified a number of process questions about their strategy and materials, including issues related to the accuracy and clarity of the information and their success in reaching their intended population.

Example 3: The Wellness Clinic

The Wellness Clinic staff are interested in outcomes such as their success in increasing screening rates. Because they provide education in a one-on-one setting, they are also interested in patient satisfaction with the services provided. It is important that participants are comfortable with the discussions and perceive the staff as knowledgeable and helpful.

GETTING STARTED

The next chapters will walk you through each of the evaluation steps in more detail. Before you begin to work through the steps, take a few minutes to write down your initial goals for the evaluation. Why are you interested in evaluating your program? What are you hoping to learn? What project partners or stakeholders are interested in your program, and what do you think they want to know?

STEP 1: Describe and map your intervention

Chapter overview

By the end of this chapter, you will be able to:

- **Understand how describing and mapping your intervention can help you explain how and why your intervention is supposed to work.**

- **Describe your own intervention's approach, including the evidence to support your intended outcomes.**

- **Map your intervention in order to connect activities with expected outcomes.**

"Our team was struggling with which activities to include in our logic model and program theory. There are so many activities that we do to deliver our program, it was difficult to narrow our focus on the most important ones. Through review of the toolkit, we were able to more clearly distinguish those key activities that comprised the bulk of our intervention, and were able to narrow our focus on those activities for evaluation." – Joan Schmidt, R.N., M.S.N, Community Cancer Liaison. Cancer Center, St. Joseph Mercy Hospital, Ann Arbor MI.

DESCRIBE YOUR INTERVENTION – DEVELOP A PROGRAM THEORY

When you decide to implement an intervention [5] to increase colorectal cancer screening, your stakeholders may ask why your organization uses a particular approach, why specific policy change has been made, or why you expect an intervention to be effective. To answer these questions, it helps to have a concise and accurate way to explain what you do, what you expect to happen, and how it should lead to the intended results or benefits. This description is the underlying **program theory**. A program theory provides a logical and reasonable explanation of how and why an intervention is supposed to work. Spelling out that theory can be one of the most important things you do for the success of your intervention.

A clear program theory helps others make sense of your intervention, and helps you make sure you are implementing an intervention that has the best possible chance of increasing screening rates. A clear program theory also makes it easier to choose the most appropriate results to measure in your evaluation. Many unsuccessful evaluations fail to articulate the theory in

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[5] Throughout the toolkit, these activities may be referred to as programs, initiatives, interventions, or efforts.

advance. An evaluation will not be useful to you if it measures the wrong outcomes or is based on faulty assumptions.

Some screening and awareness initiatives sound promising, but do not result in the desired changes. Of course, this could be because a good theory is not being carried out well, but in some cases the problem is the theory itself. For example, you may not be able to reasonably expect one-on-one education courses to create large-scale community change if the reach is limited. Make sure that your theory is not only clear and makes sense on paper, but that it is based on good underlying evidence about what increases screening rates and how people really change. Evidence can be based on previous work experience, literature and research, and professional opinions from colleagues and national organizations. As mentioned previously, the Community Guide (http://www.thecommunityguide.org/cancer/index.html) reviews existing evidence about colorectal cancer screening interventions targeted toward increasing community demand for screening or moving providers to action. It may be a great place to start when developing your program theory.

The If-Then connection

Program theories can often be captured in a series of "if-then" statements—**IF** something is carried out, **THEN** something should change.

For example, an intervention to increase screening rates could have an underlying theory like this: "**IF** at-risk individuals learn colorectal cancer can be prevented with screening, **THEN** they will talk to their health care provider about being screened." A new clinic reminder system could have an underlying theory like this: "**IF** patients in need of preventative services are directly contacted by staff, **THEN** it becomes easier for the patient population to make an appointment to get screened and the clinic's screening rates are likely to increase."

A program theory should also spell out why you expect the changes to happen. Between the "if" and the "then," there should be solid evidence or some well-established connection supporting the idea that your intervention will work. For example, if your intervention plans to distribute pamphlets that encourage people to speak with health care providers about screening, there should be research that supports what you expect to happen. You should know if the message being sent will resonate with that particular group, if the pamphlets will motivate participants to get screened, and if there are potential barriers to following through with your message. Many well-intentioned interventions are not successful because the underlying research did not align with what the intervention expected to happen.

A good program theory also reflects the fact that change happens in stages. For example, you will likely change someone's attitudes or knowledge of colorectal cancer screening before changing their screening behavior. Below are sample theories of change for a targeted intervention and a PSE change:

Sample outline for theory of change: targeted intervention

- ■ **IF** a certain set of resources (such as staff, equipment, materials) are available, **THEN** the program can provide a certain set of activities or services to participants (e.g., education or outreach).

- ■ **IF** participants receive these services, **THEN** they experience specific changes in their knowledge or attitudes (e.g., understanding the importance of screening or their willingness to be screened).

- ■ **IF** individuals change their knowledge or attitudes, **THEN** they will change their behavior (e.g., getting screened).

- ■ **IF** enough participants change their behavior, **THEN** the program may have a broader impact on screening rates in the community.

- ■ **IF** screening rates go up, **THEN** colorectal cancer incidence and mortality rates will decrease.

Sample outline for theory of change: Policy change to increase colorectal cancer screening

- ■ **IF** a health center wants to deploy resources in a new way (dedicating staff time to review patient records prior to appointments to flag patients due or overdue for screening), **THEN** a policy change can help ensure more patients are getting a needed recommendation for screening (e.g., the new policy prompts staff to regularly recommend screening to patients who are overdue for screening).

- ■ **IF** more patients systematically receive a screening recommendation from a health care provider, which is an evidence-based intervention, **THEN** more patients are likely to take action when they are overdue for screening.

- ■ **IF** patients act on this screening recommendation, **THEN** the health center's screening rates will go up.

- ■ **IF** enough health centers change their screening practices, **THEN** the policy change may have a broader impact on screening rates in the community and motivate other clinics or hospitals to do the same.

- ■ **IF** screening rates go up, **THEN** colorectal cancer incidence and mortality rates will decrease.

Improvements in some smaller interventions may not lead to significant community-level changes in screening rates, to say nothing of reducing colorectal cancer mortality rates. However, the larger the PSE change, the more likely community-wide or system-wide screening rates will go up. For instance, a large-scale legislative policy change such as the Affordable Care Act has broadly increased coverage for colorectal cancer screening. For smaller interventions, focusing on drops in community-level cancer incidence or increases in community-level screening rates may be too

broad of an evaluation focus. Instead, aim to measure some of the more immediate impacts, such as changes in screening rates within a specific group.

So why do we bother including these more global impacts in a program theory? It can be helpful to continue tying an intervention and its impacts back to the larger vision or goal, such as the 80% by 2018 effort, to show how your activities support this mission, and to keep focused on the ultimate point of your efforts.

Example 1: Northside Medical Clinic

Program theory for the Northside Medical Clinic:

The clinic begins to consistently track colorectal cancer screening information and provide physicians with their own screening rates on a quarterly basis.

⬇

Physicians become more aware of the gap between their own screening rates and established recommendations and become more motivated to increase their rates.

⬇

Physicians discuss screening options with more patients and encourage them to receive screening.

⬇

Patients either make an appointment to be screened for colorectal cancer or to return a stool test kit.

⬇

Patients get screened for colorectal cancer.

⬇

Colorectal cancer screening rates will increase.

⬇

Colorectal cancer incidence and mortality rates will decrease.

Example 2: Metropolitan Colon Cancer Collaborative

Program theory for the Metropolitan Colon Cancer Collaborative:

Staff distribute brochures and educational materials at community events.

⬇

African American community members learn about the importance of screening and available community resources related to colorectal cancer screening.

⬇

African American community members talk to their families, friends, and health care providers about getting screened.

⬇

African American community members make appointments to be screened.

⬇

African American community members get screened for colorectal cancer.

⬇

Colorectal cancer screening rates increase.

⬇

Disparities in colorectal cancer incidence and mortality will decrease.

Example 3: The Wellness Clinic

Program theory for the Wellness Clinic:

Clinic staff provide one-on-one education sessions.

⬇

Wellness clinic patients gain knowledge and awareness of colorectal cancer screening options.

⬇

Patients will make an appointment to be screened for colorectal cancer.

⬇

Patients get screened for colorectal cancer.

⬇

Colorectal cancer screening rates increase.

⬇

Colorectal cancer incidence and mortality decrease.

Developing your program theory

As you develop your program theory, select one of your intervention activities and answer the following three questions:

▶ **IF** the activity is provided, **THEN** what—realistically—should be the result for the people targeted by the intervention?

▶ Why do you believe the activity will lead to this result? (In other words, what is the underlying assumption about how this kind of change occurs? Are you drawing from an established theory used by others?)

▶ What evidence do you have that the activity will lead to this result (such as previous results from your own or other interventions, published research, or consistent feedback from participants)?

Repeat the same three questions for each activity that you implement. Don't worry, you do not need to develop a theory for everything! Administrative tasks, such as training staff or doing paperwork, typically are not included in a program theory. These activities, while a necessary part of implementing an intervention, are usually not the important aspects that produce change for participants. Focus on the main services or activities you are carrying out—the ones you most count on to promote positive results.

Appendix 4.1 provides a worksheet you can use to document your program theory.

MAP YOUR INTERVENTION

Once you have developed your theory, map your intervention to illustrate the connections between what your intervention does and what you expect to happen because of it. This is often referred to as a **logic model**. Simply put, a logic model is a picture of your theory—a drawing that shows how one thing leads to the next.

A logic model uses short phrases to represent what is explained in the program theory. Most often, a logic model is presented in the form of a flow chart with multiple columns. The logic model illustrates the linkages between the If/Then statements. The following components are usually included in a logic model:

■ **Inputs** – any resources or materials used by the organization to provide its activities (e.g., money, staff, volunteers, facilities, equipment, supplies, technical knowledge).

■ **Activities** – the components that make up an intervention such as services or information (e.g., brochures, handouts, or other educational material) provided by a

program, or guidelines or practices established as a result of a policy change or systems change.

- ■ **Outputs** – amount of activity provided, described in quantifiable terms (e.g., number of group or one-on-one classes taught, number of people served, amount of educational materials distributed, number of client reminder calls made, number of clinics implementing a new colorectal cancer screening workflow).

The next components of the model are the outcomes of the intervention. Outcomes should not be confused with outputs. Outcomes are what you expect to change as a result of someone receiving services or being targeted by a PSE change effort. Outputs can tell you how much of a service was provided, but not whether the activity had the desired impact. For instance, it may be impressive to say that you distributed 10,000 brochures last year. However, knowing the brochures were distributed does not tell you whether they actually led to any changes in people's awareness of colorectal cancer, the importance of screening, or likelihood of being screened. Similarly, a clinic may implement a new system in which office staff flag the day's patients who are due for screening, but the system doesn't automatically tell you if those patients then get screened.

The number of outcomes varies depending on the underlying logic. One frequent approach is to illustrate the following three levels of outcomes, but there may be more or less:

- ■ The first level of outcomes describes the **short-term outcomes**, or results of the intervention activities. Short-term outcomes typically refer to changes in **knowledge or awareness,** as these types of changes typically precede changes in behavior or practice.

- ■ The next level describes **intermediate outcomes**, which usually refer to **behavioral changes** that follow knowledge and awareness changes.

- ■ Following the intermediate impacts are the **long-term outcomes**. These outcomes usually refer to more **global changes**, such as a community-wide increase in colorectal cancer screening rates or drop in colorectal cancer mortality. At this level, the direct impact of the activity decreases.

The following logic models illustrate the underlying program theory for our three sample interventions. An example of a more complex logic model is included in Appendix 3.3.

Example 1: Northside Medical Clinic

INPUTS	ACTIVITY	OUTPUTS	SHORT-TERM OUTCOMES	INTERMEDIATE OUTCOMES	LONG-TERM OUTCOMES
-Staff -Computers -External reporting tool to extract rates	Clinic staff track colorectal cancer screening information and provide physicians with their own screening rates on a quarterly basis	Quarterly screening rate summaries	Physicians become more aware of the gap between their own screening rates and established recommendations and become more motivated to increase their rates	Physicians discuss screening options with more patients and encourage them to receive screening Patients make an appointment to be screened for colorectal cancer or agree to return a stool test kit. Patients get screened for colorectal cancer	Colorectal cancer screening rates will increase Colorectal cancer incidence and mortality rates will decrease

Example 2 : Metropolitan Colon Cancer Collaborative

INPUTS	ACTIVITY	OUTPUTS	SHORT-TERM OUTCOMES	INTERMEDIATE OUTCOMES	LONG-TERM OUTCOMES
Brochures/ educational materials	Distribute materials at community events	-Number of materials distributed -Number of community events attended	African American community members learn about the importance of screening and available community resources related to CRC screening	African American community members talk to their families, friends, and health care providers about getting screened	CRC screening rates increase
				African American community members make appointments to be screened	Disparities in CRC incidence and mortality decrease
				African American community members get screened for colorectal cancer	

Example 3 : The Wellness Clinic

INPUTS	ACTIVITY	OUTPUTS	SHORT-TERM OUTCOMES	INTERMEDIATE OUTCOMES	LONG-TERM OUTCOMES
-Educational materials -Trained staff	Provide one-on-one education sessions	-Number of one-on-one sessions completed - Number of patients receiving one-on-one sessions	Hospital patients gain knowledge and awareness of CRC screening options	Patients make an appointment to be screened for CRC Patients get screened for colorectal cancer	CRC screening rates increase CRC incidence and mortality decrease

Why should I develop a logic model?

If developed thoughtfully, a logic model can provide a starting point for your evaluation design. The model can be used to decide which outcomes are most important and the appropriate timing for measuring success. Logic models can also serve a number of other purposes, including:

- Illustrating the important features of your intervention to stakeholders such as funders, participants, collaborating agencies, or public health officials.

- Training new staff members about the program theory and approach—programs can use the model to help staff understand how the program works and their role in promoting benefits for participants.

- Controlling 'program drift'—some programs review their model periodically to ensure that their services are still consistent with the program's intended purpose and approach.

- Facilitating management of an intervention—the logic model may help programs plan their services, identify necessary resources, or help staff implement the intervention with fidelity.

- Identifying potential unintended consequences or outcomes of your intervention. While these do not have to be explicitly noted in the logic model, it may be helpful to think about the potential unintended outcomes that could arise. For example, a clinic's new colorectal cancer screening policy may be adapted for a different type of cancer screening, or participants may become motivated to make other risk-reduction changes, such as improving their diets or getting more exercise.

- Identifying aspects of your intervention that may yield interesting evaluation findings worth sharing with program participants, stakeholders, organization partners, or others. The process of developing a logic model is as important as the final product, especially when stakeholders are involved. The process can help the organization and stakeholders gain a shared vision of the initiative. Further information can be found in the Appendix, including tips for creating a logic model (Appendix 2.4) and a sample logic model worksheet (Appendix 4.2).

In addition, some people may find it helpful to think through how to strengthen a logic model. An example of a weak logic model is included in Appendix 3.4, as well as a description of how that example may be improved.

TAKING THE FIRST STEP

Using the information presented in this chapter and the supplemental resources in the Appendix, develop a program theory and logic model. Take time to carefully review the theory, including the linkages that you made between each step of the process (for example, between your activities and your short-term outcomes). Share the program theory and logic model with your core stakeholders, such as your staff or funders. Make sure it is clear and understandable. Begin thinking about what you want to measure based on the discussions about your logic model.

STEP 2: Prioritize your evaluation questions

Chapter overview

By the end of this chapter, you will be able to:

- **Review the importance of all of your potential evaluation questions.**

- **Select the most important evaluation questions to include in your design.**

Developing your logic model will help you start thinking about what outcome, process, and satisfaction issues you *specifically* want to address in your evaluation. Well-constructed evaluation questions will direct the entire evaluation, so it is important the questions make sense. A good evaluation question needs to be focused and meaningful. It also needs to be clear and understood by people outside the immediate evaluation process.

At the beginning of this toolkit, a number of evaluation questions relevant to interventions designed to increase screening were listed. No evaluation can answer all of these questions, and your intervention [6] might have different evaluation questions. Regardless, now is the time to identify the most important evaluation questions that you will continually refer to as you go through the evaluation process.

PRIORITIZING OUTCOME QUESTIONS

If your logic model is complex, or if you have very limited evaluation resources, you might not be able to measure each outcome listed in the model. Ask the following questions to prioritize the one or two most important outcomes:

▶ Which outcomes will be most useful in understanding your intervention's success and guiding improvements?

▶ Which outcomes are most important to the people targeted by the intervention?

▶ Which outcomes are most important to other stakeholders, including funders?

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[6]   Throughout the toolkit, these activities may be referred to as programs, initiatives, interventions, or efforts.

PRIORITIZING PROCESS QUESTIONS

Process evaluations allow you to scrutinize your services or policies and see new connections between the ways services are provided or policies are implemented and participant outcomes or satisfaction. To decide which implementation issues are most important, consider:

▶ How much would having more information about this part of your intervention influence participant outcomes or satisfaction?

▶ How strong of an interest is it to staff members or other key stakeholders?

▶ How substantially would it help with planning or program improvement decisions?

PRIORITIZING SATISFACTION QUESTIONS

Your intervention could ask about dozens of aspects of stakeholder satisfaction, and each question would probably hold some interest and value. To prioritize, ask yourself the following questions:

▶ Do you suspect certain elements of stakeholder satisfaction make a substantial difference in positive outcomes?

▶ If it turns out satisfaction with a certain aspect of the intervention is low, will you be able to do anything about it, or is it beyond your resources or control?

▶ Are there key stakeholders whose satisfaction will strongly influence your intervention, such as those who can refer clients or partner with you?

ADDITIONAL TIPS

As you narrow down your list of evaluation questions, consider:

■ Reviewing your intervention materials to determine the degree of fit between your publicly stated objectives and each outcome listed in the model. Which outcomes do people expect you to accomplish?

■ Learning from others' experiences by looking at the activities and outcomes described by similar interventions.

■ Talking to people most interested in your intervention, such as staff, current and potential funders, health care providers, participants, community members, and advocacy groups. These stakeholders are all concerned about what changes occurred because of your efforts and can provide input on prioritizing your evaluation questions. For more information on engaging stakeholders, please see Appendix 2.5.

PRIORITY EVALUATION QUESTIONS FOR THE SAMPLE INTERVENTIONS

As described in an earlier section of the toolkit, our sample interventions all identified a number of evaluation questions of interest. Before proceeding with their evaluation design, the staff must take some time to confirm their priorities.

Example 1: Northside Medical Clinic	**Example 2: Metropolitan Colon Cancer Collaborative**	**Example 3: The Wellness Clinic**
The clinic has two core questions for the evaluation work. First, they want to know what the current screening rates are, by physician and across the clinic as a whole. Second, if the rates prove to be lower than their goal of screening 80 percent of all eligible adults, they are wondering whether screening rates will increase as physicians see their own data each quarter. .	Ultimately, staff are most interested in whether their materials help to increase screening rates, as that is their overall mission. However, evaluating their success in increasing screening rates would be a complex evaluation, and they do not want to embark on something this rigorous without knowing whether their materials are being read or understood by their target audience. With feedback from their core stakeholders, they decide to focus first on whether or not the target audience reads and understands the brochures.	Since there is a large amount of money and time allocated to the one-on-one interventions, board members want to know if the costs are justified. Increased screening rates depend on whether patients like the educational materials and discussion they are receiving in the one-on-one sessions, so asking patients about their satisfaction is seen as the highest priority.

TAKING THE NEXT STEP

Compile all of your potential evaluation questions. Review the questions in this chapter to determine which questions are most important. If you need input in establishing your priorities, talk to your intervention's core stakeholders, such as staff, funders, or collaborators.

STEP 3: Design the evaluation

Chapter overview

By the end of this chapter, you will be able to:

- **Assess your program's budget and capacity for conducting an evaluation.**

- **Understand the difference between primary and secondary data.**

- **Understand different methods of data collection and how to select the most appropriate strategy for your intervention.**

- **Select a strategy for collecting your data.**

ASSESS YOUR CAPACITY

While it does not need to be cumbersome or elaborate, conducting an evaluation is a commitment. Before proceeding with your evaluation, it is important to have an honest and accurate assessment of your agency's capacity to design and implement the evaluation. Your evaluation design has to make sense in light of your available financial resources and staff capacity. However, you do not have to conduct an evaluation all on your own. You can draw on the expertise of fellow staff or other organizations to assist you or you may be able to access existing data sets that are tracking needed information for you. This toolkit will also help you conduct simple but effective evaluations. You may find that answering your highest priority evaluation questions is beyond your current resources. If so, you may want to explore ways to increase your evaluation capacity by training internal staff, hiring consultants to help you, or partnering with schools of public health, whose students may be interested in evaluating an intervention [7] as a part of their graduation requirements.

Available budget

Evaluation does not need to be expensive, but it does take some time and resources to plan an evaluation, collect the right information, and use the results to strengthen your intervention. A commonly recommended starting point is to allocate 10 percent of the total program budget to evaluation, but the cost will ultimately depend on the activities offered and the evaluation methods

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[7]   Throughout the toolkit, these activities may be referred to as programs, initiatives, interventions, or efforts.

used. Many can be done less expensively. Also remember that your full cost includes the value of the time staff will spend on the evaluation; it won't all be out-of-pocket costs.

While it may be difficult to allocate funding to evaluation, it is important to remember that the information received through an evaluation can be extremely valuable. This information can help you understand areas in need of improvement and document your successes and strengths. This information can ultimately help your intervention grow by impressing funders. The funds dedicated to an evaluation should be seen as an important aspect of the intervention itself, rather than drawing funding away from services. Overall, it will be beneficial to allocate a percentage of your budget toward evaluation to know that your intervention is running efficiently and effectively, rather than spending funds on an intervention that may not be meeting the needs of your clients. Remember that money you spend on evaluation is an investment in your intervention and can save you money in the long run.

The most common evaluation costs include:

- Salary and benefits for staff, based on the time they will spend on the evaluation.

- Travel expenses to and from meetings and evaluation sites.

- Incentives for evaluation participants, like food or gift cards.

- Communication tools such as postage, telephone, or internet access.

- Printing and duplication of surveys, reports, or other documents.

- Supplies and equipment, such as computers or software; or subscriptions to survey tools.

Additional information is found in the Appendix, including tips for constructing a budget (Appendix 2.6) and reducing evaluation costs and a sample budget worksheet in Appendix 4.3.

Evaluation skills

To successfully complete an evaluation, staff must have some evaluation skills and knowledge. These include:

- Understanding of evaluation methods and the ability to design evaluation studies.

- Computer and database skills.

- Data analysis skills.

- Ability to collect data using a variety of strategies.

- Ability to summarize results and identify implications.

This toolkit will help you build your skills and knowledge, thus increasing your organization's capacity to evaluate your colorectal cancer screening intervention. Taking note of the skills that you and your colleagues bring to the evaluation identifies areas of expertise and areas where capacity building may be necessary. While the scope of your evaluation does depend on your available resources, you may be able to conduct a larger or more complex evaluation than previously thought by assessing your current skills. The Appendix includes several worksheets for assessing the current evaluation capacity of your staff (Appendix 4.4) and overall agency (Appendix 4.5), as well as some tips for building capacity (Appendix 2.7).

In some cases, you may require external evaluation assistance, such as when it is required by a funder or if you intend to conduct a time-intensive evaluation. External support may also be needed if internal staff do not have the time or interest to build their own capacity. Information about hiring and working with external evaluators is located in Appendix 2.8.

Capacity of the sample interventions

Example 1: Northside Medical Clinic	Example 2: Metropolitan Colon Cancer Collaborative	Example 3: The Wellness Clinic
The Northside Medical Clinic is small and does not have funds specifically allocated to evaluation. The clinic was struggling with their EHR functionality, which limits their ability to compile consistent screening rate information. They do have several other resources available, however. Their staff includes one person who is adept at extracting and analyzing data from the EHR. They also have access to several medical students from a nearby academic medical center who are interested in volunteering their time to participate in clinical projects or programs at the clinic several afternoons each week.	The Collaborative has a small evaluation budget, as well as some large donors who may be interested in evaluation. Several staff members took undergraduate courses in research methods.	The Wellness Clinic has some funding available through a grant to support evaluation, and the hospital board authorized some funds to support the evaluation. The Wellness Clinic manager lacks formal training in evaluation, but was able to build her knowledge and skills with a useful colorectal cancer evaluation toolkit.

DECIDE WHAT DATA YOU NEED

Once you have selected the key evaluation questions and assessed your capacity, you can develop a plan for gathering the right information. You have created a list of outcome issues to explore through your evaluation and prioritized a few that are most important. You may also have identified a few process issues to examine and decided whether to assess satisfaction of any core stakeholders. Now you are ready to develop a measurement plan and a strategy to collect information.

PRIMARY VERSUS SECONDARY DATA

When deciding how to measure each issue, you may have several options. Often, those impacted by your intervention can provide you with the information you would like to learn. For instance, you could conduct a follow-up survey with participants to see whether they were screened after an educational phone call. There may also be other people who could provide useful information, such as your own staff or staff at other community agencies. For example, they might describe challenges they face when conducting one-on-one education classes or implementing a new office policy. Information gathered specifically for your evaluation is called **primary data**.

Before setting out to collect data through evaluation, you should consider whether existing information is available, such as national- or state-level data, clinic medical records, or community assessments.

Secondary data are data that have already been collected. This information can be used to further evaluate or understand those impacted by your intervention, and may provide an overall picture of colorectal cancer screening awareness and behaviors for a particular group. For example, if you want to report colorectal cancer screening rates within your community, consider comparing these rates to statewide rates as measured by the Behavioral Risk Factor Surveillance System (BRFSS) survey or the Medicare Claims database, which allows you to search for colorectal cancer screening rates for the Medicare population by zip code. Information extracted from client-specific sources, such as medical records, would also be considered secondary data.

Using existing information may save you time and money, but can also present challenges. In some cases, it may be difficult to obtain information from clinics or medical offices about specific participants. You may need to get permission to use data from the clinic or from patients or clients themselves.

Here are some tips when considering using secondary data:

- Make sure the source of the information is reputable, such as government or medical data.

- Be sure the available information aligns with the question you are trying to answer.

Many agencies are interested in knowing the overall colorectal cancer screening rates, both for their community and for the nation. Appendix 5 contains general information about calculating baseline screening rates and details several good information sources, including the Behavioral Risk Factor Surveillance System (BRFSS), the National Health Interview Survey (NHIS), the Healthcare Effectiveness Data and Information Set (HEDIS), the Uniform Data Set (UDS), and Medicare Claims data. The Appendix resources describe what information is available from each source, how to access and use the information, and the strengths and weaknesses in what is available as it applies to the evaluation of colorectal cancer screening interventions.

■ Take into account the methods that were used in collecting the data to make sure they are reliable and valid (e.g., Are the methods sound? Did they collect data from an appropriate range of people? Are there other limitations in what was collected, or how it was collected?).

■ Know when the information was collected and determine whether it is still relevant.

■ Understand the limitations of the data and be transparent about those limitations.

"With our evaluation, we knew we were going to be able to identify how our participants felt and what they learned from our program overall, through our pre/post surveys. What we felt was missing, however, was the impact of the program on participants. What were the stories of those who participated in our program? What was the impact on their lives? By doing a case study of a participant who was impacted by the program, we're able to convey that story to others." - Tawana Thomas-Johnson, Director, Health Disparities. American Cancer Society. South Atlantic Division, Inc.

QUALITATIVE VERSUS QUANTITATIVE DATA

Primary data can be collected using qualitative and quantitative approaches. It is important for you to think about which approach will be most useful to helping you answer your evaluation questions.

Quantitative data are numerical information, such as responses gathered through surveys or baseline colorectal cancer screening rates. Quantitative approaches are useful for gathering and summarizing information from a large number of participants. They can also be useful if your goal is to create results that are generalizable. The analysis of quantitative data can be done fairly quickly, especially if you use a software program and are looking for basic descriptive statistics (e.g., mean, medium, and frequencies). However, you may need assistance conducting more complex statistical analysis.

Qualitative data are non-numerical information, such as responses gathered through interviews, observations, focus groups, written documents or journals, or open-ended survey questions. The data take the form of stories, observations, or written notes, which can take time to analyze in a meaningful way. Qualitative approaches are useful for gathering in-depth information from participants.

On their own, or in combination, qualitative and quantitative approaches can provide key data about the impact of an intervention. For example, certain findings from a survey could be explored in more depth using key informant interviews or focus groups. However, in some cases, one approach may be more preferable. It is also important to think about which data the audience for your evaluation would find most useful. For example, a funder may want stories from participants detailing their experience in a program, in addition to quantitative survey data.

COLLECTING NEW INFORMATION

Secondary data may not always be available to answer your questions. If this is the case, you will need to collect new information, or primary data. When collecting new information, select a manageable approach that will provide accurate information. Some of the most common methods include:

- **Surveys or questionnaires** – collecting information from respondents without direct contact. Paper versions of a survey may be handed out or mailed. You might also ask people to complete surveys electronically via email or the internet.

- **Interviews** – collecting information verbally from informants, using a question and answer format. Interviews can be conducted in different ways, such as in person or over the phone. Interviews can be unstructured, allowing flexibility in deciding what questions to ask or how to best ask the question, or can be tightly scripted, requiring you to ask the same questions of all respondents.

- **Focus groups** – conducting group interviews with a small group of participants or other informants at the same time.

- **Case studies** – conducting interviews with one or two individuals who were involved with or impacted by an intervention. Interviews may be tailored to match the experience of each individual.

- **Medical record review/chart audit** – tracking patient information through medical records. Medical charts or Electronic Medical Records (EMRs) can be audited to determine whether screenings for certain patients have been completed. This may be particularly useful when trying to assess whether a policy or procedure change had a desired impact.

There is not one ideal way to gather information. Each approach has advantages and disadvantages. It is important you select one best suited to your intervention. The following table summarizes some of the advantages and disadvantages of these common methods of data collection:

Method	Advantages	Disadvantages	Examples for when to use this method
Surveys – paper or online/email	Surveys can be relatively easy and inexpensive to conduct.	Surveys are less successful with respondents with limited literacy, language barriers, or motivation to respond.	If you are holding an event such as a 5k walk/run, you can email surveys to participants using the information they provided when registering for the event. This information can be used to understand changes in colorectal cancer screening intention or behavior.
	You can collect responses from more people compared to conducting interviews.	Response rates are often low, requiring multiple attempts to obtain information.	A survey of participants at an event can assess what they enjoyed or disliked about the event, and if they have any suggestions for improvement.
	If conducted online or through email, responses can be loaded directly into data analysis software, which saves data entry time.	Surveys become more difficult to analyze as you collect more open-ended information (results will be much cleaner with structured, closed-ended questions).	Brief surveys can be distributed at health fairs to understand participants' knowledge of colorectal cancer, their perception of risk, and intention to get screened. Respondents can also be asked to do a follow-up survey (to assess whether they ended up getting screened) by providing an incentive to leave their contact information.
		Mailed surveys are usually more costly than online surveys (due to postage and printing costs).	
		Not all potential respondents may have an email address or internet access.	Surveys can be used after trainings for health care providers or insurers about new knowledge or skills they learned, the impact of the training on their work, their satisfaction with the training, and suggestions for how the training could be improved.
Interviews	If done in person, you have a chance to establish rapport and help the respondent feel comfortable.	Interviews can be expensive and time-consuming to conduct (especially if done in person).	Interviews can be used with program staff during a process evaluation to understand potential barriers to their work.
	If done in person, you can see and react as needed to a respondent's emotions and body language.	It may be difficult to reach possible interviewees by telephone.	
	There is often a high response rate.	Interviewers need to be trained to make sure that interviews are done well.	A sample of community members can be briefly interviewed to understand what they liked about your small media campaign, what messages they took from it, and what they would improve.
	If relatively unstructured, interviews allow you to be flexible in deciding what questions to ask and how to ask them.	Respondents may change their answers to try to please the interviewer or to avoid embarrassment.	

Method	Advantages	Disadvantages	Examples for when to use this method
Interviews continued	You have the opportunity to explore topics in more depth than you can with a survey. If needed, you can explain or clarify questions, increasing the likelihood of useful responses.	If the interview is not tightly scripted, you may ask inconsistent questions across respondents, making it difficult to summarize your results. You may end up with a lot of information, which would be time-consuming to transcribe and summarize.	A sample of clinic patients who are appropriate for screening (based on age or risk factors), but have not yet made an appointment could be interviewed by phone to identify the reasons why they have not pursued screening.
Focus groups	Group interaction generates ideas and insights that would be unlikely to emerge with one individual. Like interviews, focus groups allow you to explore topics in more depth than you can with a survey. Like interviews, you can explain or clarify questions, which may increase the likelihood of useful responses.	You can usually only include a small number of participants. Focus group participants may not be representative of your entire target audience. Focus groups should be facilitated by someone who has been trained to conduct groups. Focus groups can be vulnerable to group dynamics, and the conversation may be dominated by a few individuals. It may be difficult to transcribe and summarize results.	Similar to an interview, focus groups can be held with community members to assess attitudes toward colorectal cancer screening and understand barriers to screening. If you are conducting a small media campaign, focus groups can be held to understand what people liked/ disliked about the materials, what they understood the main message to be, and what they would improve. Focus groups might also be held with health care providers to better understand approaches and barriers to communicating with patients about colorectal cancer screening or their satisfaction with a clinic's screening workflow.
Case studies	Case studies can highlight the experience of one or two people who were impacted by the intervention, or highlight the impact of a policy change in one or two settings. Case studies offer additional context to survey results. With case studies, you can explore experiences in a more unstructured way.	Case studies are limited to only a very small number of participants. The experience of one or two individuals or interventions may not reflect the experience of the majority. This method can be easily biased by who is selected to participate in the case study.	Case studies can be a great complement to a survey or other more quantitative method. This method can be useful to help illustrate impact of intervention on one or two people for funders or others interested in the intervention. A case study might also be used to understand the development and implementation of an intervention, including promising practices and challenges that were encountered.

Method	Advantages	Disadvantages	Examples for when to use this method
	Case studies offer the opportunity to clarify questions that arise during data collection.		
Medical records review or chart audit	Medical record reviews or chart audits can be used by clinics and medical practices to help guide improvements in quality of care. Unlike surveys or qualitative methods, medical record reviews and chart audits do not rely on people to self-report or recall information which can be subject to bias or remembered incorrectly. Medical record reviews and chart audits can be used with other methods such as surveys, interviews, focus groups, and case studies to help capture information about the impact of changes in a clinic's policies and practices.	Medical records used for reviews or audits may be missing important information. For example, EMRs may be missing data from a prior year's screening activities, which would not allow multi-year assessment of colorectal cancer screening rates. (This is particularly problematic for colonoscopy, as a patient may have had a colonoscopy several years prior to joining a practice that is not reflected in an EMR). EMRs may also not be organized to track specific information that a clinic or medical practice is looking for. Strategies are needed to make sure that the information in the EMRs is able to help answer the evaluation questions. There may be HIPAA or other restrictions or protections in place regarding the use of medical data. These need to be addressed before any data is accessed for evaluation purposes.	Medical record reviews or chart audits could be used by clinics or practices to help calculate their colorectal cancer screening rate, which could be used to assess progress on new policies or strategies intended to increase their screening rate.

CULTURAL CONSIDERATIONS

■ Consider the strengths and weaknesses of different data collection strategies and select those that will be most appropriate given available resources.

■ In addition to quantitative approaches, consider qualitative measurement approaches (e.g., focus groups, narrative accounts, case studies)—not only can these be useful for exploring issues in greater depth, but they may also be more successful with some cultural communities.

■ Seek guidance from the cultural community to ensure the proposed methods will be appropriate and yield meaningful data.

■ If a comparison group is going to be used, make sure the group is comparable to the target population in terms of relevant characteristics (e.g., ethnicity, age, gender, socioeconomic status, community). If an appropriate comparison cannot be found, consider using a different design.

■ Consider using multiple data collection approaches and be creative in considering non-traditional data collection strategies.

DATA COLLECTION APPROACHES SELECTED BY THE SAMPLE INTERVENTIONS

Our sample interventions have prioritized their evaluation questions and assessed their capacity. They are now ready to select their data collection methods.

Example 1: Northside Medical Clinic

The Northside Medical Clinic decides to systematically review patient records and ensure documentation is more consistent with respect to whether patients are up to date with screening, if unscreened patients age 50 and older received a screening recommendation, and whether the patient ultimately followed through with the recommended screening. As their record keeping and documentation improve, they can regularly run reports about colorectal cancer screening rates.

Example 2: Metropolitan Colon Cancer Collaborative

Experts in the field of colorectal cancer screening have already reviewed the Collaborative's materials, and they know the information is accurate. However, they don't know how it comes across to African American community members.

They would like to talk to their priority audience in-depth about reactions to the materials. Were the materials easy to understand? Did the materials change awareness, knowledge, or intent to be screened?

While interviews are a good option, the Collaborative decides to conduct focus groups. Staff felt it would be easier to arrange a small number of focus groups rather than many individual interviews. They were also interested in having the participants react to the comments and suggestions of others, to help them identify areas of consensus and disagreement. The questions would not be very personal, so participants should be comfortable speaking in groups.

Example 3: The Wellness Clinic

The clinic's evaluation questions relate primarily to participant satisfaction with the one-on-one education sessions. This will require gathering information directly from participants to understand whether they felt comfortable or perceived staff positively.

Because their board wants evidence that awareness and knowledge increased, clinic staff decide to do a pre-test/post-test/ follow-up survey design. They would like to collect surveys from participants before and after the sessions, to see if there are any increases in knowledge, awareness, or intent to be screened. They are also interested in knowing whether patients subsequently take any steps towards screening. To explore this issue, they decide to mail a follow-up survey to patients three months after the education session.

Some of these questions could be addressed using other approaches, but surveys have several advantages. They will be able to include more of their patients in the evaluation rather than conducting more costly and time-consuming interviews. Patients may also feel more comfortable sharing their feedback in a survey rather than directly with program staff, especially if they were not satisfied with the services.

TAKING THE NEXT STEP

Based on your prioritized evaluation questions and your capacity and resources to conduct an evaluation, what are the most appropriate strategies for gathering the information that you need? Why is this strategy appropriate? What are the advantages and disadvantages of your proposed approach? Don't forget that you can choose a combination of these approaches, as needed.

STEP 4: Identify or develop data collection instruments

Chapter overview

By the end of this chapter, you will be able to:

- **Understand the characteristics of a good evaluation tool.**

- **Identify databases and resources for locating existing data collection tools.**

- **Develop your data collection materials.**

There are several existing data collection tools related to colorectal cancer. If an existing data collection tool does not capture what you would like to measure, you can develop new ones, such as surveys or interview guides. This section will provide information on existing data collection tools, as well as recommendations for creating new instruments.

CHARACTERISTICS OF GOOD EVALUATION TOOLS

Whether you use an existing data collection instrument or develop your own, you'll need to know that these materials will provide useful information. The following characteristics of a good tool should be kept in mind, whether you create your own or use existing materials. Make sure they are:

- Valid – accurately measuring the concept or idea you want to measure.

- Reliable – yielding consistent results over time when used the same way with similar respondents.

- Culturally appropriate – being appropriate for the target population in terms of language and literacy, measurement approach, and questions asked.

- Ethical and legal – conforming to all established standards and laws for the ethical treatment of evaluation participants.

- Sensitive to change – being able to identify changes in participant outcomes over time.

- Focused – addressing your specific questions and only including questions that are essential to know.

The materials must also be easy to use. For example, you may find a set of interview questions that fits all of the above criteria, but it is too long for participants or staff would need extensive training in order to conduct the interview. In that case, it may not be a feasible evaluation tool, even if you believe it would provide useful information. Other considerations:

- Reasonable cost.

- Reasonable time for administration.

- Clear guidelines for how to collect information and interpret the results.

- Easy-to-use format.

EXISTING DATA COLLECTION INSTRUMENTS

Before you develop your own data collection materials, look for existing tools such as questionnaires or surveys. Finding these materials can be challenging, but this guide will help you get started with sample instruments. The Appendix contains sample survey instruments with questions from existing tools in English (Appendix 3.5) and Spanish (Appendix 3.6). The Appendix also contains sample materials related to the Links to Care program (Appendix 3.13), a tool for evaluating collaborative work (Appendix 3.14), and resources related to the evaluation of patient navigation services (Appendix 3.15).

If you don't find what you need in the Appendix, a good search may be worth the effort since developing valid and reliable questions can be surprisingly difficult. Using materials developed by someone with specific test development expertise will help ensure quality data.

Once you have found some possible materials, ask yourself the following questions and identify the potential strengths and limitations of the tool:

▶ Is the instrument's intended use similar to what I intend to do?

▶ Will it provide useful information? Does it measure the right things given my evaluation priorities?

▶ Is the instrument appropriate for the audience? Will people be able to understand and complete the instrument? Can the instrument be easily adapted to fit the community?

▶ Are the procedures for collecting information clear and reasonable?

▶ Is the instrument free to use? If not, is the cost reasonable and affordable?

▶ Do I need any special training or authorization to use the instrument?

▶ How long does it take to complete the instrument? Is this reasonable?

LOCATING EXISTING INSTRUMENTS AND TOOLS

Including established questions as part of your data collection instrument may allow you to compare your results with statewide or national data. Finding existing instruments, data sources, and tools can require some investigative skills.

Consider the following tips in locating and using existing information:

- **Explore national or statewide databases.** A number of national and state-level surveys contain questions about colorectal cancer screening. In addition to being able to use the data from these surveys, you can also review the survey tools and look for sample questions to use. Aligning your survey questions with ones used regionally or nationally may provide you with useful comparison information. Appendix 5 contains information about several good information sources, including the Behavioral Risk Factor Surveillance System (BRFSS), the National Health Interview Survey (NHIS), the Healthcare Effectiveness Data and Information Set (HEDIS), the Uniform Data Set (UDS), and Medicare Claims data.

- **Use online resources.** You might also want to explore sites such as Cancer Control P.L.A.N.E.T. This site provides data and resources to design, implement, and evaluate evidence-based cancer control programs. The colorectal cancer section contains five steps to effective cancer control planning, including how to evaluate your program. Click on "Find research-tested programs and products" to find information on Research-Tested Intervention Programs (RTIPs) relating to colorectal cancer. Some of the program descriptions also include instruments. http://cancercontrolplanet.cancer.gov/colorectal_cancer.html

- **Review the published literature about the type of intervention [8] you are implementing.** It is always a good idea to look for evaluations of similar interventions or activities. There are many good literature search systems available. If you are unfamiliar with these systems, consider getting help from a reference librarian at a college or university library. When reviewing existing studies, make note of how other interventions were evaluated and the tools that were used. If any of these look promising, track them down either by finding the reference for the original source or by contacting the author directly.

- **Talk to others in the field to see what materials they have used and what they recommend.** These individuals include other program directors or staff, as well as those conducting research or evaluation.

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[8]   Throughout the toolkit, these activities may be referred to as programs, initiatives, interventions, or efforts.

DEVELOPING NEW DATA COLLECTION INSTRUMENTS

"It's important to be culturally sensitive in the questions you ask. Cancer is a sensitive issue, but can be especially sensitive for some communities of color. We needed to have questions that were direct and straightforward." - Tawana Thomas Johnson, Director, Health Disparities. American Cancer Society, South Atlantic Division, Inc.

Sometimes existing data collection instruments will not capture the information you would like from your program participants. In this case, it may be necessary to create new tools specific to your intervention. Developing new tools may take time, but questions may be more focused on the information you hope to receive. Here are some things to keep in mind if you plan to create your own instruments.

- **Surveys or questionnaires** – There are various things to consider when creating a survey or questionnaire, including content, formatting, and strategies for getting a good response rate. Survey questions can be closed- or open-ended, depending on how structured you would like responses to be. You may choose to use pre- and post-surveys, or post-only surveys (Appendix 2.9). Writing effective questions can be tricky, and there are important literacy issues to keep in mind when preparing a survey. Pilot testing your survey is also a good idea to ensure the order and wording of your questions are understandable. Information on writing and conducting a survey can be found in Appendix 2.10, including information about strengths and weaknesses of different survey questions. Appendix 2.11 provides tips for increasing your survey response rate.

- **Interviews** – Interviews can take various forms and can be as structured as necessary. When writing your interview questions, pay attention to formatting and how long the interview will take. To build trust, consider placing the more sensitive questions toward the end of the interview. Remember, the interviewer may need to probe for more information, so consider any follow-up questions that may arise in advance. Further information on writing protocols and conducting interviews can be found in Appendix 2.12.

- **Focus groups** – Since focus groups require input from multiple people, you may have to limit the number of questions so that everyone is heard without taking too much time. A moderator can probably get through five to seven questions in a 90 minute session. Keep group dynamics in mind and encourage participation from all participants. The Appendix contains a checklist for items needed when conducting a focus group (Appendix 3.7), a sample focus group protocol in English (Appendix 3.8) and in Spanish (Appendix 3.9), and tips for conducting a focus group (Appendix 2.13).

- **Case studies** – Case studies can be done in different ways, and can include interviews with participants, their families, and their providers. As one of the benefits of case studies is to highlight the experience of one or two individuals, questions can be tailored to best capture the unique experiences of those individuals (see Appendix 3.10). Information is likely to be identifiable, so ensure you have appropriate informed consent processes in place.

- **Chart audit** – Chart audits could be used in a number of ways to guide program or system improvements. Clinics or practices could use chart audits to help calculate their colorectal cancer baseline screening rate, which could be used to measure impacts of policies or strategies intended to improve screening rates. Chart audits may be done with electronic medical records or with paper medical charts. To learn more about how to implement a chart audit, see Appendix 2.14.

Be sure to consider the social desirability of any questions you include as part of an evaluation, whether survey questions, interview questions, or other types of questions (see Appendix 2.15). Social desirability bias can occur when respondents answer questions in a way to make themselves look more positive or favorable to others, that is, trying to give the "right answer." There are a number of ways social desirability bias could emerge in your evaluation.

When selecting a data collection tool, it is important to review the tool and its instructions to make sure it is appropriate for your project. As you are reviewing your options, take time to:

- Directly assess the adequacy of existing instruments (e.g., validity, reliability, relevance to goals, sensitivity to change, developmental appropriateness, cost, time required, user-friendliness, and clarity of instructions).

- Consider using instruments that are useful for multiple purposes (e.g., providing clinical knowledge to guide service delivery while also measuring outcomes).

- If no appropriate data collection instruments exist, consider developing your own – obtain consultation if you are not skilled in test development.

- Consider order of questions – start with least threatening questions and avoid more sensitive issues until some level of trust has been established.

- Consider alternatives to direct questioning (e.g., key informant data, secondary data).

CULTURAL CONSIDERATIONS

■ If participants from different cultural communities will be providing data, give community representatives the opportunity to review materials in advance to ensure that the questions and concepts are understandable and culturally relevant.

■ Before using any instrument, test it with a few members of the target population and directly obtain feedback regarding their perceptions of the information, instructions, layout, and questions.

■ To the extent possible, offer a choice of languages to participants – instruments should be translated both linguistically and conceptually.

■ Be cautious about use of Likert-type response scales, as these types of questions are not familiar to members of all cultural communities.

DATA COLLECTION MATERIALS DEVELOPED BY OUR SAMPLE INTERVENTIONS

Our sample interventions have selected their data collection approaches and must now develop tools for gathering the needed information.

Example 1: Northside Medical Clinic	Example 2: Metropolitan Colon Cancer Collaborative	Example 3: The Wellness Clinic
The Northside Medical Clinic staff regularly pulls a registry of patients age 50 and older. The registry includes the patient ID number, physician name, medical visit date, type of colorectal cancer screening recommended, date the screening is completed, screening result, and follow-up.	Collaborative staff members with some survey development skills make the first effort to write up some focus group questions. Because nobody on staff has specific focus group experience, however, they hire a consultant to review the protocol in advance.	Wellness Clinic staff write a survey for patients to complete before and after their one-on-one education session. They create a separate survey for the three-month follow up. In order to compare their data to results nationwide, they include questions from HINTS and BRFSS.

Sample data collection tools for each of these three programs follow:

Example 1: Northside Medical Clinic tracking spreadsheet

Tracking spreadsheet

Patient ID	Physician	Medical visit date	Screening recommended	Screening performed	Screening result	Follow-up
97358713	Brown	8/5/2016	Stool blood test	8/30/2016	Negative	Recheck next year
74532850	Alvarez	8/6/2016	Stool blood test	9/25/2016	Positive	Colonoscopy
48735561	Gillespie	8/10/2016	Colonoscopy	10/15/2016	Adenoma	Repeat colonoscopy at appropriate interval
67784533	Alvarez	8/15/2016	Stool blood test	8/25/2016	Negative	Recheck next year

Example 2: Metropolitan Colon Cancer Collaborative focus group protocol

First, I would like to go around the room and give each of you the opportunity to briefly introduce yourselves. Please tell us your **first name and how you learned about the work of the Collaborative**.

Once again, your personal information will not be shared and your answers will be confidential.

We would like for you to take a look at these written materials.

What is your first impression of them?

What do you feel is the main message?

Are the materials understandable? [PROBE: If no, what could make them more easily understandable to you?]

Who do you think is the target audience? What about the materials made you believe that is the target audience?

Does the message motivate you to get screened for colorectal cancer? What kind of messages would motivate you? How could the materials be improved?

Where would be the best place to distribute the materials in order to reach people in your community?

Thank you for your time!

Example 3: The Wellness Clinic post-test survey

The Wellness Clinic would like to know your thoughts about colorectal cancer screening and the education session you had with a health care professional today. Your responses will be kept confidential, and the health care professional that assisted you today will not see your answers. You may skip any question you feel uncomfortable answering. Thank you for taking our survey!

Would you say you strongly agree, agree, disagree, or strongly disagree with the following statements?

1. **There's not much you can do to prevent colorectal cancer.**
   ☐ Strongly agree   ☐ Agree   ☐ Disagree   ☐ Strongly disagree

2. **Colorectal cancer develops over a period of several years.**
   ☐ Strongly agree   ☐ Agree   ☐ Disagree   ☐ Strongly disagree

3. **There are ways to detect colorectal cancer early when it is highly curable.**
   ☐ Strongly agree   ☐ Agree   ☐ Disagree   ☐ Strongly disagree

4. **People with colorectal cancer almost always have pain or other symptoms prior to being diagnosed.**
   ☐ Strongly agree   ☐ Agree   ☐ Disagree   ☐ Strongly disagree

5. **What is the recommended age to start colorectal cancer screening for most individuals?**
   ☐ 40   ☐ 50   ☐ 60   ☐ 70

6. **Have you thought about getting screening for colorectal cancer?**
   ☐ Yes   ☐ No

   If yes, would you say that you plan to get screened, you don't plan to get screened, or you're undecided?
   ☐ I plan to get screened   ☐ I do not plan to get screened   ☐ I am undecided

Please indicate whether you strongly agree, agree, disagree, or strongly disagree with the statement:

7. **I feel the information on colorectal cancer screening I received from the health care professional today was helpful.**
    ☐ Strongly agree   ☐ Agree   ☐ Disagree   ☐ Strongly disagree

8. **The health care professional I met with today was very knowledgeable about colorectal cancer screening.**
    ☐ Strongly agree   ☐ Agree   ☐ Disagree   ☐ Strongly disagree

9. **I felt comfortable asking her questions about colorectal cancer screening.**
    ☐ Strongly agree   ☐ Agree   ☐ Disagree   ☐ Strongly disagree

10. **The information I received today during my meeting with the health care professional convinced me to get screened for colorectal cancer.**
    ☐ Strongly agree   ☐ Agree   ☐ Disagree   ☐ Strongly disagree

11. **I would recommend meeting with a health care professional to discuss colorectal cancer screening to my family and friends.**
    ☐ Strongly agree   ☐ Agree   ☐ Disagree   ☐ Strongly disagree

Demographics

12. **What is your sex?**
    ☐ Male   ☐ Female

13. **What is your age?**
    Age (in years) _____

Thank you for completing our survey!

CORE QUESTIONS

One of the challenges of comparing evaluation results from one intervention to the next is that organizations may write survey questions in different ways. For the most part, that is fine and to be expected. Still, there are benefits to comparing program results nationwide or with work done in previous years. As such, the National Colorectal Cancer Roundtable suggests programs consider including the five "core" questions on the next page in their evaluation instruments to improve the ability to compare results on a few key measures.

The core questions have been pulled from the Behavioral Risk Factor Surveillance Survey (BRFSS). The BRFSS is the largest, ongoing telephone health survey. It has tracked health conditions and risk behaviors in the United States annually since 1984. Survey data can be accessed by year, by state or territory, and by metropolitan/micropolitan areas. The BRFSS provides reliable and valid questions that have been asked for a number of years. Not only will you be able to compare what you learn from your survey to what has been gathered using past survey questions, but you will have the confidence of using questions with considerable research behind them.

In addition, you can use the core questions to make the case for additional support for your intervention. Maybe your intervention is doing much better than the national average. Or perhaps you can show steady progress toward national screening rates, despite working in an underserved community with limited funding. If everyone uses these core questions in their evaluation instruments, it will help improve the overall understanding of effective programming in a wide variety of settings.

Programs are encouraged to use the following five core questions, pulled from the BRFSS survey, in their evaluation instruments.

Core questions:

1. A blood stool test is a test that may use a special kit at home to determine whether the stool contains blood. Have you ever had this test using a home kit?
    - ☐ Yes
    - ☐ No
    - ☐ Don't know / Not sure
    - ☐ Refused

2. How long has it been since you had your last blood stool test using a home kit?
    - ☐ Within the past year (anytime less than 12 months ago)
    - ☐ Within the past 2 years (1 year but less than 2 years ago)
    - ☐ Within the past 3 years (2 years but less than 3 years ago)
    - ☐ Within the past 5 years (3 years but less than 5 years ago)
    - ☐ 5 or more years ago
    - ☐ Don't know / Not sure
    - ☐ Refused

3. Sigmoidoscopy and colonoscopy are exams in which a tube is inserted in the rectum to view the colon for signs of cancer or other health problems. Have you ever had either of these exams?
    - ☐ Yes
    - ☐ No
    - ☐ Don't know / Not sure
    - ☐ Refused

4. For a sigmoidoscopy, a flexible tube is inserted into the rectum to look for problems. A colonoscopy is similar, but uses a longer tube, and you are usually given medication through a needle in your arm to make you sleepy and told to have someone else drive you home after the test. Was your most recent exam a sigmoidoscopy or a colonoscopy?
    - ☐ Sigmoidoscopy
    - ☐ Colonoscopy
    - ☐ Don't know / Not sure
    - ☐ Refused

5. How long has it been since you had your last sigmoidoscopy or colonoscopy?
    - ☐ Within the past year (anytime less than 12 months ago)
    - ☐ Within the past 2 years (1 year but less than 2 years ago)
    - ☐ Within the past 3 years (2 years but less than 3 years ago)
    - ☐ Within the past 5 years (3 years but less than 5 years ago)
    - ☐ Within the past 10 years (5 years but less than 10 years ago)
    - ☐ 10 or more years ago
    - ☐ Don't know / Not sure
    - ☐ Refused

TAKING THE NEXT STEP

Before you use a data collection instrument, make sure it fits the criteria of a good evaluation tool. Consider using existing tools, or create new data collection instruments if existing materials do not address your evaluation questions. Use the materials in the Appendix to help you get started. If you are using a survey, please consider including the core questions in your instrument, to help advance the knowledge base in a variety of settings.

STEP 5: Collect the data

Chapter overview

By the end of this chapter, you will be able to:

- **Develop a data collection plan for your evaluation.**

- **Understand the importance of time, budget, and appropriateness for your target population when creating your plan.**

- **Learn how to ensure that you have a thorough evaluation plan.**

WHEN AND HOW WILL YOU COLLECT INFORMATION

Once you have selected a general approach for collecting information, you need to develop a data collection plan. To develop your plan, first list all of the outcome, process, and satisfaction issues you want to measure in your evaluation. For each issue, identify the data collection strategy you will use, the people who will provide the information, and your plan for collecting the information. Identifying the person responsible for gathering the data is also important to ensure accountability for the task.

As you develop your data collection plan, consider:

▶ When is the activity going to take place, and what are logical data collection points?

▶ What do funding sources expect? When will you need to report the results?

▶ When does staff have the most availability to help?

▶ When and how will you collect data?

Answering these questions will increase the likelihood of collecting useful data. If you want to gather objective data about whether people have changed their knowledge or behavior over the course of your program, it is often a good idea to have people complete data collection before (pre) and after (post) your intervention. Comparing what people have said at these two time points can give you a more rigorous comparison that is less subject to errors in memory. However, in some cases, it can be adequate (and even advantageous) to collect evaluation information only once, after the services have been provided. For example, if your two data collection points would be very close together (such as before and after a brief intervention, like a short educational activity), it might be better to collect information only after the event so that you do not annoy

participants by spending a disproportionate amount of time on evaluation activities. A post-test only design would also be sufficient if, for example, you are only interested in whether program participants understood materials or found the staff helpful. The Appendix includes additional information about data collection timing.

Sample data collection plans:

It can be helpful to summarize your data collection plan in a chart or grid. Several templates for creating and describing your data collection plan can be found in Appendix 4.6.

SAMPLE DATA COLLECTION PLAN FOR THE WELLNESS CLINIC

The chart below lists each of the priority evaluation items for the Wellness Clinic, along with a plan for collecting the data. It is helpful to think separately about each of your evaluation priorities to ensure that you have a plan for gathering each item. You will note that two separate types of information should be collected in the post-test survey. This does not mean that two surveys are needed, only that the survey should include both the needed outcome evaluation items and questions related to participant satisfaction.

Information to be collected	Possible data collection strategy	Data source	Data collection procedures	Person responsible for data collection
PROCESS: How well are the one-on-one education courses meeting the education and awareness needs of our patients?	Pre-test survey	Patients	Pre-test survey answers will be compared to post-test surveys in order to see if there is a change, or whether patients should be provided different information.	Staff providing the one-on-one course
OUTCOME: Are there any changes in colorectal cancer screening awareness and knowledge after completing a one-on-one education session?	Post-test survey	Patients	Patients who receive a one-on-one education session will receive a survey immediately after the session.	Nurses and medical assistants
SATISFACTION: Do patients like the one-on-one sessions, and do they feel comfortable with the staff who are providing them?	Post-test survey	Patients	Questions on satisfaction with materials and staff will be included in the post-test immediately after the one-on-one session.	Nurses and medical assistants
OUTCOME: Did patients who received the one-on-one education courses take any steps toward getting screened?	Follow-up survey	Patients	Three months after their visit, patients will receive a follow-up survey in the mail along with a $5 incentive.	Clinic administrative staff

DATA COLLECTION PLANS CREATED BY OUR SAMPLE PROGRAMS

Example 1: Northside Medical Clinic

Once the reports are produced, clinic staff and HIPAA-consented volunteer medical students review the files for their patients age 50-75. They began to clean up the data such as ensuring test results are entered into the correct field, paper records are reflected in the EHR, test or lab results are scanned into the chart, and structured fields are used more consistently. For each patient, they review the files and record the history of colorectal cancer screening (looking for colonoscopies conducted during the previous nine years, flexible sigmoidoscopy conducted during the previous four years, or a stool blood test done during the previous year).

Once the historical information is updated, the medical students help train the staff on maintaining consistent screening records for all adults age 50-75 after each visit.

Example 2: Metropolitan Colon Cancer Collaborative

The Collaborative staff recruit focus group participants by handing out fliers at community events and posting information on their web page. Community members are offered $25 to participate in one of three hour-long focus groups, which will take place at the local community center. Food will be provided.

The consultant they hired to review the protocol is also a trained focus group facilitator. They hire the consultant to conduct the focus groups.

Example 3: The Wellness Clinic

Hospital staff collect surveys while patients are in the waiting room before their appointments. They ask them to do the post-test immediately following the one-on-one education session. Clinic administrative staff also mail a follow-up survey three months later, along with a self-addressed stamped envelope. Participants receive a $5 incentive when they return the follow-up survey.

IMPORTANT CONSIDERATIONS WHEN COLLECTING DATA

Time and budget considerations

Keep time and budget in mind when implementing an evaluation. For instance, if you want to measure participants' satisfaction with your intervention [9], consider the method you'd like to use to gather the information, the time involved with implementing the method, and the cost associated with the task. Measuring participant satisfaction can be done in a variety of ways, with varying resource implications.

Participant	Method	Time intensive?	Budget implications
Program participants	Written survey	Medium (survey development, piloting, coding)	Low
Program participants	Web survey	Low-medium (survey development, programming survey into computer)	Low
Community members	Focus group	High (interview guide, piloting, transcribing)	Potentially high, if a stipend/ incentive is offered or if an outside trained facilitator is used
Members of community agencies	Interviews	Medium-high (depending on the number interviewed)	Potentially high, depending on number of interviews

Asking about colorectal cancer screening

There are several important points to consider when planning your evaluation and data collection tasks. Cultural differences among people involved in the evaluation, language comprehension, and discomfort with the subject of colorectal cancer must be taken into account (see cultural considerations later in this chapter). In addition, it can be challenging to ask questions directly about colorectal cancer screening for a variety of reasons. Be mindful of the following when collecting information:

- Avoid using jargon or terms that may be unfamiliar to some respondents. This is especially important when describing colorectal cancer screening tests, including stool tests, flexible sigmoidoscopy, or colonoscopy. If you are asking people whether they have been screened for colorectal cancer, include a brief description of the screening tests they might have used.

- Be mindful that the topic of colorectal cancer may be uncomfortable for some individuals to discuss. People may also feel uneasy discussing particular screening tests, such as sample collection for a stool test. When conducting interviews or surveys, it will be important to take respondents' sensitivity into consideration and to build trust into the process.

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[9]   Throughout the toolkit, these activities may be referred to as programs, initiatives, interventions, or efforts.

- Including jargon or technical terms may be appropriate for a survey of medical providers, but brief descriptions of screening types may need to be included in a survey of their patients. See the Appendix for a description of screening tests in English (Appendix 3.11) and Spanish (Appendix 3.12)

Paper vs. online

Many surveys are done on paper, however online surveys have become increasingly popular. To complete a survey online, potential respondents receive an internet link that allows them to answer questions directly on their computers, tablets, or smart phones. While this may be quick and convenient, online surveys are not always the right choice. Consider issues such as your intended audience's access to the internet and comfort with technology before selecting this approach. People are also increasingly accessing surveys on devices such as tablets and smart phones. Not all online surveys translate well into these formats, and you may need to revise surveys to keep questions as short as possible and spend extra time piloting your survey through several different formats to make sure it is easy to complete. If you do choose to do an online survey, there are numerous internet sites, such as Survey Monkey, Survey Gizmo, or Zoomerang, that allow you to create and collect surveys for a small fee and in some instances, for free.

Anonymity and confidentiality of survey data

Anonymous surveys collect no identifiable information from a respondent. It is often desirable to keep surveys anonymous and not request information such as the respondent's name or social security number. If survey respondents do not need to provide this information, they may feel more comfortable being honest. However, there are a number of reasons you may need identifying information and, therefore, choose to keep surveys confidential. Confidential surveys collect personal identifiable data but keep the information private. If you are collecting surveys at two points in time (such as before and after the program), you need to have a way to match surveys together. You may also need to collect names in order to distribute incentives to those who completed surveys. For a more advanced evaluation, you may need to connect survey data to other information, such as medical records or background information about participants.

Collecting names or other identifying information does not need to be a deterrent for respondents, however. Often people are comfortable providing their names, as long as the reasons for collecting that information and the precautions that will be taken have been explained to them. Regardless of whether surveys are conducted anonymously or not, personal information should be kept private and secure.

Making your evaluation design more "thorough"

There are always opportunities to make your design more detailed, so it is more accepted by the medical and academic communities. If you have the budget, time, and staff to add pre-tests, follow-ups, and comparison groups, you may be able to understand the impact of your program

more comprehensively. Keep in mind that the more you are able to measure and compare, the more information you will have about what works.

Multiple time periods. Post-tests will give you information about how participants changed after receiving the intervention. If you test participants before (pre-test) and after (post-test) the intervention, you will have a sense of how they have changed over the course of the program. To go further, if you are able to follow up with participants after they complete or leave a program, you may see evidence that attitude, knowledge, and behavior changes were maintained over time. For example, you may be able to follow up with patients at a community clinic to see if they continued to complete an annual FOBT test over a period of years.

Keep in mind, however, that pre-post tests are not always necessary. Review your evaluation questions to decide if one is needed.

Comparison groups. Your evaluation will also be stronger if you include both a participant group and a comparison group, made up of people who do not receive the intervention, but are like the intervention group in other ways. The design is particularly strong if you randomly assign participants to receive the intervention. Using randomly assigned groups is the strongest method to determine that attitude, knowledge, and behavior changes are due to the program itself, and not to other factors. This approach may be ideal in demonstration studies of new approaches.

ANTICIPATING DATA COLLECTION CHALLENGES AND POSSIBLE SOLUTIONS

Many common problems in data collection can easily be avoided with planning on the front end. See below for common challenges and how to avoid them.

Challenge: "I developed a data collection plan, but collected too much/too little information. What could I have done differently?"

Having a plan is only the first step—it is important that your plan is realistic and can be carried out. Consider the following:

- Focus on your priorities, and limit questions to those that are necessary for understanding program outcomes and operation. It is better to measure a few things consistently and reliably than try to collect more comprehensive information that may be unreliable or too time consuming to analyze.

- Assign responsibility for overseeing the data collection and make it part of that person's job description.

- Ask staff for input into the evaluation design and procedures to increase their "buy-in" when the time comes to collect information.

- Integrate data collection into program activities when possible, rather than making it an "add-on" activity to tackle later.

- Consider using existing data before you develop plans for collecting new information.

- Identify potential barriers to data collection and develop strategies to address them.

Challenge: "It is not clear who specifically benefited from a PSE change that was implemented."

PSE changes are generally designed to reach a large number of people, rather than targeting specific intervention participants. For example, an environmental change may reach anyone who was present in that environment. Depending on the scale and scope of your PSE change, it may be difficult to know exactly who benefited. It may be hard to tell who exactly was impacted by a change in policy, who benefited from a system change, or who was exposed to an environmental change. Your logic model should clearly state what groups or individuals the policy change intends to reach. You could also ask those who implemented the policy change about who they observed to have been reached; testing the assumptions noted in your logic model and identifying other groups or individuals who were not originally intended to be reached by the policy change. This information could be valuable for describing the impact of your policy change and informing which groups or individuals should be the focus of your data collection strategy.

Challenge: "I want to collect follow-up information from program participants, but I'm worried I won't be able to find them."

When needed, ask participants for their contact information when they receive services. In addition to asking for their phone number or email address, you may want to ask for an additional phone number or email address of someone who will have the participant's current contact information. When appropriate, you could also increase the chances of getting the data by asking all or some of the evaluation questions at the conclusion of a service, rather than after a follow-up period. For instance, if a person receives an educational phone call, include some questions about their understanding of colorectal cancer screening at the end of the phone call.

It may be necessary to partner with another organization in order to follow up with participants to see if they ended up getting screened. For example, if you conduct a campaign to increase community awareness of colorectal cancer screening, it would be optimal to partner with a local health clinic that provides stool tests or assists participants with colonoscopy appointments. The clinic could then ask patients how they received the referral.

Challenge: "My initiative reaches hundreds of people. There's no way we can include all of them in our evaluation, given our limited time and resources."

With a very large initiative, it may be more manageable to gather information using a survey, rather than interviews. If interviews are your best strategy, interviewing only a sample of the participants should suffice. For example, you could conduct interviews with people served or reached in specific months or select every tenth person to interview. As long as your sample is large enough and similar to the overall group of people served or population reached, your results should generally reflect the opinions and experiences of your entire group of clients or your intended population.

Challenge: "I don't know when to schedule my data collection."

Scheduling data collection should be decided, in part, by whether your program is conducting ongoing program evaluation to assess quality or evaluating a specific initiative. For an ongoing evaluation, you can collect information through program attendance or service records. You can also ask participants questions relating to satisfaction to learn of any issues that should be addressed. To evaluate a specific activity, your program should have an understanding of its goals and when you expect these outcomes to be achieved. You may be able to collect some information, such as participants' satisfaction with services, at the time services are completed or even midway through a longer-term program. However, if you want to know about changes people have made in their lives, you will need to allow more time and plan accordingly. Use your program theory and logic model to help you decide when to collect information.

> *If it is important to your evaluation to show change in someone's attitudes, behavior, or situation over time, you may need to collect information at least two times, such as at the beginning and end of services.*

CULTURAL CONSIDERATIONS

- Take time to establish rapport with participants prior to collecting information—in some cases, it may be necessary for interviewers to provide information about themselves beyond what is customary.

- Use a communication style that approximates the style of the cultural groups participating in the evaluation (e.g., formal and direct questioning may be appropriate for some audiences while others prefer informal conversation).

- Be aware of familial and cultural dynamics during data collection (e.g., is it appropriate for individuals to be interviewed alone or should a family member be present?).

- Provide adequate training and ongoing support to data collection staff to ensure data are collected appropriately, consistently, and safely.

- Consider participants' fluency and familiarity with English. It may be necessary to translate surveys or interview protocols. If you translate the survey into another language, have bilingual individuals review the original survey and the translated version to ensure that the question meaning did not change.

- Identify someone from the cultural group to recruit participants or collect data. Keep in mind, however, that some individuals (especially those in tight-knit communities) may have concerns about being interviewed by someone from their own community who knows their family and friends.

- Any collaboration or support from community leaders should be made clear to potential participants through letters of support or having the leader actively recruit participants.

TAKING THE NEXT STEP

Before you create a data collection plan, think through logical data collection points and expectations from funders and other stakeholders. Determine the staff members who will assist in collecting the data and keep time and your budget in mind. Before you collect data, consider the method's appropriateness for your target population. Brainstorm any possible challenges that may occur when collecting the data and come up with potential solutions beforehand.

STEP 6: Organize and analyze information

Chapter overview

By the end of this chapter, you will be able to:

- **Understand quantitative and qualitative analysis.**

- **Organize your evaluation information effectively.**

- **Interpret results accurately and report sound conclusions.**

Once data have been collected, you need to organize and analyze the information. The best time to start thinking about the analysis plan is while you are identifying key evaluation questions and determining the data collection plan. Your analysis strategy should match the type of information you have and the evaluation questions you are trying to answer. You will first need to prepare your data by entering the information into an appropriate format. Appendix 2.16 includes some tips for effectively entering data.

Depending on the scope of your evaluation and your available resources, you may want to create a database or spreadsheet to organize your information. Readily available computer programs, such as Microsoft Excel and Access, can be useful. Excel tends to be easily accessible for most people who have access to a computer with Microsoft products. Other software is available to help you analyze both quantitative and qualitative evaluation results, such as SPSS or ATLAS-ti. Some of this software is expensive and requires specific training, however, you may be able to analyze your findings without it. The decision to use specialized software should be based on considerations of the complexity of your data and the analyses required. Before investing in this software, seek outside consultation to determine if it is needed.

ANALYZING QUANTITATIVE DATA

Quantitative data is information you collect in numerical form, such as counts, percentages, and rating scales. Closed-ended survey questions, which limit responses to predetermined categories (e.g., yes or no), are typically given a numerical value so they can be analyzed quantitatively.

Summarizing results

Once you have collected your data, you must decide on what types of analysis to use. Some relatively simple statistics can provide useful information. Descriptive statistics are analyses

intended to help you summarize your data and identify key findings. Descriptive analysis is used to reduce your raw data to an understandable level.

Common methods include:

- ■ Counting how many of your participants fall into various categories of interest (e.g., how many said they "strongly agree," "agree," "disagree," and "strongly disagree"), often called "frequency distributions."

- ■ Finding the number that best represents the "typical score," such as the average, called "central tendency."

- ■ Calculating the amount of variation or disagreement in your results, called "variability."

Detailed, step-by-step instructions for calculating this information is included in Appendix 2.17. Additionally, if you are using Microsoft Excel to store, organize, and/or analyze your quantitative data, it may be helpful to review some basic Excel functions, as well as learn some more complex analysis tools. Here are some helpful free tutorials that can guide you through the vast majority of Excel functions.

- o **GCF LearnFree.org**
  http://www.gcflearnfree.org/excel2010

- o **Baycon Group**
  http://www.baycongroup.com/el0.htm

- o **Free Training Tutorial**
  http://www.free-training-tutorial.com/

- o **Excel Exposure**
  https://excelexposure.com/

- o **Microsoft Office**
  https://support.office.com/

Determining whether results are meaningful

The overall goal of inferential analysis is to determine whether results are meaningful. For example, did participants in your colorectal cancer screening awareness program change in important ways over time? Were participants really different from people who did not participate in the program activities? Did organizations adopting a policy change see more of an increase in colorectal cancer screening rates than those that did not? In statistical terms, the meaningfulness of findings is typically described in terms of "significance."

Many statistical tests can be used to conduct inferential analysis. Common statistical tests include chi-squares, correlations, t-tests, and analyses of variance. These statistics would most likely NOT be familiar to people without evaluation or research experience. If these statistics are not familiar to you, but you want to see if your results are "statistically significant," seek consultation to ensure you select the right type of analysis for your data and interpret the findings appropriately.

To be considered significant, there has to be a high likelihood that the results were not due to chance or random variation. When this occurs, you can conclude that a relationship between two variables is strong and reliable. For example, your program would want to know whether participant knowledge of colorectal cancer screening options increased due to your small media campaign, or if another program's activities caused this change. Several factors influence the likelihood of significance, including the strength of the relationship (i.e., how related are your results to your program activities?), the amount of variability in the results (i.e., did the results from one group differ greatly from another?), and the number of people in the sample.

Quantitative analysis tips

- Review and correct data entry before beginning your analysis.

- Leave enough time and money for analysis—it is easy to focus so much on data collection that you do not leave enough time to analyze the results.

- Identify the appropriate statistics for each key question—get consultation if needed.

- Do not use the word "significant" when describing your findings unless it has been tested and found to be true.

ANALYZING QUALITATIVE DATA

Qualitative data are non-numerical information, such as responses gathered through interviews, observations, focus groups, written documents or journals, or open-ended survey questions. On its own, or in combination with quantitative information, qualitative data can provide rich information about how programs work. However, meaningful analysis of qualitative information can take time.

The first step in analyzing qualitative information is to reduce or simplify the information. Because of its verbal nature, this simplification may be difficult. Important information may be scattered throughout interviews or focus group proceedings. During this first stage of analysis, you must make important choices about which aspects of the information should be emphasized, minimized, or left out altogether. While it can be difficult to remove comments provided directly by participants, it is important to focus on the questions you are trying to answer and the relevance of the responses to these questions.

Depending on the amount and type of data that you have, you might want to identify the common themes in your data. Identifying these themes is often called "coding." You can begin developing a set of codes or themes before you collect your information, based on the theories or assumptions you have about the anticipated responses. However, it is important to review and modify your codes as you proceed to ensure they reflect the actual findings. When you report the findings, the codes will help you identify the most prevalent themes that emerged. You might also want to identify quotes that best illustrate the themes for use in reports. The following example illustrates some sample coding for Example 2, the focus groups conducted by the Metropolitan Colon Cancer Collaborative.

For more information on analyzing qualitative data, access the Effectively Using Qualitative Data tip sheet from Wilder Research. If you are looking for a comprehensive source for qualitative analysis, consult the book *Qualitative Research & Evaluation Methods* by Michael Quinn Patton.

Coding example

Question: Are the materials understandable?

Focus group responses:
- "I get that the brochures are supposed to give us more information about colon cancer and how to get screened, but the language used to talk about the screening tests is confusing. I can't keep all the '-oscopies' straight!"
- "Honestly, I still don't know the difference between a sigmoidoscopy and a colonoscopy after reading this. Maybe you can talk about what each test looks for specifically, and what it's supposed to be like."
- "I know I've had one of these tests before, but I can't tell which one by looking at the brochure. The big words on the handout make it a little confusing. It would be helpful to know which one, though, since I think it's important for me to get one done again."

A code for the three responses to the question would be that the **language used to describe the screening test options is too complicated**. People reading the educational materials may be confused by the different screening test options and would like the tests to be described in simpler terms. Since multiple people had the same feeling about the brochures, it may be fair to say that this is an important concern for the group to address.

INTERPRETING YOUR RESULTS AND DRAWING CONCLUSIONS

Both quantitative and qualitative analyses only get you so far. While the analysis can help to summarize and identify key findings, you still need to interpret the results and draw your conclusions. Drawing conclusions involves stepping back to consider what the results mean and what they imply about your work. During this phase, ask yourself the following types of questions:

▶ What patterns and themes emerge in the results?

▶ Are there any deviations from these patterns? If yes, what might explain these deviations?

- ▶ Do the results make sense?

- ▶ Are there any findings that are surprising? If so, how do you explain these results?

- ▶ Are the results statistically significant? Are they meaningful in a practical way?

- ▶ Do any interesting stories emerge from the responses?

- ▶ Do the results suggest any recommendations for improving the program?

- ▶ Do the results lead to additional questions about the program? Do they suggest that additional data may need to be collected?

Involve stakeholders. Consider including key stakeholders in this process by reviewing findings and preliminary conclusions with them prior to writing a formal report. If you collected qualitative data, you might want to ask informants to review your notes or summaries, to ensure that you have correctly captured their thoughts or feedback. Involving stakeholders in the review and interpretation of data helps ensure their interests have been met through the evaluation and that any questions have been answered.

Consider practical value, not just statistical significance. Statistically significant results are those that are unlikely to have occurred by chance. Do not be discouraged if you do not obtain statistically significant results. While a lack of significant findings may suggest a program was not effective in promoting change, other factors should be considered. You may have chosen to measure an outcome that was too ambitious, such as a community-wide increase in colorectal cancer screening rates. These outcomes may take longer to emerge. Or, you may simply not have had enough cases to produce statistical significance. In interpreting your results, consider whether there are alternate explanations to the lack of significance. It is also important to consider the practical significance of the findings. Some statistically significant results do not yield important information to guide program enhancements, while some findings that are not significant are still useful.

Watch for, and resolve, inconsistencies. In some cases, you may obtain contradictory information. For example, you may find that stakeholders describe important benefits of your group education classes, but these improvements do not play out when you examine post-test screening rates. Various stakeholders may also disagree. For instance, staff may report changes that are not reported by the participants themselves. It can be challenging to determine which information is accurate, especially when comparing different viewpoints or perspectives. Remember that various stakeholders can have valid viewpoints that vary based on their unique perspectives and experiences. Try to resolve these discrepancies and reflect them in your findings to the extent possible.

CULTURAL CONSIDERATIONS

- Make sure sampling procedures result in an evaluation sample that reflects the priority population of interest.

  — Use sampling techniques that provide for adequate representation among all priority audiences and address appropriate subpopulations, not merely broad racial or ethnic categories. In colorectal cancer screening for instance, it may be important to understand the impact of a screening intervention [10] by insurance status or by age.

  — Consider outreach to priority groups.

- If the sample of participants does not constitute a representative sample of the cultural groups of interest, findings should not be attributed to cultural differences.

- Collect data from enough people to allow you to see patterns in the data and to be able to make generalizations about the results.

- When interpreting data, avoid explanations that are based on cultural stereotypes or use "deficit model" interpretations (e.g., explanations that compare diverse groups to a monocultural standard).

- When exploring cultural differences, make sure culture is appropriately measured and other relevant variables are also included.

  — Consider not only differences that arise from culture but also other plausible variables that may account for the observed differences between the two groups (e.g., gender, age, socioeconomic status, insurance status).

  — Consider measuring issues such as acculturation, biculturism, and ethnic identity to aid interpretation of data. For example, recent immigrants from a particular ethnic group may have very different views about colorectal cancer screening compared to second or third generation members of the same ethnicity.

- Have people with knowledge of the particular group being evaluated analyze the data alongside the evaluators in order to point out variables that should be considered.

- Be cautious when collapsing data across subgroups for the sake of analysis. Doing so can reinforce the idea that the group is homogenous and you might miss distinctions between subgroups that may be relevant to your work. Conduct analyses in a manner that reflects the heterogeneity in the data.

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[10] Throughout the toolkit, these activities may be referred to as programs, initiatives, interventions, or efforts.

Example 1: Northside Medical Clinic

The Northside Medical Center staff use their improved processes and calculate their screening rate overall and by physician. To calculate these screening rates, they divide the number of patients age 50-75 who received appropriate colorectal cancer screening by the total number of patients age 50-75 seen that year. They exclude certain patients (such as patients who previously had cancer) based on standard colorectal cancer screening rate calculation processes. They prepare a summary for each physician that summarizes the screening rate for his or her own patients.

When the clinic staff first compile their screening rates, they find that the clinic as a whole was screening about 45 percent of their adults age 50-75 for colorectal cancer. Individual physician rates ranged from 25 to 62 percent. After the first quarter, the clinic's overall rate increased to 58 percent, with individual physician ratings rating from 42 to 70 percent. For a few quarters, the clinic's overall screening rate continued to climb; however, the rate eventually leveled off.

Example 2: Metropolitan Colon Cancer Collaborative

The Collaborative advocacy group reviews detailed notes from the three focus groups. With their consultant's assistance, they create a list of codes, reflecting key issues that emerged. They then use the list of codes to categorize the focus group comments into themes. They review the coded notes to identify the most prevalent and/or significant issues (see page 57 for an example of how to code the focus group results).

Focus group participants provided useful suggestions for the Collaborative. For the most part, they liked the educational materials. They felt the brochures did a good job of conveying the importance of screening, and that that they were visually appealing.

Participants offered a few suggestions for improvement. They recommended using simpler language when describing screening test options and providing more suggestions for local screening resources. They also suggested a stronger focus on encouraging men to pursue screening, through changes in the materials and greater outreach at community events.

Example 3: The Wellness Clinic

The Wellness Clinic staff collect surveys over a period of six months. They enter all of the survey results into an Excel spreadsheet. They run a number of cross-tabs analyses, to compare changes in survey responses (for example from pretest to posttest) and to explore differences in responses based on the gender or age of the participant.

They first compare patient knowledge and awareness ratings before and after the one-on-one education session. They find that patients did generally increase their knowledge, and they were more likely to say that they would pursue screening following the session.

They compare these ratings to those in the follow-up surveys and find some decline. Some people did not remember the material covered, and many of those who had indicated an intention to seek screening on their post-test survey did not subsequently get screened.

Satisfaction ratings were generally high, with most people rating the person who provided the education as helpful and competent. However, males reported less comfort with the discussion and with the educators, all of whom were women.

TAKING THE NEXT STEP

Now is the time to sort through all the valuable information you have received through data collection. If you collected quantitative data, look for any patterns or surprising results. Qualitative data can give you a detailed picture of how participants perceived your activities and how satisfied they are with the program. Involve stakeholders in reviewing the results, as they may be interested in learning about the information you received through the evaluation.

STEP 7: Using and sharing evaluation results

Chapter overview

By the end of this chapter, you will be able to:

- **Explain how evaluation results can be used to improve program outcomes, stakeholder satisfaction, and service delivery.**

- **Select the right strategy for sharing evaluation results and prepare an evaluation summary.**

- **Understand cultural considerations for presenting evaluation findings.**

SELECT THE RIGHT COMMUNICATION STRATEGY

Once you have obtained your evaluation results, you should share the findings with your key audiences and stakeholders. Sharing results is beneficial for a number of reasons, as they can inform the public, make health information meaningful, help other public health partners improve their programs, and translate research into action. They can also assist your organization build community relations, develop partnerships with funders, and help to sustain or secure future funding. You may have several different audiences, each with their own interests and preferences regarding the report format. For example, an evaluation designed to help staff improve their methods for increasing awareness of colorectal cancer screening may lead to a report that is very different from one required by an external funding source or one designed to share lessons learned with a broader professional community.

As you are developing a communications strategy, consider opportunities to share information back to your evaluation participants. Hearing about what was learned, and what your organization intends to do with the information, can help them understand the value of their contribution and increase their willingness to participate in future evaluation or research projects.

As you prepare to share your evaluation findings, think about what you want to communicate to various audiences. Content is not always best shared in a long and complicated report. A few concise pages may have more impact than a larger report. Instead of producing a document describing a complex set of ideas, consider dividing the results into several smaller reports. In determining your approach, consider what will be the easiest and clearest way to present the information to your key stakeholders. With any stakeholder audience, it is critical that the method of

sharing information is consistent with the needs of the audience. Tips for writing a report can be found in <u>Appendix 2.18</u>.

MAKE YOUR FINDINGS RELEVANT

As you talk to stakeholders, take note of what might be of interest to them. Health care agencies might be interested in findings and implications of your outreach efforts and advice for improving similar programs, whereas policy makers might only want to hear about return on investment, recommendations, and next steps. A report for staff within your organization will differ significantly from a report for a funder in terms of length, content, language, form, and key points. It is important to present your information specifically for the intended audience. This frequently will mean multiple versions of reports containing similar information. A template for identifying research implications, such as the one below, can also be found in <u>Appendix 4.7</u>.

Research question	Method	Findings	Implications	Recommendations
What do we want to know?	**What was done?**	**What was learned?**	**What does this mean?**	**Where do we go from here?**
To what extent do services meet the needs of clients?	Satisfaction survey administered to clients by program staff	20% of clients not satisfied with staff knowledge of resources	Clients may not receive adequate referrals to community resources	Develop training for new and existing staff related to community resources
To what extent do the colorectal cancer education brochures provided at medical clinics impact adults' awareness of colorectal cancer?	Surveys collected by health care providers within past 6 months	55% of adults have increased knowledge about symptoms and risk factors associated with colorectal cancer	Brochures provided at medical clinics are increasing knowledge among adults and may increase numbers of adults who are screened for colorectal cancer	Partner with hospitals and clinics to distribute brochures more broadly
What impact is the pilot program having on African American adults' screening rates?	Interviews with health care providers and clients participating in pilot program	15% increase in colorectal cancer screening among African Americans touched by the program	More African American adults are being screened for colorectal cancer	Consider expanding pilot program within county and promote to surrounding counties
What is the impact of a system-wide training for clinic staff to help establish new colorectal cancer screening practices?	Interviews with health care providers and tracking of clinics colorectal cancer screening rates through chart audits	Clinics that participated in the training had between a 15%-20% increase in colorectal cancer screening among their patients, providers shared strategies for sustaining their clinic's practice changes, and conveyed interest in expanding the practice change to other areas of cancer screening	More patients are being screened and the practice change may be used in other areas of cancer screening	Consider expanding the training to other clinics and measuring the impact of the training on county-level colorectal cancer screening rates

Tips for communicating your message effectively:

- Know your audience, what will impact and what might overwhelm.

- Determine whether each audience is interested in 'hard facts' or a more anecdotal narrative of the evaluation findings.

- Avoid jargon and acronyms, specifically those terms which are common within your field of interest but might be lost on the general public.

- Use clear and concise writing, and include charts and graphs where appropriate.

In addition to keeping in mind the key findings, implications and/or recommendations for each audience, it is also important to consider what your stakeholders will do with the evaluation results. Will the results be used to make changes to your colorectal cancer screening awareness program? Will the evaluation inform others or support advocacy efforts? Will the evaluation help stakeholders plan for future programs? Will the results help to secure future funding?

CULTURAL CONSIDERATIONS

Presenting the results of a study or program evaluation can be especially challenging when the audience for the report is from a different cultural background. Here are some specific items to consider, but keep in mind that many of these tips apply when presenting results to any audience:

- Be aware of your intended audience and use of the report. Be careful not to present the data in a way that generalizes to only one culture ("one size fits all" approach limits applicability to culturally diverse groups).

- Do not exclude findings that would be relevant to culturally diverse communities.

- Present in different languages and take time to get the translations done right.

- Ask yourself whether data or stories would be more meaningful to the members of this community. This may help the community "buy-in" to the results.

- Use appropriate channels of communication. Determine whether written formats (e.g., reports and summaries) or oral presentations would work best to disseminate results.

- Assess the potential impact of the evaluation results on the program or community.

- Inform community members of the actions that will be taken as a result of the evaluation. What changes will be made? How will the changes affect the services they receive?

CONSIDER CREATIVE STRATEGIES FOR SHARING RESULTS

Be creative and innovative in reporting evaluation findings. Use a variety of techniques such as visual displays, oral presentations, reports, and informal conversations. Additional ideas include:

- Writing separate executive summaries and popular articles using evaluation findings, targeted at specific audiences or stakeholder groups.

- Sharing your results with the media, through a press release and/or press conference.

- Making presentations to select groups, such as community partners or potential funders.

- Making a short video presenting the results to use in discussions with stakeholders.

- Sharing results with local, regional, and national professional communities.

- Publishing results in an academic journal, if your organization has completed a particularly rigorous evaluation or a demonstration study of a new approach.

Here are some journals that include articles on colorectal cancer:

- **Journal of Cancer Education**
  http://www.springer.com/biomed/cancer/journal/13187

- **Preventive Medicine**
  http://www.journals.elsevier/com/preventive-medicine

- **American Journal of Health Behavior**
  http://www.ajhb.org/

- **American Journal of Health Education**
  http://www.shapeamerica.org/publications/journals/ajhe

- **Health Promotion Practice**
  http://hpp.sagepub.com/

- **Cancer**
  http://onlinelibrary.wiley.com/journal/10.1002/(ISSN)1097-0142

- **CA: A Cancer Journal for Clinicians**
  http://onlinelibrary.wiley.com/journal/10.3322/(ISSN)1542-4863

INVITE STAKEHOLDERS TO REVIEW AND DISCUSS RESULTS

Review the results with colleagues and program staff before finalizing an evaluation report. Circulate a draft report and hold a meeting to discuss it together. Having this conversation in advance can provide you with additional views regarding the meaning of the data. For example, your colleagues can discuss and help interpret any findings that are puzzling or surprising. Their interpretations or opinions about the findings may help you determine strategies for framing your conclusions and recommendations in the final report.

There may be political considerations as well. Before a report is released publicly, you may want to brief important stakeholders. The briefing gives board officials or others some time to digest the findings and think about the implications, and provides them with an opportunity to prepare a response. Through this process, you will also learn what appear to be the most important findings from the perspective of the groups that will use them.

> *So often the energy behind an evaluation of a program is to suit the needs and desires of a funding source, or, like a lot of programs, several funding sources. It's easy to think of evaluation as a means to an end, a process that must be endured in order to get the funds you need to get the work done. Evaluation can have a significant impact in other ways, such as program improvement. It is important for evaluation staff and stakeholders to remember that evaluation can be incredibly useful in making your colorectal cancer screening initiatives more effective and will likely increase the likelihood of the program continuing. Evaluation is much more than a final report. The evaluation process teaches many lessons, and the process is most meaningful when different groups of stakeholders are involved from the beginning.*

An action plan for using your evaluation results can be found in Appendix 4.8.

EVALUATION RESULTS FOR PROGRAM IMPROVEMENT

There are many different ways an evaluation can have impact. Perhaps you learned something interesting about program outcomes or learned something about participant characteristics that predicts their satisfaction with the program. The following will help identify some of these findings and guide you and your stakeholders to use these results successfully.

Outcomes

If your evaluation measured the outcomes of your intervention [11] on participants, you should now have some information about the extent to which the initiative met its goals. Think about the following:

▶ What knowledge, awareness, intention, or behavior outcomes showed the highest success rates? What initiative components do you think contributed to these outcomes the most? Why do you think these components were important?

▶ What outcomes showed the lowest success rates? Were these success rates below the level expected or below an acceptable level? How do these rates compare to those of other initiatives, in other states, or nationally? Why do you think outcomes were not as positive? How could existing strategies be strengthened to promote positive outcomes? Are there new strategies that should be considered?

▶ How could current PSE changes be redesigned or implemented differently to lead to better outcomes? For example, is there additional training or communication that should be employed to support a policy change?

Process

In addition to providing information about program participants or those reached by a PSE change, an evaluation often includes an assessment of the activities that were provided. This information allows you to look at the connections between service delivery and outcomes or participant satisfaction. Consider the following:

▶ What kinds of activities did participants engage in? Was this consistent with the program's intended approach? If not, does the program need to be modified to increase or decrease the amount of activities each individual participates in?

▶ Did the policy change impact the people it was intended to? What barriers do people continue to face in getting screened that were not addressed by the policy change?

▶ What strategies have worked well in implementing the policy? What challenges have been encountered? Does variation in activities (i.e., type or amount of service provided) relate to differences in either participant outcomes or satisfaction? If so, are there changes in the activities that should be considered?

▶ Are there ways the program should be modified to increase the percentage of participants who complete screening? For example, do multiple calls need to be made to remind participants they are due for screening?

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[11] Throughout the toolkit, these activities may be referred to as programs, initiatives, interventions, or efforts.

▶ Are there ways system change should be modified to ensure that it is being implemented correctly and having the desired impact? Do those who are implementing the system change require additional training to ensure strong, consistent implementation? Are those responsible for the system change completely supportive of it? Is there buy-in from the highest level of a health system?

▶ If the program was attempting to replicate an established model used by another agency, was it implemented with conformity to the original model? If not, why not? How do you think the changes in the model may have impacted outcomes? What strategies can be used to ensure stronger fidelity in the future?

▶ What challenges and barriers did participants or those reached encounter? How can these barriers be reduced in the future? For example, could materials be provided in a different language if there were communication barriers?

Satisfaction

Assessing satisfaction provides valuable information about how participants experienced the intervention. If you collected satisfaction information, you will want to consider these questions:

▶ What satisfaction areas showed the most positive ratings? What intervention components do you think most contributed to these ratings?

▶ What satisfaction areas showed the lowest ratings? Were these ratings below the level expected or below an acceptable level? Why do you think satisfaction was not positive? How could intervention activities or components be strengthened to increase satisfaction?

Participant background/characteristics

Review the information you have learned about the program participants or those reached by a PSE change and ask:

▶ Who participated in the activities, received services, or was reached by the policy change? What were their major demographic characteristics? What kinds of issues brought them to the program or were addressed by the policy change?

▶ Which stakeholders participated in bringing about the system change? Which stakeholders will be impacted by the systems change?

▶ Are there any features of the population served that have changed over time, such as an increase in older adults or a different cultural group? If so, do these changes have any implications for changes in outreach?

▶ Do any characteristics of participants or those reached predict differences in outcomes or satisfaction? If so, do activities or components of the policy change need to be modified to better meet the needs of diverse individuals?

Evaluation design

If you intend to evaluate your intervention again in the future, it is also important to reflect on the evaluation process itself. You may be able to save yourself time, money, and headaches if you can apply lessons learned from carrying out the evaluation the first time around to future evaluation work. Consider the following:

▶ What challenges emerged during the implementation of the evaluation plan? Should the evaluation design be revised to minimize these challenges?

▶ Based on your review of the results, will you modify your services or activities or the design of the PSE change? If so, do these changes require modifications to the evaluation design?

▶ Did your review of evaluation results raise any questions that you could not answer? Do you want to revise the evaluation materials to explore this issue further in the future?

TIPS FOR USING RESULTS TO ENHANCE PROGRAMMING

Consider the following suggestions when making programmatic or policy decisions based upon your evaluation findings:

■ Set goals for outcomes and stakeholder satisfaction—they can help you gauge your success in meeting outcomes and help you prioritize program improvement efforts.

■ When reviewing the evaluation results, be open in discussing different options, explanations, and alternatives.

■ Review your list of key stakeholders and consider including them in your discussion.

■ Consider both short-term and long-term strategies to improve your initiative

■ Review other colorectal cancer screening awareness programs or evaluation studies for suggestions for promoting the effectiveness of your program.

■ Consider a broad range of improvement strategies, but prioritize those follow-up steps most likely to help you achieve your goals.

Example 1: Northside Medical Clinic

The clinic leadership is pleased to see the clinic's screening rate increase steadily for the first few quarters. However, the rate levels off before they reach their goal of screening 80 percent of all adults age 50-75. Deciding that more efforts were needed, they decide to take three additional steps.

First, knowing that there are significant differences between the screening rates of individual physicians, they decide to start providing physicians with their own screening rates along with those of their colleagues. The clinic leadership hope that seeing the screening rates of others may further motivate physicians to increase their own rates. Second, they decide to try to address potential barriers to screening, outside of the physicians' recommendations to their patients. They decide to devote resources to more messaging to patients regarding the importance of colorectal cancer screening, including patient newsletters and posters in the waiting room. Third, they decide to apply for a grant to recruit and train a patient navigator to assist with patient reminders, providing information, and answering questions during the process between recommending and completing the screening test.
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Example 2: Metropolitan Colon Cancer Collaborative

The Collaborative uses the feedback from the focus groups to modify their materials. They revise the brochures by simplifying their descriptions of the screening and adding more local resources. They also identify some new opportunities for dissemination and outreach.

As they move forward with these revisions, the Collaborative revisits their initial evaluation questions. They are still interested in broader issues regarding the ultimate impact of their materials—are people who read the brochures more likely to pursue screening? They begin planning the next phase of their evaluation to explore these issues.

Example 3: The Wellness Clinic

The clinic decides to make two changes to their approach. First, they decide to recruit and train several male staff to provide the one-on-one education, so that they can match the gender of the patient with the gender of the educator. Second, they add a follow-up step in which the educator calls patients approximately six weeks after the education session to see if they have any questions and encourage them to pursue screening if they have not already done so.

Both of these actions result in higher costs for the clinic, but they are able to use their evaluation findings to obtain grant funds from a local foundation.

WRAP UP

Through this toolkit, we have outlined the basic steps for conducting a program evaluation, including describing and mapping your program, prioritizing your evaluation questions, designing your evaluation, creating the tools for gathering information, gathering information, sorting and analyzing the information, and using and sharing the information. Remember that doing an evaluation well does require attention to the concepts and tips we outlined here. However, our best advice is to just get started. If you experience difficulty, review the tips in this toolkit, and do not be afraid to seek additional support from professional evaluators if needed. With experience, you should find that your evaluation provides you with useful information about your services.

FOR MORE INFORMATION

For more information about colorectal cancer, please visit the American Cancer Society website at cancer.org, the Centers for Disease Control and Prevention website at http://www.cdc.gov/ or the National Colorectal Cancer Roundtable at http://nccrt.org. For questions about evaluation of colorectal cancer related interventions, please contact Mary Doroshenk, Director of the National Colorectal Cancer Roundtable at Mary.Doroshenk@cancer.org.

APPENDIX 1 – CASE STUDIES

Case study

1.1 Patient reminders case study

This case study describes a fictional program at a community-based clinic. Like many clinics, the clinic in this case study has been using reminder calls to prompt patients to make an appointment to get screened. Staff are interested in learning about whether these efforts are impacting screening rates, but have limited resources for evaluation. The evaluation steps in this study are recommendations from Wilder Research based on information in the Evaluation Toolkit.

Background

Bayshore Medical Clinic, a small community-based clinic that relies on FIT testing, has been calling patients who are due or overdue for colorectal cancer screening to remind them to make an appointment to be screened. While developing their annual budget, Bayshore's executive director expresses concern about the cost of the calls in terms of staff time and questions whether it is worth it to continue. She wonders if they are making a difference. Are people more likely to get screened? Would another strategy, like postcards, be equally effective and less resource intensive?

Step 1: Describe and map your program

Before jumping into any data collection activities, the executive director works with program staff to develop a program theory and logic model for these efforts.

Program theory for Bayshore Medical Clinic's reminder call program:

IF health clinic staff call clients who are due or overdue for screening to remind them it is time to be screened for colorectal cancer, **THEN** clients learn that their health care provider recommends colorectal cancer screening for them and that colorectal cancer screening is important.

IF clients learn about the importance of screening and that they are due for screening, **THEN** they will make an appointment to be screened for colorectal cancer.

IF clients make appointments, **THEN** they are more likely to get screened.

IF clients are more likely to get screened, **THEN** colorectal cancer screening rates will increase.

IF screening rates increase, **THEN** colorectal cancer incidence and mortality rates will decrease.

Logic Model for Bayshore Medical Clinic's reminder call program:

INPUTS	ACTIVITY	OUTPUTS	SHORT-TERM OUTCOMES	INTERMEDIATE OUTCOMES	LONG-TERM OUTCOMES
-Telephones -Staff	Call clients to remind them to be screened for CRC	-Number of calls made -Number of clients reached	Clients learn that their health care provider recommends CRC screening for them and that CRC screening is important	Clients make an appointment to be screened for CRC	CRC screening rates increase
				Clients are more likely to complete screening	CRC incidence and mortality decrease

Step 2: Prioritize evaluation questions

The director follows up with the staff making the calls, and together they brainstorm a variety of other questions that they would like information about: How often do they successfully reach people? Are people comfortable being called? When is the right time to call in order to reach the most people? Staff are interested in outcomes such as the impact of the reminder calls on screening behavior. They also identified process questions about the implementation of the calls, such as their success in reaching people by telephone.

Staff decide they are most interested in whether reminders increase screening rates. According to their logic model, reminders will educate patients about the importance of screening and encourage them to make an appointment. The clinic would also like to learn whether postcards or telephone calls are more effective and cost-efficient.

The clinic is also interested in knowing what their patients think about the reminders and whether they influenced them to get screened. However, answering these questions would require them to contact patients directly. They decide not to do this at the present time due to capacity concerns.

Step 3: Design the evaluation

The Bayshore Clinic is small and does not have funds specifically allocated to evaluation. They do have several other resources available to them, however. Their staff includes one person who developed several surveys as part of a graduate school project and another who is good at making databases in Excel. They also have access to some medical students who help out at the clinic several afternoons each week.

The Bayshore Clinic decides to track all information internally, using a combination of primary and secondary data sources. Staff want to know the number of people who made a screening appointment within two months of the reminder. This information can be extracted from medical records. However, they also want some additional information, including the number and type of reminders given and the number of contacts that were unsuccessful. They decide to create a spreadsheet to track this information.

Step 4: Identify or develop data collection instruments

The Bayshore staff person with database skills sets up an Excel tracking system. The spreadsheet includes the patient number, information on whether patients were given a reminder phone call or postcard, and whether that patient eventually was screened for colorectal cancer. They also include a number of other fields that go beyond this specific evaluation question, including the outcomes of the screening test and the recommended follow-up steps. They thought this

information might be useful to collect for future evaluation questions, and that it would be more efficient to track the information concurrently.

Tracking spreadsheet

Patient ID	Date of reminder	Type of reminder	Date of CRC screening	Date screening kit returned	Result of CRC screening	Follow-up
05034563	7/9/2016	Phone	8/12/2016	9/15-2016	Negative	Recheck next year
04385964	7/9/2016	Postcard				
93837542	7/11/2016	Phone				
02843459	7/13/2016	Postcard				

Step 5: Collect the data

The clinic decides to track reminders for six months. Some patients receive postcards, and others receive telephone calls. They track which patients were given a reminder and how many contacts were unsuccessful (because phone numbers were incorrect or because mail came back as non-deliverable) using their Excel database.

Medical students, who already have access to patient files, review files to see how many people receiving reminders made an appointment to be screened within two months of the reminder. They enter this information into the Excel database as well.

Staff also keep track of their expenses, including staff time to make calls and printing and postage costs for the postcards.

Step 6: Organize and analyze information

The Excel spreadsheet that Bayshore Clinic staff created contains all of the information needed. Staff run simple frequency distributions to explore issues of interest. Comparing their two reminder strategies (phone calls and postcards), the staff calculate:

1. The number of patients contacted who made an appointment to be screened.

2. The average cost, by dividing the total costs (including staff time and postage) by the number of reminder calls or mailings made. Using Excel, they created the following two charts:

Percentage of people reached who made appointments for screening

22%	30%
Postcard (N=230)	Telephone (N=310)

Average cost per reminder

$2.00	$4.00
Postcard	Telephone
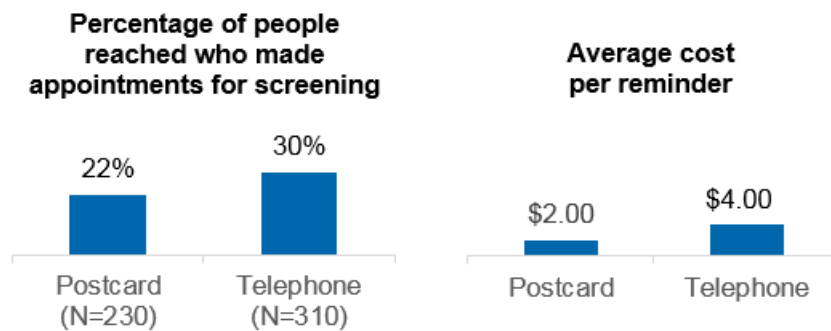
As a result of their analyses, Bayshore Clinic staff learn that success rates are higher for the telephone calls. There were significant cost differences, however. The relative costs of the telephone calls were twice the costs of the postcards.

Step 7: Using and sharing evaluation results

Based on their analysis, the Bayshore Clinic staff decide to switch their reminder approach to a two-pronged approach. Postcards are initially sent to those patients who are due or overdue for screening. If those patients do not make an appointment within one month of receiving the postcard, clinic staff call those patients with a reminder. In this way, staff time is used more efficiently and reserved for those patients who need more than a postcard reminder to respond.

1.2 Group education/small media case study

GROUP EDUCATION CASE STUDY

This case study describes a fictional group education/small media program that takes place in a community setting, in this case, a church. The evaluation steps in this study are recommendations from Wilder Research based on information in the Evaluation Toolkit.

Background

After a much-loved parishioner was diagnosed with colorectal cancer, St. Joseph's Church decided to begin hosting group education sessions to encourage screening. A parishioner, who is a gastroenterologist, volunteered to lead a series of group educational sessions and answer questions after Sunday services. The doctor also provided educational materials from his clinic. While many people had informally said that they were interested in participating, turnout was relatively low at the first few sessions.

Step 1: Describe and map your program

Group education is a relatively common strategy for promoting colorectal cancer screening. While there is insufficient evidence to support colorectal cancer screening group education programs [12], the CDC does say the intervention can be effective, when combined with one or more evidence-based interventions, such as small media, which St. Joseph's fictional program does. The program theory for this initiative would be:

IF group education combined with small media is provided, **THEN** parishioners will learn about the importance of screening.

IF parishioners learn about the importance of screening, **THEN** they will be motivated to make an appointment to talk to their own health care provider about colorectal cancer screening.

IF parishioners talk to their own health care providers about screening, **THEN** their health care providers will make a colorectal cancer screening recommendation.

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[12] While there is insufficient evidence at this time to support group education as an evidence-based intervention for CRC screening, according to the CDC's community guide at https://www.thecommunityguide.org/findings/cancer-screening-group-education-clients-colorectal-cancer, this does not mean that the CDC recommends against group education; it simply means that there is not enough evidence to say whether group education is effective or not. Further, the group education in this scenario is combined with small media, which *is* an evidence-based recommendation. Still, since group education is not yet a recommended strategy, it makes it all the more important to evaluate the effectiveness of programs that rely on group education to promote CRC screening. Additionally, sharing outcomes can help inform future work and contribute to our overall knowledge-base about screening.

IF parishioners receive a screening recommendation from their health care provider, **THEN** they will be more likely to get screened.

IF parishioners are more likely to get screened, **THEN** colorectal cancer screening rates will increase.

IF colorectal cancer screening rates increase, **THEN** colorectal cancer incidence and mortality rates will decrease.

The logic model for this project would look like this:

INPUTS	ACTIVITIES	OUTPUTS	IMMEDIATE OUTCOMES	INTERMEDIATE OUTCOMES	LONG-TERM OUTCOMES
-Materials -Location -Trainer	Group education sessions combined with small media	# of trainings # of people attending # of materials provided	Parishioners learn about the importance of screening	-Parishioners health care providers will make a CRC screening recommendation -Parishioners get screened	-CRC screening rates increase -CRC incidence and mortality rates decrease
			Parishioners make an appointment to talk to their own health care provider about CRC screening		

Step 2: Prioritize evaluation questions

The staff at St. Joseph's Parish considered a number of evaluation questions. The most urgent issue that they wanted to explore was the low turnout, and to find out if another time would work better for the parishioners to attend the group sessions (a process issue). However, as they talked about it further, they also decided that it would be helpful to know more about their outcomes to date. Did people feel they learned something about colorectal cancer screening? Were they more likely to want to be screened? Did they understand what to do next to get screened?

Step 3: Design the evaluation

St. Joseph's was fortunate to have time and experience donated by a staff member to assist with the evaluation process. Other staff were willing to help with the administrative and clerical aspects of the evaluation, including making copies of data collection materials. They know that they would like to gather information from everyone who attended the group education session, as well as from a larger group of parishioners. They decide that surveys will be the most cost-effective strategy for gathering most information. However, they also would like to gather some deeper information about steps that participants may have taken toward getting screened, and they decide to gather this information through in-person interviews.

Step 4: Identify or develop data collection instruments

The St. Joseph's staff create the following two surveys:

- **Survey collected at the conclusion of a group education session**: Staff design the first survey to be completed by all church members (age 50 or over) who participate in a group session. The primary purpose of this survey is to determine if there are any perceived changes in participants' colorectal cancer screening awareness and knowledge, and if they understand what to do to get screened. At the same time, they use this survey to gather information about participants' satisfaction with the group education activities. Questions were added to the survey to find out whether they liked the education session, and whether they felt comfortable with the volunteer who provided the sessions.

- **Survey of all church members**: The staff also design a survey for all church members age 50 and older. The primary purpose of this survey is to collect information about parishioners' preferred times to attend group education. They decide to collect this information in a separate survey, so that they can hear from parishioners who did not attend one of the group education sessions.

The staff also decide to conduct interviews with participants three months after the group education session. The purpose of these interviews is to find out whether church members who attended a group education session took any steps toward getting screened.

Step 5: Collect the data

The church staff use three different strategies to collect the needed information. First, the volunteer conducting the group education collects surveys at the conclusion of each group education session. Second, church staff help distribute a survey to all of their parishioners age 50 or older. They decide to administer the survey online, and put links to the survey in the church bulletin and on the church website. Third, a volunteer graduate student intern from the church conducts interviews with a random sample of members who participated in the group sessions. Interviews are conducted three months after each session and everyone who is interviewed receives a $25 incentive.

Step 6: Organize and analyze information

The program staff create Excel spreadsheets with the responses to the two surveys and the interviews. They conduct some basic analyses and discover some helpful information:

- 90% of parishioners age 50 and older want to have these meetings held at a more convenient time.

- 55% of participants reported increased knowledge of the importance of colorectal cancer screening, screening recommendations, and screening options.

- 40% of participants understood what to do next to get screened.

- 15% of participants interviewed, who had not been screened for colorectal cancer previously, had now been screened.

Step 7: Using and sharing evaluation results

Based on their analysis, the church staff make the following decisions:

- Because parishioners did not find the meeting times to be convenient, the staff decided to move the sessions to Wednesday evening, when the parish is already offering other community events.

- The staff were pleased to find that more than half of the participants reported increased knowledge of the importance of colorectal cancer screening, screening recommendations, and screening options. Because of these findings and implications, the parish decided to continue providing the monthly educational sessions at the church.

- Less than half of attendees understood what to do next in order to get screened. The staff and volunteer gastroenterologist agreed to strengthen the instructions given in the educational session about the next steps for parishioners wanting to get screened.

- Some participants who had not previously been screened for colorectal cancer sought screening after receiving group education. With this information, the church decided to consider expanding programs to other faith-based organizations in surrounding counties, and they considered expanding their program to help younger parishioners learn how to assess their family health history.

1.3 Provider case study

This case study describes a provider-focused intervention developed and implemented by the Pennsylvania Family Physicians. The case study describes the evaluation that they designed and implemented for this initiative.

Background

The Pennsylvania Family Physicians (PA Family Physicians) received a grant from the CDC to increase colorectal cancer screening rates. The PA Family Physicians are working with physician groups to raise awareness, provide education, and ultimately improve screening rates through systems change and improved knowledge among providers by participating in Grand Rounds with providers across the state.

Staff implementing the grant activities are interested in measuring the degree to which the Grand Rounds sessions change the knowledge and awareness of physicians regarding current recommendations for colorectal cancer screening, and the degree to which providers may change their screening behavior based on what they learned through Grand Rounds.

Step 1: Describe and map your program

The following program theory describes how Grand Rounds will lead to increased colorectal cancer screening rates:

IF PA Family Physician staff present to providers at Grand Rounds (focusing on current screening recommendations for colorectal cancer screening, including who should be referred for screening, when they should be referred, and what the appropriate screening might be for patients meeting certain criteria), **THEN** providers who attend Grand Rounds have increased knowledge of current screening recommendations.

IF providers who attend Grand Rounds have increased knowledge of the current screening recommendations, **THEN** they will be more likely to make appropriate referrals for colorectal cancer screening.

IF providers make appropriate referrals for colorectal cancer screening, **THEN** patients will receive referrals for the appropriate colorectal cancer screening from their providers at the appropriate time, given their unique characteristics.

IF patients receive appropriate referrals for screening, **THEN** they will be more likely to follow-up on that referral and get screened.

Step 2: Prioritize evaluation questions

Program staff would like to know if the education they provide to providers is ultimately resulting in increased screening rates for patients. Based on their logic model, they know that providers are more likely to make referrals for patients eligible for screening if they have the correct information about screening recommendations. Therefore, the team is interested in assessing any increases in knowledge and awareness of current screening recommendations of providers who attend the Grand Rounds. In addition, program staff want to know if providers feel they are more likely to make referrals after participating in the Grand Rounds discussion.

Step 3: Design the evaluation

The PA Family Physicians grant had some funding set aside for evaluation and limited staff time. Given the available resources, and the somewhat limited time available for intervention with individual providers (approximately 1 hour during Grand Rounds), the team determined the best evaluation design was to ask providers to complete post-surveys immediately following the Grand Rounds presentation. Staff were interested in doing both pre-and post-tests, as they were interested in measuring a change in knowledge among providers. However, given the limited amount of time they had with providers to present information, and the changes in knowledge and behavior they could expect given their limited intervention time, a post-only survey was determined to be the most appropriate evaluation method.

Step 4: Identify or develop data collection instruments

Given the unique research questions of the program, staff developed a post-only survey to be administered to providers immediately following the Grand Rounds presentations. The post-survey asks providers to indicate the degree to which they had knowledge about current screening recommendations, their intent to change their practices for encouraging patients to receive screening, and overall satisfaction with the presentation.

Step 5: Collect the data

Providers were asked to complete a paper and pencil survey immediately following the Grand Rounds presentation. Program staff collected the surveys and kept them confidential prior to entering the data into a format for data analysis.

Step 6: Organize and analyze information

Program staff developed an Excel spreadsheet to organize survey data. Once survey data was entered into the spreadsheet, program staff reviewed the survey as well as their key research questions to determine an analysis plan. Staff created some charts in Excel, as well as descriptive analysis, looking at the range of responses to key survey questions. Staff looked for results that

were actionable, or findings that indicated how the program could be enhanced or modified in future years.

Step 7: Using and sharing evaluation results

Results from the surveys have been helpful as staff report program impact to their funders, and have also been used internally as they modify the program for the future. Survey results were included in the annual report to the Pennsylvania Department of Health, detailing the program's successes and opportunities for enhancing it. Internally, staff learned which components of the training were especially meaningful to physicians, and which components they were most likely to integrate into their practice and why. Staff will take care to emphasize these components in future Grand Rounds sessions.

In addition to modifying the program, staff have modified the survey instrument for future years. Based on the results from this evaluation, staff will remove some questions that were not as helpful, and expand those questions that lead to the richest information from respondents.

1.4 Clinic screening practice/system change case study

This case study highlights the Colorectal Cancer (CRC) Screening Improvement Program offered through the Ohio Academy of Family Physicians (OAFP). The case study describes the evaluation of this initiative, while also offering possible additional routes related to evaluation for the purpose of illustration and education.

Background

The Ohio Academy of Family Physicians (OAFP) supports the Colorectal Cancer (CRC) Screening Improvement Program through a collaborative partnership with the Ohio Department of Health, the American Cancer Society (ACS), the Ohio Association of Community Health Centers, and the New Jersey Academy of Family Physicians.

The purpose of the program is to help individual primary care practices increase CRC screening rates by working with teams from each practice to create an office protocol that supports CRC screening and to improve the team engagement around screening. Other components of the program involve improving office communication, building practice efficiencies, and empowering all members of the care team to work at the top of their license. Practices that participate in the program are eligible for continuing medical education (CME) credit and American Board of Family Medicine (ABFM) Maintenance of Certification (MC-FP) Part IV requirement.

The program recruits individual primary care practices to participate in a two-part intervention plan that includes a team "Training Day," and longer-term use of a specially developed practice improvement module. During the quality improvement training session, the team develops a customized office protocol to properly identify patients at risk for colorectal cancer and to recommend appropriate screening. The customized protocol draws on three evidence-based strategies (i.e., office policies, reminder systems, and communication) to increase CRC screening rates, outlined in a toolkit called, "How to Increase Colorectal Cancer Screening Rates in Practice: A Primary Care Clinician's Evidence-Based Toolbox and Guide." The toolkit was developed by the National Colorectal Cancer Roundtable, Thomas Jefferson University Department of Family Medicine, and the American Cancer Society.

In addition to the training, the free online CRC screening practice improvement module helps the participating practices: identify areas of practice strength and opportunities for improvement through the collection of patient and practice data; develop a quality improvement plan; and implement interventions and complete a post-assessment process to determine if improvement was achieved. The module also serves as the data collection and analysis instrument by

documenting practices' pre- and post-program. The data collection and practice assessment module is housed on the New Jersey Academy of Family Physicians website and is free to access: https://www.njafp.org/content/pi-cme-activities.

Currently, OAFP staff are measuring whether family medicine practices taking part in the program expand their knowledge about: the importance of quality improvement and its impact on patient care; the importance of team communication, streamlining office processes, and empowering team members to take action; the evidence-based strategies to increase CRC screening rates; and how to create an office protocol that helps increase CRC screening rates. They are also gathering data to assess whether practices increase their screening rates.

OAFP staff administered a survey at the end of the program and discovered that respondents increased their knowledge and competence in the key areas of the training. They also discovered that after three to four months of implementing their newly formed office protocol, nearly all practices had an increase in their CRC screening rate.

As part of their future evaluation activities, OAFP staff would like to understand the long-term impact of their program on the system of family medicine practices in Ohio by seeing whether practices' protocols were sustained and re-measuring practices' CRC screening rates. OAFP staff would also like to measure how its program is influencing the state health system and the Ohio Academy of Physicians.

Step 1: Describe and map your program

Based on the current work of the program, the following program theory could be used to describe how the Colorectal Cancer (CRC) Screening Improvement Program seeks to affect the system of Ohio family physician practices engaged in CRC screening.

IF the Ohio Academy of Family Physicians offers support for teams from individual primary care practices (training, data collection and analysis support, and educational webinars), **THEN** practices will expand their knowledge about how to implement quality improvement strategies to increase CRC screening.

IF practices expand their knowledge about how to implement quality improvement strategies to increase CRC screening, **THEN** they will create or adopt new office protocols to recommend and increase CRC screening.

IF practices create or adopt new office protocols to recommend and increase CRC screenings, **THEN** they will change their screening policies and procedures.

IF practices change their screening policies and procedures, **THEN** patients will become aware when they are due for CRC screening and act on the screening recommendation.

IF patients act on the screening recommendations, **THEN** practices will see an increase in their CRC screening rates.

IF practices see an increase in their CRC screening rates, **THEN** practice teams will be motivated to sustain their new protocols over time.

IF practice teams are motivated to sustain their new effective protocols, **THEN** then more patients will be screened across a wider geographic area.

IF more patients are screened across a wider geographic area, **THEN** regional or state-level screening rates will increase.

IF overall screening rates increase, **THEN** CRC incidence and mortality will decrease.

Based on this program theory, their logic model might look something like this:

INPUTS	SYSTEM INTERVENTION	OUTPUTS	SHORT-TERM OUTCOMES	INTERMEDIATE OUTCOMES	LONG-TERM OUTCOMES
-Material -Staff -Expertise -Partners	CRC screening project activities directed at the system of Ohio family physicians: -Practice team day training -Online practice improvement module that includes data collection and analysis -Educational webinars Provide one-on-one education sessions	Number of practices and their staff who participate in the program	Practices expand their knowledge about how to implement quality improvement strategies to increase CRC screening Practices create and adopt new office protocols to recommend and increase CRC screening	Practices implement their CRC screening protocol, changing their policies and procedures Patients become more aware when they are due for CRC screening and follow through on screening recommendations Practices increase their CRC screening rates	Practices sustain their protocols More patients across the area are screened CRC screening rates increase CRC incidence and mortality decrease

Step 2: Prioritize evaluation questions

OAFP has not yet evaluated whether practices sustain their protocol and if their screening rates have maintained or improved; however, based on the logic model, they expect that sustained protocols will lead to more patients across the state being screened.

The following evaluation questions could be used to track the long-term outcomes of the program:

▶ Have practices maintained their office protocols?

▶ What modifications, if any, have practices applied to their office protocols?

▶ Have practices applied their protocol to other areas of health screening? If so, in which areas? What has been the impact?

▶ What have been practices' overall key successes and challenges to using their office protocols? What lessons have they learned about implementing and sustaining new office protocols?

▶ Have practices' CRC screening rates maintained or improved?

Although it does not appear in their logic model, OAFP staff observed some unanticipated outcomes that have occurred within OAFP and the state public health system. These outcomes include the program's model being adapted to other areas of training and education for OAFP, and the program being referenced in the state's Comprehensive Cancer Control Plan and Plan to Prevent and Reduce Chronic Disease. As a result, OAFP staff could also measure how the program is influencing other OAFP priority areas or other state public health efforts.

Step 3: Design the evaluation

Given the OAFP staff interest in gathering in-depth information on the longer-term impact of and lessons learned from the newly developed practices' protocols, OAFP staff could design an evaluation that solicits information from family practices using key informant interviews, which might allow for deeper probing than, for instance, an online survey. OAFP staff could also organize a focus group with representatives and stakeholders from OAFP and partners from the Ohio Public Health Department to gauge the program's impact beyond the existing CRC focus area. In addition, OAFP staff could ask practices to continue to track their CRC screening rates through the free online module used during the program. This would allow OAFP staff to gather additional quantitative data on screening rates beyond the intervention period.

Step 4: Identify or develop data collection instruments

The key informant interview questions could focus on modifications or adaptations practices made to their protocol, whether their protocol had been applied to other areas of health screening, the overall key successes and challenges to using their protocol, and the lessons learned about implementing and sustaining their protocol. The focus group questions would address how the program has influenced the way OAFP designs and implements screening education and training. The questions could also focus on how the program has influenced practices, policies, and procedures at the Ohio Department of Public Health.

Step 5: Collect the data

Representatives from practices could be asked to participate in a brief (i.e., 30 to 45 minute) key informant interview that is administered by staff from OAFP. Representatives and stakeholders from OAFP and partners from the Ohio Public Health Department would be asked to take part in an hour-long focus group administered by staff from OAFP. Given that key informant interviews and focus groups can be time intensive, staff could also consider engaging an external consultant to assist or lead the data collection. In addition to providing this qualitative data, practices could be asked to continue use of the online module to aid in longer-term data collection of CRC screening rates.

Step 6: Organize and analyze information

With permission from participants, OAFP staff could record the key informant interviews and focus group conversations. They could then transcribe the recordings and enter the responses into an Excel spreadsheet to facilitate sorting and organizing the data. After the data are in Excel, OAFP staff could decide on the key themes they can use to sort the data. While they are sorting the data, staff would adjust the themes as necessary to accurately reflect what respondents shared. OAFP staff could summarize the major themes in a short document, along with providing some direct quotes to help illustrate key themes or points. The CRC screening data could be gathered from the online module and summarized in a table or chart that can be shared as part of the overall reporting of the evaluation findings.

Step 7: Using and sharing evaluation results

Results from the key informant interviews and focus group could be widely shared with family medicine practices, stakeholders, and public health officials through the dissemination of reports. These groups could benefit from the lessons learned regarding implementing and sustaining the intervention, and consider how this intervention could be replicated or implemented on a broader scale for wider impact. OAFP could also invite people to comment on the findings and host conversations on how the findings could improve CRC screening education and training. In

addition, OAFP could use the findings to demonstrate the impact of its program and leverage additional support.

The NCCRT and Wilder Research would offer their sincere thanks to Kate Mahler and the Ohio Academy of Family Physicians for helping us both understand their program the evaluation methods and longer-term evaluation goals and for their generosity in sharing their time and expertise.

Case study

1.5 Day off policy case study

This case study highlights a policy change intervention by the New York State Department of Health to provide paid time off to employees for cancer screenings. The case study describes the evaluation of this initiative, while also offering some additional suggestions related to evaluation.

Background

While early detection of breast, cervical and colorectal cancer may improve treatment outcomes, research indicates that employees without access to paid sick leave are less likely to undergo recommended cancer screening than those with such access. Lack of paid leave time may be a potential barrier to obtaining preventive cancer screenings at recommended intervals [13]. The New York State Department of Health ("the department") piloted a policy change intervention in January 2013, with the overall goal of increasing rates of cancer screenings by addressing potential structural barriers. The objective was to encourage local municipalities to expand an existing State law that allows New York State public employees to take up to four hours of time off for breast cancer screening to also include colorectal and cervical cancer screening.

The pilot project was implemented with two county health departments, who worked within their respective communities to encourage adoption of paid leave policies by local municipalities. To build support for policy changes, contractors employed the following strategies:

- **Educate communities** through targeted activities that educated the public (or subsets of the public) about chronic disease and prevention. The intention was to raise awareness and influence individual opinions, beliefs, attitudes, and behaviors about the value of policies that support cancer screening. Community education included direct employee education, earned and paid media, and other types of information dissemination.

- **Mobilize influential community members and organizations** to publicly support paid leave for cancer screening by providing them with communication materials and policy examples.

- **Connect with government decision-makers** by educating, in this case, local, policy-makers about chronic disease issues, and the implications of policy change.

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[13] Peipins, L.A., Soman, A., Berkowitz, Z., White, M.C. (2012). The lack of paid sick leave as a barrier to cancer screening and medical care-seeking: results from the National Health Interview Survey. *BMC Public Health, 12*(1), 520. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3433348/

- **Engage decision-makers at the targeted local municipalities** to change their organizations' policies, programs, or practices.

To inform future work, the department evaluated this project to look at strengths and weakness of the pilot project, the activities that supported the adoption and implementation of paid leave policies, the potential reach of the policies, public support for these types of policies, and the potential impact of these policies on health behaviors.

Step 1: Describe and map your program

The following program theory describes how the paid leave policies ultimately contribute to improvements in cancer screening rates among municipal employees and reductions in cancer incidence and mortality.

IF municipal contractors offer educational events and meetings, **THEN** community members, including municipal workers and community influencers, increase their knowledge about structural barriers to cancer screening, like lack of paid leave, and support for paid leave for cancer screening policies increases.

IF community members, including municipal workers and community influencers, increase their knowledge about and support for paid leave for cancer screening policies, **THEN** the greater community support encourages municipal officials and decision makers to support paid leave for cancer screening.

IF municipal officials and decision makers are more inclined to support paid leave policies and are educated about the policies, **THEN** they will commit to adopting paid leave policies.

IF municipal officials and decision makers commit to adopting paid leave policies, **THEN** policies are adopted and implemented.

IF paid leave policies are adopted and implemented, **THEN** municipal workers will use the policies to receive recommended colorectal and other cancer screenings.

IF municipal workers receive recommended colorectal and other cancer screenings, **THEN** cancer screening rates among workers increase.

IF cancer screening rates among municipal workers increase, **THEN** cancer incidence and mortality decrease.

The following logic model describes the program theory and depicts how the adoption of policies that provide paid leave for cancer screening can lead to increased cancer screening rates:

INPUTS	ACTIVITIES	OUTPUTS	SHORT-TERM OUTCOMES	INTERMEDIATE OUTCOMES	LONG-TERM OUTCOMES
-Staff -Expertise -Partners -Contractors from county health departments -Toolkits - Training materials	-Educational events and media -Health Department contractor meetings with community influencers -Health Department contractor meetings with municipal decision-makers	-# of educational events -# of people reached through educational events -Amount of earned media generated -# of meetings # of community influencers reached -# of decision-makers reached	Community members, including workers and community influencers, increase their knowledge about and support for paid leave for cancer screening Municipal officials and decision-makers increase their knowledge about and support for paid leave for cancer screening Municipal officials and decision-makers commit to adopting the paid leave policy Paid leave policies for cancer screening are adopted by municipalities	Workers use the paid leave policy to receive recommended colorectal and other cancer screenings	Cancer screening rates among workers increase Cancer incidence and mortality decrease

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Step 2: Prioritize evaluation questions

Evaluation activities for this project were developed to answer both process and outcome evaluation questions. First, the department wanted to determine the inputs, activities, and outputs involved in the policy implementation process. For the implementation process, the department wanted to learn about progress that has been made toward achieving policy change, about activities taking place that support policy adoption and implementation, and factors that help facilitate or block a change in policy. Key process evaluation questions included:

▶ What progress has been made toward achieving a change in policy?

▶ What activities support the implementation of the policy?

▶ What factors help facilitate a change in policy?

▶ What factors can block a change in policy?

The department was also interested in determining short-term outcomes of the initiative, such as the impact of policy implementation on health behaviors. Past research has shown that workers are more likely to get screened if paid leave policies are in place. As a result, the department was interested in assessing whether adoption of paid leave policies was associated with increased screening rates for workers. To assess local-level impact, the department tracked the number of organizations that adopted policies and the number of workers impacted by the policy. To gauge the effects of policy implementation, the department was interested in assessing how the policy affected individual health behavior. Outcome evaluation questions included:

▶ How many municipalities have adopted a paid leave policy for cancer screenings?

▶ How many employees are reached by the policies?

▶ How has the policy impacted employee screening behaviors?

Lastly, the department was interested in learning about broader public support for policies supporting paid time off for cancer screenings. Additional outcome evaluation questions included:

▶ To what extent do residents living in the pilot project counties support a policy requiring employers to offer paid time off for health screenings?

▶ To what extent do residents living the pilot project counties support a policy requiring employers to allow employees to use flex time to receive health screenings?

Step 3: Design the evaluation

The department used an evaluation design that included mixed methods of data collection. Key process measures included documenting the inputs and activities of the county health department contractors implementing the pilot project, and determining if these activities did or did not correspond with the policy change. The department also tracked the number of commitments for the policy change made by organizational decision-makers in municipalities and government policy-makers as a key milestone in the policy change process.

Outcome measures included the number of sites where decision-makers supported a policy change, the number and type of sites where a policy was adopted, and the number and characteristics of individuals using the paid leave policy.

Additional outcome measures included measures of public support, such as: the percentage of adult residents in the pilot project counties who support a policy requiring employers to offer paid sick leave for employees to receive health screenings, and the percentage who support a policy that would require employers to allow workers to use flex time to receive health screenings.

Step 4: Identify or develop data collection instruments

The department developed data collection tools for county contractors to track program process measures and project outcomes. The data collection tools included monthly reports documenting progress on output measures (e.g., the number of education events) related to the strategies outlined in contractor work plans, and quarterly reports tracking key outcomes that occurred during the policy adoption process, like identifying key decision makers in the municipality and having decision-makers commit their support to adopt a policy. Additionally, to determine whether adoption of expanded paid leave led to employee utilization, contractors collected routine data from municipal payroll and personnel departments using a payroll reporting procedure that documented when employees used paid leave for cancer screening.

To measure broader public support for paid time off for cancer screening policies, the department partnered with Siena College Research Institute to conduct a random digit dial telephone survey of adult residents, age 18 and older, in the counties working to implement paid time off policies. The survey gauged residents' support for comprehensive cancer control policies, including paid time off for cancer screening. Survey respondents were read a description of a policy and asked whether they were in favor of or opposed to the policy using a four option scale.

Step 5: Collect the data

Contractors submitted the monthly activity reports and quarterly milestone reports. The department worked with Siena College Research Institute to administer the telephone survey to residents.

Step 6: Organize and analyze information

Department staff summarized data from monthly reports to describe and assess activities implemented by contractors. A contractor summarized the data, which included information like the total number and type of activities implemented, the number and type of decision-makers identified and educated, and the number and type of earned media generated. This information was important for program monitoring, accountability, and program improvement.

Information from quarterly reports was summarized by municipal site and was used to document progress toward policy adoption at each site. Overall summary data were prepared including aggregate data on the total number of sites working on the policy change initiative, and projected reach, or the potential number of employees affected by the policy change initiative.

Data from the telephone survey were summarized and indicated that over 8 in 10 residents from the pilot project counties were in favor of policies that would require employers to offer employees paid leave for cancer screening.

Step 7: Using and sharing evaluation results

The pilot project led to the adoption of a paid leave policy in two municipalities, one in each of the two counties targeted. The policies could reach as many as 3,500 municipal workers in both counties. Payroll and personnel data in one county demonstrated that the number of employees using the paid leave policy for cancer screening almost tripled in the year following the paid leave policy adoption. In addition, the telephone survey found broad support for paid leave policies among adult residents living in the counties. The findings about public support were shared with the contractors who could use them as part of their education and mobilization efforts in working with government and organizational decision-makers.

The department is using the results of the overall evaluation to inform the development of additional paid leave initiatives across New York. Department staff are also interested in using the evaluation data to identify the key characteristics associated with the successful adoption and implementation of a paid time off policy.

Case study

1.6 Reimbursement policy case study

The purpose of this case study is to demonstrate how one might evaluate the impact of legislative or regulatory change. This case study looks at regulatory improvements around the implementation of colorectal cancer screening cost-sharing protections, as prescribed under the 2010 Patient Protection and Affordable Care Act. Please note that the description of events has been simplified for the purpose of explanation.

This case study describes a hypothetical evaluation developed by Wilder Research using the steps outlined in the Evaluation Toolkit and meant to be illustrative. However, it should be noted that policy change whether in the legislative or regulatory realm is not typically so linear. Success often depends upon a variety of factors, including political considerations that can shift quickly, and actions cannot always be neatly measured or defined. For instance, sometimes the lack of action is a political win, depending on if one is trying to protect a law or regulation from repeal, rather than attempting to pass a law or implement regulations as is the example shown below.

Background

Under the 2010 Patient Protection and Affordable Care Act (PPACA), most private health insurance plans are required to provide preventive services recommended under the United States Preventive Services Task Force (USPSTF), including colorectal cancer screening free of cost sharing for consumers. However, in the first two years after the law was passed, there were reports that some patients were being billed for colorectal cancer screening procedures that they expected to be covered free of cost sharing under the PPACA.

Although many factors affect the use of preventive services, out-of-pocket costs are a barrier to seeking recommended screening tests. An extensive body of research shows that individuals—including the insured—are less likely to seek health services when they have to pay out-of-pocket costs [14].

Variations in coding and billing for colorectal cancer screening were found across health care providers and private insurers in certain scenarios, such as when polyp removal was completed

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[14]   See for example: Solanki, G., Schauffler, H.H., Miller, L.S. (2000). The direct and indirect effects of cost-sharing on the use of preventive services. *Health Services Research, 34*(6), 1331-1350. See also: Wharam, J.F., Graves, A.J., Landon, B.E., Zhang, F., Soumerai, S.B., Ross-Degnan, D. (2011). Two-year trends in colorectal cancer screening after switch to a high-deductible health plan. *Medical Care, 49*(9), 865-71. See also: Trivedi, A.N., Rakowski, W., Ayanian, J.Z. (2008). Effect of cost sharing on screening mammography in Medicare health plans. *New England Journal of Medicine, 358,* 375-383. See also: Manning, W.G., Newhouse, J.P., Duan, N., Keeler, E., Benjamin, B., Leibowitz, A., Zwanziger, J. (1988). *Health insurance and the demand for medical care: Evidence from a randomized experiment.* Retrieved from RAND Corporation website: https://www.rand.org/content/dam/rand/pubs/reports/2005/R3476.pdf

during a screening colonoscopy or when follow-up colonoscopies were performed after a stool-based screening test had been found positive. Because of the confusion over coverage, coding, and billing, many consumers were being charged cost sharing for these procedures, which they did not anticipate.

The American Cancer Society Cancer Action Network (ACS CAN) worked with the partners of the National Colorectal Cancer Roundtable and the Kaiser Family Foundation to document these patient access problems in a report, Coverage of Colonoscopies Under the Affordable Care Act's Prevention Benefit. ACS CAN brought the issue to the attention of the U.S. Department of Health and Human Services (HHS), seeking clarification of the coverage mandate and patient cost sharing responsibilities. ACS CAN requested that the agency issue regulatory guidance indicating that polyp removal during a screening colonoscopy and a colonoscopy following a positive stool blood test be provided at no cost to the patient.

ACS CAN saw partial success when the Obama Administration issued guidance that patients under non-grandfathered commercial insurance plans may not be held liable for cost sharing for polyp removal during routine screening colonoscopies [15].

Step 1: Describe and map your program

ACS CAN's efforts related to this policy tied directly to their goal of increasing colorectal cancer screening rates. Based on the information above, the following program theory and logic model explain how a request to regulators seeking clarification of colorectal cancer screening laws should lead to increased colorectal cancer screening rates, if implemented.

IF an advocacy organizations/advocates request that regulators issue guidance clarifying that commercial payers should (a) waive cost sharing for screening colonoscopies including when a polyp is found and removed and (b) waive cost sharing for colonoscopies performed as a follow-up to stool-based screening tests, **THEN** the regulatory agency may issue guidance clarifying that commercial insurance plans may not bill patients for polyp removal performed during routine screening colonoscopies or charge cost sharing for patients who undergo a follow-up colonoscopy after a positive stool test.

IF regulators clarify the policy, **THEN** health care systems and clinics will adopt billing policies that code polyp removal performed during screening colonoscopies and code follow-up colonoscopies to a positive stool test as part of the screening process **AND** insurers will no longer bill patients for these procedures **AND** states will enforce the policy requiring that cost sharing be waived for these procedures.

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[15]   ACS CAN has also sought clarification on the issue of cost sharing for follow-up colonoscopy, but the issue has not been resolved as of publication.

IF health care systems, clinics, and insurers change their billing practices **AND** states provide oversight of this process, **THEN** consumers will no longer be billed cost sharing for screening colonoscopies in applicable plans, **AND** health care providers and public health entities overall will be able to provide more accurate information to patients about screening costs, addressing affordability concerns for some consumers.

IF consumers no longer face affordability concerns about colorectal cancer screening, which is a known barrier to screening, **THEN** there will be an increase in the number of patients screened for colorectal cancer.

IF there is an increase in the number of patients screened for colorectal cancer, **THEN** mortality rates for colorectal cancer will decline.

The program theory can also be used to create a logic model.

INPUTS	ACTIVITIES	OUTPUTS	SHORT-TERM OUTCOMES	INTERMEDIATE OUTCOMES	LONG-TERM OUTCOMES
-Advocacy organization staff	-Meet with policy- makers -Share documentation of problem -Send formal request to policy-makers to clarify that polyp removal during a screening colonoscopy and colonoscopies following a positive stool blood test should be free of cost-sharing for commercially insured patients	Regulators provide guidance that commercially insured patients should not be charged cost-sharing for polyps removed during routing colonoscopies	-Health care providers increase their understanding about regulations related to coding and billing, bill appropriately, and provide accurate guidance to consumers about costs of procedures related to colorectal cancer screening. -Colonoscopies that result in polyp removal and colonoscopies that follow a positive stool blood test are coded and billed as screening -Patients no longer face cost sharing for procedures related to routine colorectal cancer screenings	-There is an increased in awareness among patients that screening colonoscopies are fully covered under commercial health care plans, and that cost as a barrier to screening has been removed	More patients receive colorectal cancer screenings Colorectal cancer morbidity and mortality rates decline

Step 2: Prioritize evaluation questions

ACS CAN saw partial success in that HHS clarified that polyp removal during a screening colonoscopy is free of cost sharing among the commercially insured, although at the time of this publication, HHS has not clarified that a colonoscopy following a positive stool blood test should be free of cost sharing.

Follow-up evaluation of the impact of HHS's guidance has not taken place, but based on this hypothetical logic model, ACS CAN might expect that changes in coding and billing have the potential to remove a common barrier to screening and subsequently, long-term screening rates. ACS CAN or other policy-minded researchers could look at short-term outcomes related to improvements in coding and billing. Long-term outcomes may take longer to be seen, and screening rates may still be stymied by other issues that have not been addressed, such as cost sharing for colonoscopies following a positive stool test or high deductible plans that may make consumers worried about "finding something."

The following evaluation questions could be used to guide an evaluation of the short-term outcomes:

▶ Are screening colonoscopies that result in the removal of a polyp covered by commercial insurers free of cost sharing for consumers?

▶ Are health care providers coding screening colonoscopies that result in the removal of a polyp as preventive?

▶ Is there a difference in the screening rate for the commercially insured, depending on if they have a high deductible plan or not?

Step 3: Design the evaluation

With these questions guiding their work, policy researchers and advocates could consider several options in designing the evaluation.

Early on in their work on cost sharing policies, ACS CAN worked with the Kaiser Family Foundation and the National Colorectal Cancer Roundtable on a project to conduct interviews with state health insurance regulators, state consumer assistance program directors, medical directors of major insurance companies, physicians, medical practice coding and billing staff, and patients to gather information about the scope of the coding and billing issue. Other policy researchers and advocates might consider conducting follow-up interviews with stakeholders in these areas about whether clinics and insurers are implementing and enforcing the new policy. Interviewing stakeholders would allow policy researchers and advocates to align their follow-up evaluation with their early work documenting the problem. However, interviews can be time-intensive and represent the perspectives of a small sample of those being interviewed, and so

may not adequately capture the full picture of how the new guidance has impacted coding and billing practices.

Another option that policy researchers and advocates might consider would be to conduct surveys of insurers and coding specialists at clinics about how they code and cover screening colonoscopies that result in the removal of a polyp. Surveys can be relatively inexpensive and easy to distribute to larger groups of people, but also can have lower response rates. In addition, survey data were not collected at baseline, before the new guidance was released, so it may be more difficult to assess change over time.

Policy researchers and advocates also might consider looking at claims data to determine whether the ratio of colonoscopies coded as preventative to colonoscopies coded as diagnostic has increased. However, increases in colonoscopies coded as preventative may be attributed to a number of factors, such as public awareness campaigns about colorectal cancer screenings.

Step 4: Identify or develop data collection instruments

Weighing the benefits and challenges of the various data collection approaches and organizational capacity, surveys are likely to be the most effective option to evaluate the impact of the new guidance on cost sharing. Surveys would allow policy researchers and advocates to gather information from a wide range of health care clinics and insurers. In addition, surveying insurers and coding specialists is more likely to show the direct impacts of the new guidance on the coding and billing practices.

A short, online survey for coding specialists could be developed, asking about how the specialists code screening colonoscopies that result in the removal of a polyp, whether coding practices at the clinic related to colorectal cancer screening have changed since 2013 when the guidance was released, and knowledge about policies related to colorectal cancer screening coverage.

A similar survey for insurers might be developed, asking about whether policies fully cover screening colonoscopies that result in the removal of a polyp and whether coverage for these procedures has changed since 2013.

The survey tools should also include geography to assess variations in enforcement across states and regions, especially given that state-to-state differences were noted in the initial assessment of the problem.

The survey tools may also include questions about cost sharing for colonoscopies that are conducted as follow up to positive stool tests, as a way to gauge progress on a related issue that was not swayed by federal regulatory intervention.

Step 5: Collect the data

Using its contacts with health care clinics and insurers, policy researchers and advocates could consider sending an online survey to health care systems, clinics, and insurers, with guidance to route the survey to the appropriate staff person. Two or three follow-up e-mails could be sent to remind clinics and insurers to complete the survey.

Step 6: Organize and analyze information

Policy researchers and advocates could then analyze the data from the survey. As noted above, data could be broken out by geography to look at variations in enforcement in different states and regions, while also comparing it to progress on cost sharing for colonoscopies that follow positive stool blood tests.

Step 7: Using and sharing evaluation results

There are several options for reporting findings from this evaluation. A report and executive summary could be created, highlighting results from the survey. A presentation or webinar could also be developed to share the findings more broadly. Findings could help policy researchers and advocates assess whether clinics and insurers are aware of the regulations about coding and billing and following them, demonstrate the impact of the guidance on coding and billing, and identify locations where more guidance and/or state oversight may be needed. Findings could be shared among partners and other key stakeholders, as well as with key regulatory agencies at the state or federal level.

The NCCRT and Wilder Research would like to thank Citseko Staples and Caroline Powers of ACS CAN for their generosity in sharing their time and expertise about the real life efforts that informed this case study.

APPENDIX 2 – TIPS

Tips

2.1 Evaluating mass media and social media campaigns

OVERVIEW: Media campaigns have become increasingly popular in recent years. The field of health communication has grown as the public's use of television, the internet, and social media has increased. Mass media campaigns can be quite costly, so it would be in your program's best interest to understand if a media campaign is using its resources as efficiently and effectively as possible. Social media efforts may be quick and easy to launch, but there are challenges in knowing whether your messaging is reaching the right people or having the intended impact. Evaluating these initiatives can incorporate each dimension discussed in this toolkit – outcomes, process, and satisfaction – as well as an assessment of community needs. Here are some tips for evaluating your media campaign, which can be integrated throughout your campaign activities.

EVALUATE COMMUNITY NEEDS AND INTERESTS TO INFORM THE DEVELOPMENT OF MEDIA CAMPAIGNS

Your media campaign will be stronger if it reflects the needs of the community. The evaluation methods described in this toolkit can be used to answer some key questions you may want to understand before designing your media campaign:

The NCCRT and the American Cancer Society have done some market research to understand barriers that prevent the unscreened from getting screened, as well as some testing of messages that resonate. More information about this research and the tested messaging can be accessed here: http://nccrt.org/tools/80-percent-by-2018/80-by-2018-communications-guidebook/. These messages are free for all to use.

▶ The population that would benefit most from your message – are there certain groups or neighborhoods that you should focus on, such as populations for whom screening rates are noticeably lower than the average population?

▶ Your campaign message – what information does your community need to know about colorectal cancer screening? What are the perceptions of cancer? Of colorectal cancer screening? What barriers to screening need to be addressed? What messages about the need for colorectal cancer screening will most align with the population's values?

▶ The resources available in your community – for example, is colorectal cancer screening free at a particular clinic?

▶ The best type of media to use to reach the community – would radio, television, websites, social media, billboards, posters, print materials, texts or some combination of these media types work best? What is your population's preferred media, and how do they use it?

▶ Trusted messengers in the community – who are leaders of the community who can help garner attention and lend credibility to the effort?

Understanding this information prior to creating and launching your media campaign can ensure that you use your resources wisely. If you are unsure about any of this information, take some time to gather additional information. You could review available research related to the use of social media, or gather community members together for a focus group to help inform the creation of specific media messages. As mentioned above, the NCCRT has some resources in this area that can serve as a starting point.

EVALUATE OUTCOMES

Assessing the impact of your media campaign can be difficult, as results often can be attributed to a number of other factors. For example, an increase in colorectal cancer screening rates within a particular community could be due to your campaign, but could also be the result of another awareness effort or a local health clinic's initiative to offer free colonoscopy appointments to underserved adults. As with other outcome evaluations, it is important to keep your program's end-goal in mind. If your program seeks to increase awareness of colorectal cancer screening, for example, your evaluation questions should explore whether people became more aware of screening recommendations, whether the target audience understood the appropriate age for screening average-risk individuals, and whether the target audience had a better understanding of testing options. If your goal is to see increased screening rates, it may be necessary to track screening rate changes within the community where your campaign is being publicized. Increases in the Uniform Data Set measure of colorectal cancer screening rates of local community health centers or screening rates gleaned from Medicare claims data for certain zip codes in your community can provide some insight into how colorectal cancer screening rates are changing in your community (see guidelines for gathering screening rate data presented elsewhere in the toolkit). Some other common methods for evaluating the outcomes of a media campaign include:

■ **Including a measurable "call to action."** Your campaign may incorporate a call to action – a designated phone number, hotline, or website to access to learn more about your program or the topic. You can track the number of people that liked or shared the messages or clicked on the web link through social media. For instance, you can attach a campaign identifier to the link you include in your social media messaging using link shorteners such as goo.gl, bit.ly, owl.ly or tinyURL. This will enable you to attribute the number of visits to web pages that have resources designed to increase knowledge levels of colorectal cancer screening to your social media campaign. You could also track the number of people that contacted your program, ask respondents

how they learned about it, and collect contact information to follow-up with people at a later date. If you are able to follow up with individuals who responded to the call to action, you may also be able to assess changes in participant knowledge, attitudes, intention to screen, or screening behavior.

■ **Conducting randomized calls or other randomized survey/interview method**. Brief telephone surveys or interviews can be used to see whether people in your broadcast area saw your materials, how they felt about them, and if they changed their behavior as a result of the advertisement. You can also ask questions relating to future campaigns, such as how often they watch television, listen to the radio, or access the internet; what sources they frequent; and what media sources they trust most for health information. Keep in mind that the information you receive through these phone calls is self-reported, so there may be some bias. Participants may also overestimate how often they saw your materials. There may also be important differences in the people that choose to answer your survey versus those who refuse. This may also take quite some time to accomplish. Additionally, if you choose to contract with a survey research center, there can be substantial cost to administer telephone surveys.

■ **Comparing target community with control group**. As a more time-intensive option, you can consider assigning certain segments of the population to receive your campaign. This way, you can assess changes in your target community compared to those who did not view your materials. Those who do not receive your campaign would be considered a "control" group, or a group whose awareness or screening behavior you would not expect to change during your media campaign. If your program is considering a large-scale media campaign, or using random assignment to determine which population will receive your message, it may be in your best interest to hire someone with previous experience conducting this type of study.

■ **Tracking key social media metrics.** A variety of options may be available to monitor the impact of a social media campaign. It is important to select the right metrics and monitoring tool, based on your specific goals and social media platform. Most social media platforms have some analytics available as a starting point, though you may have to build in some specific tracking. For instance, if your campaign was designed to increase conversation about colorectal cancer screening among your population's friends and family, the engagement rate is a good indicator and is calculated by the number of engagements (total number of times users have interacted with the message such as any clicks on the message, shares, likes and follows) divided by the total number of impressions (the number of times users saw the message). Engagement rate (the total number of engagements divided by the total number of impressions) is a common indicator included in most social media platform analytics. You can also look at other possible indicators of engagement, such as the number of people who commented on your message or shared it with others. Whenever possible,

document baseline rates, so you can compare engagement or other measures before and after you post specific messages.

EVALUATE PROCESS

A process evaluation can be used to measure your campaign's reach. It can also measure the number of times your advertisement ran and how many people potentially viewed it. Common methods for conducting a process evaluation of a media campaign include:

- **Newspaper tracking:** Clipping services can keep track of your campaign's coverage, including the volume of readers on the day your ad appeared in the newspaper.

- **Television or radio tracking:** If you are paying to air a public service announcement or commercial, you can track information about its airing for an extra fee. This information can tell you the dates and times that it aired, the areas in which your message was broadcasted, and the estimated audience size.

- **Website monitoring:** If you have an internet campaign or website, the website administrator may have software that can help you track the number of "hits" on your site, navigation patterns, who accessed the site, how long they stayed on the site, and if there are areas on the site that are more or less popular.

- **Social media tracking:** Many social media platforms offer free analytics or insights that track the number of posts, impressions, engagements, and more. These metrics are valuable for identifying how your posts encourage the posting or sharing by audience members. If you find some posts are more popular than others, you can modify or increase the number of similar posts. You can also use Hootsuite, an online application that tracks the influence of your posts to the rest of the online community. Social media metrics are available in real-time, allowing you the opportunity to review your data and adjust your messages or approach quickly.

EVALUATE SATISFACTION

Evaluating participant satisfaction can help you learn how people felt about your materials and what changes they would recommend. The information gathered through a satisfaction evaluation can determine:

- Overall satisfaction with the materials.

- Aspects of the campaign they found most helpful.

WORK WITH PARTNERS

Remember that for an intensive or in-depth evaluation, hiring an external evaluator or someone with experience in this area might be a good use of your resources, particularly if you are making a substantial investment in your media campaign. Likewise, if you have a media partner, they may also be interested in the effectiveness of their communications and may be willing to contribute to the evaluation. You can also collaborate with clinics to design and develop data collection methods that will measure whether or not a social media or other campaign truly resulted in behavior change such as increased referrals or colorectal cancer screening rates.

2.2 Identifying and addressing ethical concerns

OVERVIEW: Throughout the evaluation process, strategies to protect the rights and dignity of individuals who participate in the evaluation should be considered. This section provides a number of tips for ensuring that your project conforms to accepted ethical standards, including an overview of typical ethical considerations, tips for addressing these issues, and recommendations for solving ethical challenges.

OVERARCHING ETHICAL PRINCIPLES

The following four principles are core ethical issues identified by many professional organizations and evaluators:

- Help or benefit to others – acting in ways that promote the interests of others by helping individuals, organizations, or society as a whole.

- Do no harm – the corollary principle is not bringing harm to others, including physical injury and psychological harm (such as damage to people's reputation, self-esteem, or emotional well-being).

- Act fairly – treating people in ways that are fair and equitable, including making decisions that are independent of race, gender, socioeconomic status, and other characteristics.

- Respect others – respecting the rights of individuals to act freely and to make their own choices, while protecting the rights of those who may be unable to fully protect themselves.

KEY ETHICAL ISSUES RELATED TO EVALUATION

Consideration of risks and benefits

Your evaluation can benefit program participants and others. In some cases, there may be benefits to an individual who participates in an evaluation, such as receiving a gift certificate or other incentive in exchange for completing an interview. Other benefits emerge as a result of changes made at the program or agency level – for example, the evaluation may guide strategies for improving a program's impact, leading to more positive outcomes for current or future participants. These positive outcomes can include increased screening rates, which may help reduce the incidence of cancer or improve survival rates.

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However, associated risks can come with these benefits. You should carefully consider any harm that may result from an evaluation, and take steps to reduce it. With evaluations of colorectal cancer screening and awareness initiatives, potential consequences may include:

- Sacrificing time and energy to participate.

- Emotional consequences (e.g., anxieties or fear related to screening).

- Discomfort with discussing colorectal cancer screening.

In weighing benefits relative to risks, you want to use your resources of time and money to develop an evaluation that minimizes risk to individuals and provides information that will be used for program improvement and sharing knowledge.

Informed consent

Everyone who participates in the evaluation should do so willingly. In general, people participating in any research project, including an evaluation, have the right to:

- Choose whether or not they want to participate without penalties (e.g., participation in the evaluation should not be a mandatory requirement for receiving services).

- Withdraw from the project at any time, even if they previously agreed to participate.

- Refuse to complete any part of the project, including refusing to answer any questions.

The word "informed" is important – in addition to choosing whether or not to participate in the evaluation, people have the right to understand all implications of participating. To ensure that potential participants can make an informed decision regarding their involvement, you should:

- Provide potential participants with information about the evaluation, including why it is being done, what you are asking them to do, how you will you use the information, and how long it will take.

- Describe both the potential benefits of participation and any foreseeable risks, including possible discomfort due to participation.

- Share this information using understandable language – avoid jargon and translate if needed.

- Allow the participant the opportunity to ask any questions about the evaluation.

Participants may not need to sign a consent form if they are adults capable of making decisions, have not been coerced, and will not be put at significant risk by participating in the evaluation.

For example, if you want participants to fill out an optional anonymous survey asking them if they were satisfied with specific elements of a program, the fact that they complete and return the survey can be construed as providing consent. Signed consent forms may be necessary in other situations, however, especially if you plan to:

- Collect very personal or sensitive information.

- Use the results for purposes other than program improvement, such as publication, training activities, or participation in a larger research project.

- Gather information about participants from third parties, such as program staff, family members, or others.

- Require significant time or effort on the part of participants, such as asking them to participate in multiple or time-consuming interviews.

Confidentiality

It is not always possible for evaluations to be conducted anonymously, without collecting identifying information such as a participant's name or social security number. However, all information gathered should be considered confidential and not shared with others. To ensure confidentiality, consider these strategies:

- Collect data in a private location where surveys cannot be seen and interviews cannot be overheard.

- Do not discuss information about individual participants with other people, including other agency staff – findings should generally only be discussed at an aggregate level or with identifying information disguised.

- Shred or securely dispose of completed evaluation materials when they are no longer needed.

- Allow respondents to have a private way of returning surveys, such as providing them with a sealed return envelope. Do not require respondents to hand their surveys directly to a staff person.

- Once you have received surveys, keep them stored in a safe and secure place where they will not be seen or read by others.

You may encounter situations in which you believe that it is important to disclose confidential information. To the extent possible, consider in advance the types of disclosures that may be needed and develop a plan to handle these situations. Provide information about possible disclosure of confidential information with the consent instructions.

Other issues

Safety: In some cases, you may have concerns for the safety of your participants. Be thoughtful about participants' needs and take care to protect participants as much as possible.

Health Insurance Portability and Accountability Act (HIPAA): If you are a health care provider collecting information related to physical health, you may be required to comply with HIPAA, a federal law enacted in 1996 designed to protect the privacy and security of health information. If you are unsure whether HIPAA applies to your evaluation, research this issue in advance to ensure that your procedures comply with the guidelines. For information about HIPAA, go to http://www.hhs.gov/ocr/hipaa/

Institutional Review Boards (IRBs): An IRB is a federally recognized committee authorized to review research projects and ensure that procedures comply with ethical standards. Many colleges, government offices, hospitals, and research agencies have established IRBs. IRB approval is generally not required for program evaluations. In rare instances it may be required, especially with some types of federal funding. Evaluations may also require IRB approval when the evaluator intends to share the results outside of the program being evaluated, such as in published articles or journals. Some typical evaluations that might require IRB approval are:

- Evaluations that use sensitive health information, such as information from medical records.

- Evaluations where you contract or work with a faculty member or student from any academic setting.

More information about IRBs and research with human subjects can be found at http://www.hhs.gov/ohrp/.

ADDRESSING ETHICAL CHALLENGES

In some cases, you might face situations in which the ethical direction is not clear. Ask yourself the following questions when faced with an ethical challenge:

▶ What does my intuition tell me? Am I feeling stress or self-doubt about a direction that has been chosen?

▶ Is there an established way that my colleagues would act in the same situation?

▶ Does my profession have a set of ethical codes or guidelines? If so, do they suggest a course of action?

▶ Are there existing laws that apply to this situation? If so, what requirements do I need to follow?

▶ Which overarching ethical issues apply to this situation (e.g., helping others, doing no harm, acting fairly, and being respectful)? Does a clear solution to the challenge emerge when considering these principles?

▶ What are my personal values and beliefs? What guidance do they provide?

If you are unable to decide the best course of action, consult with others as needed, including colleagues, supervisors, your board of directors, evaluators or researchers, or legal counsel.

2.3 Assessing community needs

OVERVIEW: A community assessment helps establish the needed services and available resources in your community. Community can mean a neighborhood or geographic community, but can also refer to different systems that people are a part of, such as a collection of employees, a professional group, a church congregation, or the health care professionals and patients in a clinic. This assessment is a systematic process of gathering, analyzing, and reporting information about the needs of a community and the capacities or strengths that are available to meet those needs. This section describes the value of community assessments, and some issues to consider in conducting one.

The primary benefits of conducting an evaluation of community needs include:

- **Creating an information base for program decisions.** An evaluation of community needs allows you to select programs and services that are grounded in the needs, priorities, and resources within the community. For example, an assessment can help you decide what should be included in an informational brochure about colorectal cancer screening for a church congregation. It can also help you develop alternative strategies for solving a problem or forging networks or alliances to address issues.

- **Gaining community involvement and support.** A community needs assessment can engage community members before decisions need to be made. Allowing residents, community organizations, health care clinics, and others to be involved in decision-making may increase their investment in your program and promote effective partnerships. At a minimum, community members may be involved by sharing their perceptions of a community.

- **Creating a baseline picture of the community.** An assessment can create a baseline understanding of the current issues or resources regarding colorectal cancer that face a community. If your goal is to promote community change, this baseline information can be used over time to identify progress and changes. Baseline information will also be useful as you evaluate program effectiveness.

Identifying needs and assets can be helpful to your organization at almost any point in your initiative. Assessment should be an ongoing process. Regularly updating community information ensures that assessment results are available and relevant when you need to make a decision or take an action. It will also help you to continually strengthen relationships and networks. Fully incorporating assessment information into ongoing program management will greatly enhance the value of your evaluation process.

SAMPLE COMMUNITY NEEDS ASSESSMENT QUESTIONS

The following are sample questions your colorectal cancer screening awareness program could address through an assessment of your community:

▶ What are the characteristics of this community (e.g., relevant demographics, including size)?

▶ What are current colorectal cancer screening rates in the community? Are there disparities in these rates?

▶ Are community members aware of their potential risk for colorectal cancer? Aware of screening recommendations?

▶ What types of information do community members need about colorectal cancer screening?

▶ What are community attitudes toward colorectal cancer screening?

▶ Do community members feel they are at risk for colorectal cancer?

▶ What prevents some community members from getting screened for colorectal cancer?

▶ What encourages or motivates people to get screened?

▶ How do community members like to receive information?

▶ Do community medical clinics have the resources to screen patients for colorectal cancer?

When determining the questions you and your community want to address, it will be very helpful to engage stakeholders in the process of designing and prioritizing your assessment. This process provides an opportunity for anyone who has an interest in the findings to be involved, and helps ensure that the community assessment covers all important areas and topics. Prioritizing questions with stakeholders will increase their buy-in to the process and promote use of the findings once the assessment in completed.

There are many ways to use the findings of an evaluation of community needs, including:

■ Determining your program's goals and long-range and short-range program objectives.

■ Determining the populations that will be served by the program, if resource limitations make it impossible to serve everyone.

■ Determining the information or services that are most needed and how they are best delivered.

Now that you have established your community's needs, it is time to select program activities that will best fill the gaps in your community. Start by prioritizing the findings from your assessment. How important is addressing the need to your organization? To the community? Is your organization the best one to address this issue?

2.4 Building a logic model

OVERVIEW: A logic model can be a useful tool for illustrating your program's underlying theory. This section describes the four steps to creating a high-quality logic model. Several challenges to logic model development, as well as potential solutions, are also presented.

STEPS IN CREATING A LOGIC MODEL

1. Review and clarify the links between activities and outcomes

When you developed a program theory, you spelled out the major services that you provide and the intended benefits of those services. Review this list and make sure the connections between each activity and its outcomes are clear and logical.

Consider the order in which results should occur. What would be the first changes experienced by participants? How would these initial changes promote other, more long-term changes? Hint: behavior change is rarely the first result. People usually need to change their knowledge, attitudes, or skills before they start to change behavior. Likewise, moving farther down the line, community change usually cannot occur until enough individuals (or the right individuals) change their behavior or practices. In other words, people are not likely to pursue colorectal cancer screening unless they first know about the recommended screening guidelines and understand its importance.

2. Add inputs and outputs for each activity

Inputs are the resources and raw materials that go into your program. Consider the resources that you need to operate your program, such as funding, staff, or volunteers. Some programs may require a facility, transportation services, educational materials, and other resources. You do not need to be overly precise in the logic model regarding the amount of each resource that is needed.

Outputs quantify the services you provide. Remember, outputs are different from outcomes. While outcomes describe the actual impact (the change that results), outputs simply describe the amount of service provided. Outputs are most often expressed in numbers, such as the number of people who participate in an activity or the hours of service received.

3. Construct a draft model

The model may end up being simple or complicated, but it should accurately reflect the complexity of your program. Use arrows to show the connections between your inputs and your activities, between your activities and outputs, and between your outputs and each sequence of outcomes.

Remember that one activity could lead to multiple outcomes, or that multiple activities could lead to only one outcome. In the following section of the Appendix, a logic model template is provided to aid in this process.

4. Review and revise

Answer the following questions. If your answer to any question is "not sure" or "no," go back to the model and consider making revisions. It usually takes multiple revisions of the model before it reaches its final form.

▶ Does the logic model include all of the program's most important activities or services?

▶ Do the outcomes represent changes that are important to your program's participants? Likewise, does the model contain the outcomes of greatest interest to your stakeholders, such as staff or funders?

▶ Are the outcome goals clear enough to be understood by stakeholders who might review your logic model? Are the goals realistic?

▶ Are the connections between your inputs, activities, outputs, and outcomes realistic? Are they reasonable based on existing research, theory, or other evidence?

CHALLENGES AND POSSIBLE SOLUTIONS

The logic model process may reveal some challenges, either in your program or specific to the logic model and evaluation process. Some common challenges you face may include:

■ There is disagreement among stakeholders about which services or outcomes to include in the logic model.

■ The funders require a logic model, and staff are worried they will be accountable to outcomes in the logic model that are impacted by things beyond their control.

■ Staff do not want to spend time on logic model development.

■ The logic model is too complicated.

■ The program is intended to change the community, not a small group of individuals.

Luckily, these are challenges faced by many organizations and there are relatively simple ways of addressing them.

■ Keep key stakeholders involved, including staff, program participants, collaborators, or funders – even as a resource for reviewing materials. This will help clarify the common outcomes and expectations.

- Focus on the process, not the product. Take time to explore the reasons for disagreement about what should be captured in the logic model. Also, consider how you can use the logic model in meaningful and interesting ways.

- Logic models that are rushed often end up displaying faulty logic, insufficient evidence, or models copied from other programs that don't quite fit yours. Keep asking yourself "**IF**-**THEN**-**WHY**" questions to make sure that the model is sound. **IF** you provide a service, **THEN** what should be the impact for participants? **WHY** do you think this impact will result? What evidence do you have to support that connection?

- If needed, recruit a facilitator from outside your agency who is trained and experienced in logic model development.

- Think through each step that must occur. For instance, how does each activity impact individuals? In what ways does their behavior change? What has to occur in order for these individual changes to result in widespread community change?

- Consider issues or events outside the control of your agency that may promote or impede the change you are seeking. If needed, develop strategies for monitoring or documenting these issues.

- Focus on the most important activities and outcomes and clearly explain what will happen as a result of your activities without adding excessive detail.

- Only include (and subsequently measure) outcomes that are realistic. If you do not want to be held accountable for something, it must not be an essential outcome goal. Outcomes are not hopes or wishes, but reasonable expectations.

- Remember that a logic model should be a dynamic tool that can and should be changed as needed; it is not a rigid framework that imposes restrictions on what you can do.

BENEFITS OF DEVELOPING LOGIC MODELS

Taking the time to work through the process carefully and thoughtfully can be a very worthwhile endeavor. It can help you:

■ Build consensus and clarity among your staff and other stakeholders about your chosen awareness and screening activities and expected outcomes.

■ Identify opportunities for improving your initiatives (such as by promoting discussion of best strategies for achieving desired results).

■ Spell out the beliefs and assumptions that underlie your choice of activities and intended outcomes.

■ Assess your program's likelihood of success and identify factors that could impact success. For instance, how do the manner, amount, and quality of activities affect the likelihood of achieving the outcomes?

■ Increase your understanding of program performance by clarifying the sequence of events from inputs through outputs through outcomes.

■ Educate funders regarding realistic expectations.

Tips

2.5 Engaging stakeholders in your evaluation

OVERVIEW: An important early stage in selecting a program or designing an evaluation is to identify individuals or groups who have an interest in your program, will be interested in the evaluation, and might have a role in using the results. Stakeholders concerned with colorectal cancer prevention may include program staff, current and potential funders, health care providers, county health workers, patients, advocacy groups, community members, insurers, and others. These stakeholders are all concerned about what changes because of your efforts and can provide great input on prioritizing your evaluation questions. This section provides some recommendations for prioritizing stakeholder groups and engaging them in the evaluation process.

PRIORITIZE STAKEHOLDER GROUPS

Typically, a program or initiative has multiple stakeholders that are interested in different evaluation issues. Since it may not be possible to adequately meet the information needs of all of your stakeholders, it is important to carefully prioritize among these groups. Take time to consider the following questions:

▶ Are there groups, such as funders or a board of directors, to which you have a contractual obligation to provide evaluation information? If so, what are you required to provide?

▶ Is there information that you would like to receive from participants, such as descriptions of the benefits of services, recommendations for program enhancements, or clarification of their needs?

▶ Are there significant decisions facing your program in terms of the nature or amount of services that can be provided? If so, is there any information that would be helpful in making these decisions?

▶ Are there groups that can be helpful in ensuring program continuation or expansion? Do you need to solicit funding from new sources to meet your programming goals? What information would be helpful in this process?

▶ Are you currently collaborating with other agencies or organizations? Is there information that potential collaborators would want to know about your program?

▶ Does your program address an issue that is important to the general public? If so, are you interested in collecting information that will help shape their perceptions of this issue or effective service options?

Given your answers to these questions, which stakeholders do you feel are **most** important as you consider your evaluation needs? If you are unsure, talk to others in your organization, as interesting insights can emerge from a group discussion.

ENGAGE STAKEHOLDERS IN THE EVALUATION PROCESS

In addition to understanding the specific needs and interests of these groups prior to developing your evaluation plan, directly involving some stakeholders in the evaluation design process can be beneficial, especially if there are stakeholders who are not clear about their needs, or if they will need to approve of your resulting evaluation plan. You might consider involving stakeholders in developing evaluation questions to ensure that their priorities are addressed.

Involving stakeholders does not necessarily mean they have complete control of the evaluation, nor does it mean that the evaluation must take into account the ideas and points of view of every stakeholder. It likely cannot. Involving stakeholders does, however, help everyone understand the process of prioritizing and the logic behind the decisions that are made.

Consider these questions:

▶ Which stakeholders are **most** important to include in the evaluation planning process? Why?

▶ What steps can be taken to ensure that the perspectives of these key stakeholders are incorporated into the evaluation design process? This could mean providing opportunities for review or feedback to including them in all stages of the process.

These steps will help to ensure that stakeholders will continue to buy-in to the evaluation process and to help guide the efforts required to complete an evaluation.

Tips

2.6 Creating an evaluation budget

OVERVIEW: Evaluation does not need to be expensive, but it does take time and money to plan an evaluation, collect the right information, and use the results to strengthen your program. This section of the toolkit describes things to include in an evaluation budget, and outlines some potential strategies for reducing costs.

DEVELOP AN EVALUATION BUDGET

A commonly recommended starting point is to allocate 10 percent of the total program budget to evaluation. This includes the value of the time that staff will spend on the evaluation, as well as out-of-pocket costs. If this amount of money is simply not available for evaluation, we provide some practical tips for working on a shoestring budget. However, budgets that are inadequate for evaluation might lead to evaluations that are less comprehensive or of lesser quality. Weigh your options carefully before deciding a reasonable budget is not possible.

Until you actually design your evaluation, your specific resource needs will be rough estimates. However, you need to start somewhere in thinking about your budget and other available resources in order to design an evaluation that is doable. The most common evaluation costs include:

■ Salary and benefits for program staff who might be involved with the evaluation. Think about the amount of time each staff person will spend on evaluation.

■ Travel expenses. Think about travel to and from meetings and to and from evaluation sites.

■ Incentives for evaluation participants, like food or gift cards.

■ Communication tools. This includes costs like postage, telephone, and internet access.

■ Printing and duplication. You will need to budget money to prepare and print surveys, reports, or other documents.

■ Supplies and equipment, such as computers or software. This generally refers to equipment that you would need to purchase in order to complete the evaluation.

■ Funds to pay for an external evaluator. This can vary quite a bit, depending on the degree to which the evaluator is involved in the evaluation. Consider asking a consultant for different options for their involvement and the estimated costs associated with each option.

CONSIDER COST-REDUCTION STRATEGIES IF NEEDED

Conducting a useful evaluation does not need to be expensive. If your funding is falling short, consider these options:

- Prioritize your evaluation questions. Focus on the "need to know," not the "nice to know."

- A big chunk of many evaluation budgets goes for data collection. When you design the evaluation, consider options for gathering information as inexpensively as possible.

- If your program collaborates with others, consider opportunities to conduct a shared evaluation.

- If you're using an external evaluator, work with them to identify the phases of the project where program staff or volunteers might be able to help with some of the work.

If you're really on a shoestring budget

▶ What materials or information do you already have that could become part of an evaluation?

▶ What resources are available at little or no cost? Common examples include volunteer hours and donated goods or gift cards to use as incentives for survey participants.

▶ Can you get funding specifically for the evaluation? Some funders provide grants for this purpose.

▶ Can you find an evaluator, especially one associated with a college or university, who might provide services for free or at a reduced rate in exchange for the opportunity to publish a research article or to fulfill their service requirements? In some cases, graduate students working on degree requirements might provide evaluation assistance under the supervision of a more experienced faculty member.

Tips

2.7 Building evaluation capacity

OVERVIEW: Building capacity of the organization for evaluation is a good way to ensure evaluation is a well-integrated process for your programs. These tips might help evaluation champions in your program or agency build the awareness and capacity of other staff members.

Develop a logic model	▪ Develop shared understanding of program goals and activities ▪ Clarify expectations for outcomes ▪ Identify and address underlying assumptions
Make evaluation findings useful	▪ Provide results to other staff members and stakeholders as early as appropriate ▪ Work with stakeholders to develop actionable recommendations ▪ Identify strengths as well as opportunities for improvement
Keep the evaluation plan reasonable	▪ Build on existing data collection as appropriate ▪ Focus on the most important evaluation issues ▪ Anticipate and address challenges to implementation
Engage all staff	▪ Meet with all staff to identify questions and possible data collection strategies ▪ Listen to staff concerns ▪ Share findings and recommendations with all staff
Maintain focus of evaluation team	▪ Work collaboratively to solve problems ▪ Stress the difference between evaluation and performance assessment

2.8 Finding and working with external evaluators

OVERVIEW: Assessing the skills and backgrounds of staff members or other stakeholders will help to determine whether your program can manage the evaluation activities internally, or whether it might be best to contract with an outside evaluator for some or all of the evaluation activities. This section will provide some suggestions for deciding whether you need external support, finding potential evaluators, and deciding which one is right for you.

DECIDE WHETHER EXTERNAL HELP IS NEEDED

In deciding whether to hire an evaluator, start with these questions:

▶ Do you, or does someone on your staff, have the expertise to conduct an evaluation that meets your needs or at least a desire to learn the necessary skills?

▶ Can you (or other staff members) devote enough time to it?

▶ How important is external, objective assistance and feedback?

▶ Is external evaluation required by any funding sources?

There are other considerations that go into the decision to work with an outside evaluator, as opposed to doing the work internally. Working with an outside evaluator can bring specialized knowledge and experience in program evaluation. External evaluators have likely conducted dozens if not hundreds of different evaluations and have experience working with many different groups of stakeholders. They will be able to draw on practical experience to address any obstacles encountered throughout the evaluation. External evaluators might also have increased objectivity and credibility when it comes to reporting evaluation findings.

On the other hand, working with an external evaluator often increases the cost of an evaluation as compared to doing the work in-house, and it will take time and resources to not only select and hire an evaluator, but also for the evaluator to become familiar with your organization and program. You may also encounter resistance or skepticism among other staff members or stakeholders who may view a contracted evaluator as an "outsider." Here are some practical tips for working effectively with an outside evaluator:

■ Develop a formal contract that spells out the responsibilities of the evaluator, the products that they are to deliver, and a timetable for completing the project. Specify how the evaluator will bill for services and include a payment schedule.

- It is not uncommon for evaluation clients to withhold some of the fee (20 to 30 percent) until a final report has been submitted and accepted. The contract should also specify the program's responsibilities in the evaluation – to provide timely and appropriate guidance, to review and approve materials, and to assist in problem-solving.

- Allow time for the evaluator to become familiar with your project or program. It is important for the evaluator to understand the project and implementation and also to develop rapport with staff members and other stakeholders. This rapport will help increase evaluation buy-in.

- Work closely with the evaluator throughout the entire project. You should have regular meetings with the evaluator. In addition, invite them to program events and activities as appropriate. The more they understand your project, the more effective they are likely to be.

- Learn as much as you can about evaluation – this will help you to be an effective partner with your evaluator.

- Formally or informally, you should periodically assess the evaluation process itself. Consider how the evaluation is progressing, what could be done differently, and how you might improve the process.

FIND AN EXTERNAL EVALUATOR

- Search online evaluator databases such as the W.K. Kellogg Foundation.

- Contact local colleges and universities, starting with the departments that are the best match for the services you provide. Faculty members or advanced graduate students sometimes do evaluation work.

- Advertise in publications specific to your type of work.

- Contact local professional organizations, such as local chapters of the American Evaluation Association. They may have websites or other resources for finding evaluators in your area.

- Contact other local, state, or national organizations focused on your field of service for recommendations.

- Ask colleagues about evaluators they have worked with.

SELECT AN EVALUATOR

The two most important criteria are an evaluator's qualifications to provide the services you need and their ability to work effectively with your agency. Here are a few tips to help select the most compatible evaluator for your program:

- Start your search with a clear idea of what you need the evaluator to do. For instance, someone who can help you conduct in-person interviews might not also be able to develop a computerized database.

- Pay attention to formal education. Although relatively few people actually have a degree in evaluation, an evaluator should have graduate training (master's or doctoral level) in research methods. Be skeptical of someone who has only undergraduate training (college classes), unless they have a tremendous amount of on-the-job evaluation experience.

- Look for someone with relevant experience. Ideally, you want an evaluator who has worked with organizations or programs similar to yours. However, it is more important that they have solid experience in evaluation work (research design, data collection, statistics) than strong knowledge of colorectal cancer screening programs.

- If the evaluator does not have experience evaluating colorectal cancer programs, look for a basic understanding of the special issues involved in the work you do. Perhaps they have done work on other cancer screening programs or other prevention efforts.

- Ask about the evaluator's general approach or philosophy. The strongest external evaluators are typically those who take a collaborative approach – working together to create a credible, useful evaluation that fits your circumstances. Someone who comes in as an "expert" with little interest in listening or adapting to your needs and interests, or as a researcher more interested in scholarly recognition or theoretical exploration, is less likely to give you the practical results that you need.

- Assess the communication skills of the potential evaluators. They should be able to clearly explain the evaluation process. You will need them to present findings in a clear and interesting way to your staff and other stakeholders.

- Whenever possible, select an evaluator in your geographical area. When this is not possible, make sure that they are available to travel to your site when needed.

- Review previous evaluation reports written by potential evaluators. Ask for examples of their evaluation reports. Are the reports clear, readable, well organized, and useful? Avoid candidates whose reports are overly technical, poorly written, disorganized, or difficult to understand.

- Ask candidates to provide references for similar organizations or projects. Ask the references if the evaluation was done in a timely fashion. Did the costs stay within their budget? Was the evaluation report useful? Would they hire the consultant again?

- Ask your top candidates to submit a proposal. This proposal should detail their work plan, timeline, and budget for completing your evaluation.

- And finally, pay attention to your general reaction to potential evaluators. You will want to find an evaluator that is compatible with your organization and your staff. You will need to work together effectively and efficiently.

Before selecting an external evaluator, it is appropriate to interview your top candidates. The Centers for Disease Control and Prevention suggests covering the following topics with potential evaluators:

- ▶ How do they understand the difference between research and evaluation?

- ▶ How do they understand your program?

- ▶ What would be their general approach to the evaluation?

- ▶ Can they conduct the evaluation with the available funding?

- ▶ How do they handle supervision by the program director or evaluation committee?

- ▶ What is their prior evaluation experience?

- ▶ Will their current commitments interfere with their ability to do your project?

2.9 Timing of data collection – pre/post or post only?

OVERVIEW: This section provides guidance about deciding whether to collect data before (pre) and after (post) your intervention, or just after (post). It provides information about when you might use each approach, as well as their benefits and limitations.

If you want to gather objective data about whether people have changed their knowledge or behavior over the course of your program, it is often a good idea to have people complete data collection before (pre) and after (post) your intervention. Comparing what people have said at these two time periods can give you a more rigorous comparison that is less subject to errors in people's memory. However, in some cases, it can be adequate (and even advantageous) to collect evaluation information only once, after the services have been provided.

Example: You are providing a one-hour group education session at a local community center. You really want to do a rigorous evaluation, so you decide to measure participants' knowledge about colorectal cancer and screening options before and after your program. You devote the first and last 10 minutes of the session to completing surveys, reducing your total education time to only 40 minutes. When you review the surveys, you find that people clearly rushed through the post-test surveys. Several express annoyance at the amount of evaluation, and most do not take the time to answer your open-ended questions. Many people simply leave following the program, leaving their uncompleted surveys on the table.

In this case, doing two evaluation forms for such a brief intervention may simply have been too much evaluation. The potential advantage of having a pre and post comparison was overshadowed by the loss in intervention time and the increased burden for participants. In this case, it would have been better to just do one evaluation at the end, asking people questions related to whether they feel they gained knowledge due to the group education result. People are generally reliable in answering these types of questions accurately, and you will likely get more complete and useful information to work with. In general, the shorter the intervention, the less appropriate it is to do data collection at multiple time periods. A pre/post design may be a good option, however, if your intervention extends over a longer period of time, or if you want to give people time to make behavioral changes following an intervention.

Tips

2.10 Writing good surveys

OVERVIEW: This section provides some suggestions to consider if you are going to write your own surveys. It describes some issues to consider when deciding to use a survey, as well as detailed recommendations for how to write clear and effective survey questions.

WHEN TO CONSIDER USING A SURVEY

Surveys allow you to gather information from people in a written form, such as paper-and-pencil or online questionnaires (as opposed to interviews, which are completed in-person or over the telephone). Compared to other data collection approaches, surveys are relatively easy to conduct and allow you to gather information from a large group of people in a cost-effective way. However, a survey may <u>not</u> be your best choice if:

- You want information from people who have limited literacy skills.

- You need in-depth information about people's experiences or perspectives.

- You want to interact with your respondents, by clarifying questions or providing them with information.

- You only need to gather information from a few people.

- Your intended respondents represent cultural communities for whom structured surveys are a less familiar or uncomfortable strategy for gathering information.

- You do not have a way to contact potential participants.

DEVELOPING YOUR SURVEY

Closed-ended versus open-ended questions

Closed-ended questions are structured and provide respondents with response choices (e.g., yes/no, or agree/disagree). Open-ended questions ask respondents to provide answers in their own words (e.g., How would you improve the services that you received?).

Closed-ended questions should be used whenever possible since these questions tend to be easier to answer and analyze. It is often recommended that at least 70 percent of the survey be closed-ended. Save open-ended questions for areas where you want deeper responses or where you cannot provide a useful set of response options.

- To gather the most useful information, be careful when selecting the response choices for closed-ended questions. Remember that your response options should be:

- Mutually exclusive and non-overlapping.

- Exhaustive, containing every logical alternative response.

- As specific as possible.

- Balanced, with both positive and negative answers.

- Relevant and appropriate from the respondent's perspective.

Order of questions

Respondents should understand the order in which questions are asked and be able to move easily through the questions without confusion. Consider the following:

- Choose your first question carefully. It is crucial in determining whether the respondent will participate. Make sure it is relevant, easily understood and answered, applicable to everyone, and interesting.

- Group questions into coherent sections (e.g., those that deal with a specific topic or those that use the same response options).

- Place "sensitive" questions that respondents may be uncomfortable answering as close to the end of the survey as possible.

Writing effective questions

It seems like writing a good survey should be easy. However, there are some common errors in survey writing that can limit respondents' ability or willingness to complete the survey. To avoid these errors, consider the following:

- Keep each question short and use simple sentence structure – it is generally recommended that surveys be written at a fifth- or sixth-grade reading level.

- Use basic vocabulary that is free of professional jargon. Provide definitions for terms that may not be common. If your question includes definitions, however, be sure to include them before the question itself. An example of a good question would be, "A Fecal Occult Blood Test, or FOBT, is a test to determine whether you have blood in your stool. You use a stick to obtain a small amount of stool at home and send it back to the doctor or lab. Have you ever had a blood stool test using a take home test kit?"

- Present questions neutrally – make sure nothing in the question or the response choices suggests a "right" answer.

- Think carefully about words and phrases that may have double meanings – especially if you are of a different age, ethnic/cultural background, or educational level than the respondents.

- Be specific about time frames.

- Be clear about what constitutes an acceptable answer to a question. For example, if you ask, "When did you have your last colonoscopy?" responses can potentially range from "last year" to "when I was 58." Although these are both correct answers to the question, information cannot be easily compared or analyzed. To prevent this from occurring, a better question would be, "In what year did you have your last colonoscopy?"

- Avoid questions that are too abstract. People usually cannot predict what they will do or how they will feel in a situation they have not yet experienced. Therefore, hypothetical questions should be left out of a survey. An example of a hypothetical question to avoid would be, "Do you think the discomfort of a colonoscopy will prevent you from asking your health care provider about receiving one?"

- Avoid asking questions that require unreasonable amounts of time or work to answer. Survey questions should be concise and to the point.

- Avoid asking two questions at once.

- Use existing survey questions where you can. Surveys such as the Health Information National Trends Survey (HINTS) or Behavioral Risk Factor Surveillance Survey (BRFSS) provide reliable and valid questions which have been asked of people for a number of years. Not only do you know you are using a question with considerable research behind it, but you will also be able to compare what you learn from your survey to what has been gathered using past survey questions.

Likert scales

Likert scales are commonly used in questionnaires. They are often used to assess a respondent's level of agreement with a statement. They are also used to understand a participant's level of satisfaction with an activity. Here are some rules of thumb for writing questions using a Likert scale:

- Likert scales measure both positive and negative feelings toward a statement. Be sure that the response options are balanced and include an equal number of positive and negative statements.

- Likert scales commonly include 5 response options (including a "neutral" category). You may also choose to use a 4-point scale and include a "non-applicable" or "don't know" response. Research has shown that if respondents are given too many answer choices (e.g., 9), they can be hard to differentiate.

- Response options should be mutually exclusive. Each option should have a different meaning, so that responses cannot overlap. Here is an example of a common error when writing a question using a Likert scale:

  NOT mutually exclusive:
  ☐ Agree
  ☐ Somewhat agree
  ☐ Somewhat disagree
  ☐ Disagree

  Mutually exclusive:
  ☐ Strongly agree
  ☐ Agree
  ☐ Disagree
  ☐ Strongly disagree

It can be argued that if someone "somewhat agrees" with a statement, they also "somewhat disagree" as well. Therefore, the respondent may be unsure of what their answer to the question should be. There is a greater distinction, however, between "strongly agreeing" with a statement and "agreeing."

- A qualitative meaning should be assigned to each response option. Here is an example of a common error when writing questions with a Likert scale:

  How satisfied are you with the training?

Very Dissatisfied									Very Satisfied
1	2	3	4	5	6	7	8	9	10

This might be confusing for some respondents, since there is no way, for example, to distinguish between a "3" and a "4." In order to analyze results properly, all respondents should be asked the same question in the same way. By doing so, you do not leave room for the person to interpret the question in their own way. A better example for this type of question would be:

How satisfied are you with the training?

Very dissatisfied	Dissatisfied	Neither dissatisfied nor satisfied	Satisfied	Very satisfied
1	2	3	4	5

Assigning a qualitative meaning to each response option makes it clear to the respondent what each number means. It will also be easier to analyze results, since it will be clear what sentiment each number corresponds to.

Formatting

- The appearance of the survey is also important – the fonts used and the layout of the survey will influence how easy or difficult it is for respondents to complete the survey.

- Provide a title that identifies the purpose of the survey – use a bold, prominent font.

- Separate each distinct section of the survey with appropriate headings and subheadings.

- Use an easy-to-read, clean font such as Times or Helvetica.

- Do not crowd the survey – make sure that the survey has "white space."

- Include brief instructions in each section, explaining how to respond.

- If using a two-sided survey, clearly indicate that additional questions are on the other side.

Important considerations

Be sure to keep in mind the group and sub-group you are evaluating. Making sure everyone is literate, for example, is important when asking participants to fill out a survey. If there are language barriers, you want to be sure to offer the survey in different languages. To help you prepare, follow some of these tips.

- Attempt to find data collection tools that have been developed specifically for your target population, by factors such as race or socio-economic level.

- Attempt to find tools that have been translated if necessary. This can save time and the expense of getting translations done, and you can be more certain that the translations were done well.

- If collecting information about participants' race or ethnicity, have them self-identify. Interviewers or surveyors may make inaccurate assumptions about the race or ethnicity of a participant.

- Answering questions about colorectal cancer screening can be uncomfortable. Consider conducting an anonymous survey, or ensure participants that their answers will be kept confidential.

Review and pre-test the survey

Before you begin to collect data, it can be especially helpful to read the survey out loud, so that you can determine how the survey flows and identify questions that sound awkward or unclear. Also, have several people similar to your intended respondents complete the survey and provide you with feedback about questions that were unclear.

STRONG AND WEAK SURVEY QUESTIONS

Because those doing evaluation are usually unable to directly interact with participants taking a survey, it is important to have well written survey questions that are clear, concise, and unbiased. The way a survey question is worded will affect the clarity and validity of the subsequent responses and data. Here are some examples of common errors that result in poorly written survey questions, and corresponding examples of poorly written and well written survey questions.

Error	Weak Example	Stronger Example	Explanation
Lack of Specificity	When is the last time you visited the doctor's office?	On what date did you complete your most recent screening test for colorectal cancer?	It is important to have precisely worded questions in order to prevent any possible confusion or misinterpretation. In the first example, a visit to the doctor's office may be interpreted as any visit, such as paying a bill or scheduling an appointment. It also doesn't specify what kind of doctor. The second example specifically asks for the date of the colorectal cancer screening test completion, in order to be very specific.
Double-barreled	Agree or disagree: I felt comfortable discussing screening options with my doctor and finding the necessary resources for screening.	Agree or disagree: I felt comfortable discussing screening options with my doctor. Agree or disagree: I felt comfortable finding the necessary resources for my recommended screening.	Each survey question should be asked in such a way that elicits a single response. With the first example, it may easily result in confusion for anyone who may have felt comfortable with discussing screening options but not finding resources, and vice versa. The second example corrects this error by creating two questions that address each area of interest separately.
Verbosity	Colorectal cancer is a commonly diagnosed form of cancer in both men and women. Early detection is critical. Are your patients generally aware of current screening recommendations for colorectal cancer?	In general, how knowledgeable are your patients about current screening recommendations for colorectal cancer? -No knowledge -Very little knowledge -Some knowledge -Very knowledgeable	It is important to not have overly lengthy questions and unnecessary information. Keep your questions concise and direct. The first example provides what is most likely redundant information to the clinic staff about the prevalence of colorectal cancer and the importance of screening and early detection. Although it is related to the question at hand, it is not necessarily critical information that affects the integrity of the question being asked. On the other hand, the second question focuses specifically on the question being asked.

Error	Weak Example	Stronger Example	Explanation
Negative Wording	Yes or no: Would you say that you are not satisfied with the ease of scheduling appointments at this clinic?	Agree or disagree: I am satisfied with the ease of scheduling appointments at this clinic.	Negative words in a question can often result in confusion and incorrect responses. A person taking the survey may overlook the word "not" in the first example and accidentally select the opposite response. It is best to avoid using negative terms in a question, and instead use positive terms that directly and clearly align with the possible responses.
Biased Wording	Don't you agree it is necessary to educate others on the importance of regular colorectal screening?	Agree or disagree: It is necessary to educate others about regular colorectal cancer screening.	The way a survey question is worded can easily bias the responder toward a certain answer that they may not have selected if given a more neutrally worded question. The first example is biased inasmuch as the wording appears to imply that the responder should agree that educating others is important. The second example poses the same question in a more neutral light by avoiding using such phrases like "don't you…?"

Sample flawed survey questions

Question	Critique
In the last 12 months, how many doctor's visits have you had? a) None b) 1 – 2 visits c) 3 – 4 visits d) 5 – 10 visits e) 10 – 12 visits f) 15 or more visits	Response options are overlapping, making it difficult for respondents to select the correct answer. For example, someone who attended 10 visits could select option (c) or option (d). This will also make it harder to interpret the results. Respondents may also have different definitions for "doctor's visits," so it would be important to clarify.
How helpful was the material covered in the training? a) Very helpful b) Somewhat helpful	The response options do not contain every possible response that people may want to give. They are also not balanced, since they do not allow respondents to provide negative answers.
How often have you been checked for colorectal cancer? a) Very frequently b) Somewhat frequently c) Somewhat infrequently d) Very infrequently	The question itself is vague, as it requires each participant to define for themselves what it means to be checked for cancer. It will be difficult for you to interpret their responses, as you will not know what they meant by "checked." The response options also need more clarity. Terms such as "frequently" can be defined differently by different respondents.
How often have you failed to get screened for colorectal cancer after your doctor recommended the procedure?	The question has a judgmental, rather than a neutral, tone. Participants may feel as though they are being criticized for not getting screened. Response choices should also have been provided, so that survey responses could be easily tabulated.
Have you had a FSIG in the past 5 years? a) Yes b) No	Survey respondents may or may not know what is meant by "FSIG." It may be more useful to ask respondents whether they have had a flexible sigmoidoscopy, and include a description of the procedure.
How many times have you seen a health care provider for gastrointestinal concerns? _____ times	The time frame for this question is unclear. Survey respondents will not know whether this refers only to services recently received through your intervention or to a longer time period, such as their entire lives. Unless the number of appointments was very small, most respondents will have difficulty answering the question accurately. Many will either need to spend a great deal of time reviewing records to answer the question correctly, or may simply guess at the answer. It may be better to obtain this information from agency service records.

Tips

2.11 Getting a good survey response rate

OVERVIEW: A significant disadvantage of surveys is the risk of a low response rate. People may choose to not complete surveys for a variety of reasons, such as being too busy, not being interested, or feeling that it is not important. However, there are ways to help overcome this. This section provides recommendations for increasing your response rate.

- **Keep it focused.** Review your data collection goals before designing your survey. What is essential to find out? How will the information gained through the survey help you answer key evaluation questions? Make sure that each question appears relevant to the respondent.

- **Keep it short.** Make the survey long enough for you to gather needed information, but not so long as to tire or annoy respondents. There is no set rule about how long a survey should be. Many respondents will take the time to complete a survey, so long as it is relevant and easy to answer. If your survey is too long to be easily completed, consider whether all of the information is necessary and whether you could gather some evaluation information using a different strategy.

- **Keep it clear.** Provide respondents with clear, brief, and easy-to-follow instructions. Some surveys use "skip patterns," which means that respondents may be asked to skip some questions depending on how they answered other questions. Skip patterns should be used only if necessary. If they are used, they should be easy to follow.

- **Encourage participation.** Explain the purpose of the survey, why it is important, and how you will use the information.

- **Make it easy to return.** If the survey is being done by mail, provide a stamped addressed envelope for respondents to use to return the survey. If the survey is being done at your agency, provide a clear and easy place to return the survey.

- **Allow enough time, but not too long, to complete.** If the deadline is too far away, respondents may be more likely to forget to complete or return it. Depending on your target group, this may range from a few days to a few weeks.

- **Provide reminders.** Issuing even a single reminder can increase the likelihood of someone completing a survey. If time allows, two to three reminders are better. Reminders may be given multiple ways: email, phone call, postcards, personal contact, or signs in your agency.

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- **Offer incentives for participation.** It does not need to be large or expensive; a small gift certificate or amount of cash can be effective, or, depending on your audience, free participation in an event or a t-shirt may do the trick. If you would like to follow-up with program recipients, you can offer a larger prize and indicate that you plan on contacting winners through email. If you do not have funding, consider seeking donations.

While it is extremely unlikely that you will receive surveys from everyone that you invite to participate, it is important to collect surveys from as many people as possible. The lower your response rate, the more cautious you should be in interpreting your survey results. As your response rate declines, it becomes less likely that the opinions of your respondents will reflect the perceptions of your entire target population.

2.12 Conducting interviews

OVERVIEW: Interviews allow you to gather information from respondents by directly asking them questions. Interviews may be done in-person or over the telephone. Interviews tend to be more time consuming and expensive (in terms of staff time) to conduct than surveys. However, they can also yield a better response rate. Interviews may be most useful when you need in-depth information about people's experiences or perspectives or when you want to interact with your respondents, by clarifying questions or providing them with information. This section provides tips for conducting interviews, including probing for more information and avoiding bias.

TYPES OF INTERVIEWS

Interviews vary in their degree of structure and formality. Less formal interviews may be useful if you are exploring a broad topic or conducting interviews with very diverse participants. More structured interviews are most useful when it is important to collect consistent information across participants. Interviews generally fall somewhere along the following continuum:

- **Informal, conversational interview:** there is no predetermined order for the questions asked in order to remain as open and adaptable as possible to the respondents' nature and priorities.

- **Semi-structured interview:** a guide is used to ensure that the same general areas of information are collected from each respondent. This provides more focus than the conversational approach, but still allows a degree of freedom and adaptability in getting information.

- **Structured interview:** all respondents are asked exactly the same questions and provided the same set of response options. This format ensures that the same information is collected from each respondent, making it easier to analyze responses.

When interviews are structured or semi-structured, it is important that they be done consistently each time. If more than one person is going to be conducting the interviews, provide training in advance, including opportunities to conduct practice interviews.

THE INTERVIEW PROCESS

Explaining the project to potential respondents

While people are usually willing to be interviewed, some may refuse. The likelihood that people will agree to an interview is higher when their initial contact with an interviewer is positive. On making initial contact:

- Maintain a positive attitude and be enthusiastic.

- Explain the purpose of the interview, the kinds of questions you will ask, how long the interview usually takes, and how the information will be used.

- Allow the respondent to ask questions before beginning the interview.

- If someone seems reluctant to participate, ask about their concern or objection and try to address it – this is more effective than being pushy.

Practice your introduction before contacting respondents. People respond much more favorably when you sound like yourself and not as though you are reading from a script.

Conducting the interview

Interviews provide a chance to establish rapport and help respondents feel comfortable. Before starting an interview, it is perfectly acceptable to engage in small talk to give both yourself and the person you are interviewing a chance to get comfortable. Once you begin the interview:

- Ask questions at a reasonable pace.

- If the interview is structured, read each question exactly as it is written and in the order given in the interview guide.

- Read the entire question before accepting an answer.

- When asked to repeat a question, repeat the entire question.

- Do not skip a question because the respondent answered the question earlier or because you think you know the answer.

- Encourage responses with occasional nods of the head, "uh huh"s, etc.

- Provide transition between major topics, e.g., "We've been talking about (some topic) and now I'd like to move on to (another topic)."

- Do not count on your memory to recall their answers. Ask for permission to record the interview or bring along someone to take notes. Occasionally verify that the recording device (if used) is working.

- Do not allow the person you are interviewing to continually get off topic. If the conversation drifts, ask follow-up questions to redirect the conversation to the subject at hand.

- Avoid getting into casual conversation or discussing issues, topics, and viewpoints that are unrelated to questions on the survey.

- Remember that the topic of colorectal cancer screening may be uncomfortable for some people to discuss. Before asking questions related to the subject, ask questions to build trust and rapport. This can include questions related to what they believe the benefits of colorectal cancer screening are or the steps they are taking to maintain their health.

If you plan to conduct the interview in person, be thoughtful about where it will take place. Make sure the location is comfortable for the respondent, such as their home, work place, or other location they prefer. The setting should be quiet and should allow enough privacy to conduct the interview without jeopardizing confidentiality.

Probing for more information

Interviews provide the opportunity for you to explain or clarify questions and allow you to explore topics in more depth than you can with a survey. A good technique to use to get more information is to ask a "probe" question. A probe question can obtain more information about answers that are unclear, incomplete, or irrelevant. Common probes include: "Could you be more specific?" "Could you give me an example?" or "Could you explain that?" Probes should be asked in a neutral way and should not be used to pester a person or to coerce someone into answering uncomfortable questions. If someone does not want to talk about an issue, you should respect their desire. Other recommendations when using probe questions:

- Never use leading probes. If you are not sure what a respondent means, ask the question again or ask for clarification.

- Probe responses to closed-ended questions if the respondent selects an answer that was not read from the list. Repeat the entire list of response options, instead of trying to guess what the respondent meant.

- Respondents sometimes say "I don't know" because they didn't understand the question, didn't hear the entire question, or are not sure how to answer. If someone says that they "don't know" the answer to a question, probe at least once. Reading the question again can be effective.

- If someone says that they do not want to answer a question, probe one time. If they don't answer the question following the probe, move on to the next question. Sometimes it is helpful to reassure the respondent that all answers are confidential.

- Probe for clarification and inconsistencies. Make sure that you understand what the respondent is saying. If you do not understand what a respondent means, ask.

- Probe for details when needed. Use probes to get a complete response that fully answers the question.

- Stop probing when you have obtained the necessary information, the respondent becomes annoyed or irritated, or the respondent has nothing more to say.

Probe examples:

Survey question	Response	Good probe	Wrong! Leading probe
What did you like best about the program?	Everything!	Can you provide some specific examples?	What were some of the best things about the program staff?
How many meetings did you participate in?	Oh, about 10 or 12 meetings.	Would that be closer to 10 or to 12?	Interviewer writes 11.
How would you improve the program?	I don't know.	Even if there is only one thing you could tell us, that would help us improve the program.	You mean you wouldn't improve the program at all?
What is your race or ethnicity?	Well, I'm a mixture.	A mixture?	Are you part Black or Hispanic?
How much would you agree that the information you received was useful? Would you strongly agree, agree, disagree, or strongly disagree?	I think it was okay.	So . . . would you say you strongly agree, agree, disagree, or strongly agree?	(Interviewer records "agree" without probing further).

Avoiding bias

One disadvantage of interviews is the possibility of respondents changing their answers to please the interviewer or avoid embarrassment. It is important to avoid bias when conducting interviews. Try to avoid expressing your own attitudes, opinions, prejudices, thoughts, or feelings during the interview. The following tips can help you avoid influencing the respondent's answers:

- Do not show surprise, approval, or disapproval with your words, gestures, or expressions to anything the respondent says or does.

- Do not disagree or argue with someone even if they express opinions you feel are wrong.

- Do not provide feedback – if necessary, say something neutral like, "I see" or "I understand."

- Do not become too familiar or casual by sharing personal information.

- Do not laugh too much or make the interview seem like a friendly conversation.

- Do not seek clarification in such a way that leads the respondent toward one particular answer.

Tips

2.13 Conducting focus groups

OVERVIEW: Focus groups are interviews conducted with a small number of people simultaneously. Focus groups also allow you to generate insights based on the interactions among participants. Many of the recommendations for conducting interviews also apply to focus groups. However, there are some additional things to consider when conducting a focus group. This section provides some tips for conducting an effective focus group.

CONDUCTING A FOCUS GROUP

▶ If possible, find someone trained in group facilitation to conduct the focus group.

▶ Keep the number of questions reasonable – you can generally expect to thoroughly address 5-7 questions during a 1.5 hour focus group. Have an established protocol and be upfront with participants about the content of the group.

▶ Make it easy for people to participate by providing transportation and refreshments, as appropriate.

▶ Establish ground rules to ensure that participants stay focused, feel comfortable, and respect the privacy of others.

▶ Select participants who are opinionated and comfortable sharing information in a group.

▶ Limit participation to 6-10 individuals.

▶ Allow opportunities for each person to share information, rather than letting a few people dominate the conversation.

▶ Have a second person present to take notes and to help facilitate the focus group if needed.

2.14 Conducting chart audits

OVERVIEW: Medical record reviews or chart audits are used by clinics or practices to help guide improvements to quality of care. They could be used to track immunization rates or the percentage of patients with a chronic disease such as asthma or diabetes. Medical record reviews or chart audits are also useful for calculating a clinic's or practice's colorectal cancer (CRC) screening rate, which could be used to measure changes in policies or strategies intended to improve CRC screening.

CONDUCTING A CHART AUDIT

In order to calculate a CRC screening rate, the following steps should be taken, which are based on the standards established by the National Quality Forum:

▶ **Identify the patients to be assessed.** Patients included in a CRC screening rate calculation should be age 51-75.

▶ **Identify the patients who have been screened for colorectal cancer.** Patients are considered appropriately screened if they received any of the following: colonoscopy conducted during the measurement year or previous nine years, flexible sigmoidoscopy conducted during the measurement year or previous four years, or fecal occult blood test during the measurement year. The United States Preventative Services Task Force (USPSTF) recently expanded its list of tests recommended for CRC screening to include computed tomography colonography (CTC) and stool DNA. You will need to decide if you want to include these tests as well. You'll need to decide if you want to report on the entire patient population or draw a random sample of patients. See the "Manual for Community Health Centers" link at the end of this document for more guidance on this step.

▶ **Create an audit tool.** Create a tool that you can use to record your findings (i.e., patient name or ID, medical visit date, and screening procedure performed and its result) from performing an audit of patient charts. The tool can be a paper document or digital spreadsheet or electronic health record system. See the "Manual for Community Health Centers" link at the end of this document for more guidance on this step.

▶ **Calculate the screening rate.** The following denominator and numerator should be used to calculate your CRC screening rate:

- The **denominator** is the total number of patients who were age 51-75 as of the end of the measurement year. You would exclude patients with a diagnosis of colorectal cancer or total colectomy.

- The **numerator** is the number of patients age 51-75 who have received appropriate colorectal cancer screening, which includes patients who have received any of the following: colonoscopy conducted during the measurement year or previous nine years, flexible sigmoidoscopy conducted during the measurement year or previous four years, or fecal occult blood test during the measurement year. You may also want to include stool DNA or CTC.

Resources

▶ For more information on useful codes for identifying patients who have received colorectal cancer screening, please consult the National Quality Forum (NQF). Select participants who are opinionated and comfortable sharing information in a group.

▶ For additional information from the electronic Clinical Quality Measures (eCQMs) Resource Center and the eCQM logic, please visit the eCQI Resource Center site.

▶ For more information on calculating CRC screening rates for community health centers, please consult Steps for Increasing Colorectal Cancer Screening Rates: A Manual for Community Health Centers.

▶ For more guidance on measuring CRC screening rates in health system clinics, please consult this CDC resources Guidance for Measuring Colorectal Cancer Screening Rates in Health System Clinics.

▶ For more information on steps in a quality chart audit, please consult Eight Steps to a Chart Audit for Quality.

▶ For more information about best practices for electronic health record audits, click here: EHR Best Practice Workflow and Documentation Guide to Support Colorectal Cancer Screening Improvement with eClinicalWorks

Tips

2.15 Social desirability

You'll need to be mindful of the tendency of respondents to answer questions how they think they *should* answer questions, due to social desirability bias**.** Below are some examples that illustrate how social desirability bias can be overt, or can be more subtle.

Example 1: You complete a one-on-one education session regarding colorectal cancer screening with a nurse. Following the education session, the nurse asks if he can complete a brief survey with you. Sitting across the table from you, he asks "How would you rate my communication skills?" You thought his skills were weak, but you don't want to hurt his feelings. You give him a positive rating.

Example 2: You participate in a group education event at your church. At the conclusion of the event, the trainer says that their evaluation procedures include counting how many people plan to pursue a colorectal cancer screening within the next three months. You still are not sure if you want to be screened, and you'd like a chance to ask more questions before making up your mind. However, as your friends and fellow parishioners around you all raise their hands, you feel embarrassed keeping yours down. You raise your hand to be included in the count.

Example 3: You are a physician who has just completed a session where a speaker is presenting a summary of key colon cancer research news, and discusses her interpretation of a newly published major study and its results. At the end of the session, the coordinator hands out a survey to all participants. The evaluation survey asks you how helpful this information was. You disagree with the speaker's interpretation of some of the research discussed, but because you must include your name and the speaker is a colleague of yours, you check "very helpful."

In all three examples, participants feel some subtle or explicit pressure to answer evaluation questions "the right way." As a result, the information provided will not be accurate or valid, and will not be useful in determining whether the related activities were effective. As you design your materials, take a step back and think carefully about how participants will feel completing the evaluation. Avoid language or procedures that may guide people towards a "correct" answer that may not actually be true for them.

Other tips:

■ Pretest your materials with people who are similar to your intended evaluation audience – ask for feedback about your questions and people's comfort answering them honestly.

■ Be clear with participants about the purpose of your evaluation and the importance of honest feedback.

■ Keep the evaluation anonymous wherever possible. In cases where you need to gather names, explain why you need the names and how the data will be used.

■ Avoid having people directly collect evaluation information about themselves. If you want to evaluate your services, consider confidential ways for people to turn in a survey or have another staff person conduct the interview.

Tips

2.16 Entering and managing data

> **OVERVIEW**: Data entry is often thought of as a time-consuming process, but there are steps you can take to make the process more efficient. You will save time in the long run if you take time up front to prepare for data entry. This section provides some general steps to help you get started.

ENTERING DATA

- Assign an ID number to each form or survey to be entered, and write the number at the top of each survey. These can be numbers such as 1, 2, 3, 4, but each number should be used only once, even across different batches of surveys. This will make it much easier to go back and re-enter data if you realize you have made a mistake. In some instances, like surveys you collect on a recurring basis from the same people (such as doctors), you may wish to assign one ID for each respondent. You will need to maintain a master list that you can reference for assigning and tracking these ID numbers in the future.

- Schedule a large enough block of time to enter an entire batch of data at once. The time needed for this will vary depending on the length of the survey and the number of participants, but it is best to enter all of the information at the same time if possible. This will minimize the chance that you enter the same survey twice or forget to enter any remaining surveys.

- Before you begin entering the data, take time to go through each completed survey and identify questionable responses. By taking time up front to identify potential problem areas, you can make consistent decisions about what you plan to enter in each situation, and you will save time once you begin entering the data. See the section on making data entry decisions to identify some common mistakes that survey respondents make, and take note of the tips for working with difficult or confusing surveys.

MAKING DATA ENTRY DECISIONS

No matter how clearly a survey is written, there will be some survey respondents who do unexpected things. For example, respondents may choose multiple answers even when asked to choose only one, they may skip questions, or they may just make it difficult to understand their intended response. The following are some common issues that you may discover and some ideas for navigating those difficult surveys. Once you have made a decision about how to treat a particular issue, make note of it in a separate document, or even in the margin of these instructions, to reference later and build consistency in your decision-making process.

- If data are missing or unintelligible, just leave the space blank in the database. You should not try to guess what the respondent might have been thinking.

- A participant may respond to a numerical question with a range of numbers (e.g., "1 or 2" or "5-7") or a vague reference (e.g., "a couple" or "several") instead of a single number. In these cases, the response is too vague to translate into a single representative number, so you will simply leave this cell blank.

- Sometimes respondents will be unable to choose between "agree" and "strongly agree," and will select both. Unless it is clear that one of the responses was the intended response (e.g., the other is crossed out or one is obviously indicated), you are safer to just leave that space blank in the database. We don't want to try to read our participants' minds.

- For those surveys in which an "other" category is possible, you will have to decide how to treat these answers. You may enter them into the spreadsheet as described above. However, sometimes respondents choose "other," but then provide an answer that closely aligns with one of your response categories. See the example below:

  In what capacity did you attend this training?
  ☐¹ Nurse
  ☐² Physician
  ☐³ Physician Assistant
  ☐⁴ Other: <u>Geriatric doctor</u>

  In this situation, you would probably choose to recode the response "other" to "physician," as a geriatric doctor is a type of physician.

MANAGING YOUR DATA

You have put time and effort into completing data entry. The last thing you want is to lose or misplace your paper versions of surveys. The following tips will help ensure that the data you have entered has integrity and will provide useful information for your projects.

- You or someone else should double check the entered data. Be sure to check a minimum of every 5 cases to make sure the data were entered in your spreadsheet correctly. If there are more than a few discrepancies, you may want to check every case.

- If the surveys contain any identifying information (respondent's name, social security number, etc.), be sure to keep the surveys in a locked place when not using them. Never leave them laying around, even if you get up for only a moment. Also, if you are sending data that contain identifying information by fax or email, make sure to take the necessary precautions before sending it, such as encryption.

- Save your data often! In fact, it is a good idea to save a back-up copy of the database once all of the data for a particular session has been entered. If anything were to happen to the original, these steps could save a lot of time, energy, and stress.

2.17 Analyzing quantitative data

OVERVIEW: Quantitative data analysis allows you to make sense of the numerical data collected through surveys. This section provides some basic tips for analyzing your data, with a goal of summarizing the information that you obtained.

Descriptive statistics include frequency distributions, central tendency, and variability. These can be used to summarize the information received from your participants in order to get a better picture of the population you are reaching through your activities.

Frequency distributions: counts that show how many of your evaluation participants fall into various categories of interest (e.g., how many said they "strongly agree," "agree," "disagree," and "strongly disagree"). These statistics are only reported when there are defined response options, like in the example. You can find these statistics in the data summary spreadsheets under the columns labeled "#" or "%."

Central tendency: the number that best represents the "typical score," such as the average. The average is calculated by adding up all the numbers and then dividing by the number of numbers. The "median" is the "middle" value in the list of numbers. The "mode" is the value that occurs most often. The "range" is the difference between the lowest and highest values. Central tendency is usually only reported when the responses are numerical and continuous (e.g., number of months of participation, ages, number of people in a household).

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Variability: the amount of variation or disagreement in your results. Common measures of variability include reporting minimum and maximum scores, range (difference between the highest and lowest scores) and standard deviation (a more complicated calculation based on a comparison of the each score to the average). Variability is also only reported when the responses are numerical and continuous (e.g., number of months of participation, ages, number of people in a household).

Make sure you check your data entry work and your analysis thoroughly. If something in your analyses looks strange to you, first go back and make sure there are not any errors in your data entry.

Tips

2.18 Writing the report

OVERVIEW: Once your evaluation data are collected and analyzed, you will usually want to prepare a report of the findings. This section provides a sample outline for an evaluation report, and provides tips for organizing and summarizing your information.

SAMPLE REPORT OUTLINE

No one approach fits all written evaluation reports. Remember to tailor the report to your audience. Most reports should include, at a minimum, the Who, What, Where, When, Why and How of the evaluation. How you present that information, and the level of detail and technicality, will depend on your audience. The following outline provides a common framework for presenting evaluation results.

Report example
I.   Executive summary
II.   Program background
a. Participants *(who)*
b. History
III.   Review of evaluation questions *(what)*
a. Goals of evaluation *(why)*
b. List questions and why each was addressed
IV.   Methods *(when, where, and how)*
a. Evaluation design
b. Participant criteria
c. Data collection approaches
d. Data analysis procedures
V.   Strengths and limitations of methods
VI.   Key findings
a. Characteristics of evaluation participants (demographics, etc.)
b. Services provided by program
c. Results for each evaluation question
VII.   Conclusions
a. Strengths of program as identified by evaluation
b. Recommendations for improving program

        c. Other implications

        d. Suggestions for improving future evaluation activities

VIII.   Appendix

        a. Examples of survey instruments

        b. Copies of consent forms

        c. Graphs, charts

        d. Copy of program logic model

REPORT WRITING TIPS

Organize your information

Organization can be one of the main challenges in preparing an evaluation report. Your readers should be able to easily understand the structure of the report and find the information that interests them. Consider the following recommendations:

- List each of your key evaluation questions and then attempt to answer them with the available information.

- Provide an introduction that summarizes the format and content of the report.

- Use headings and subheadings consistently to help readers follow your organization.

Key findings

If you have a lot of information to report, it can be easy for readers to lose track of your main findings and conclusions. Make your key findings stand out, so that your stakeholders can easily find them and determine their significance and usefulness. Consider the following suggestions:

- Within each section, start with the most important information.

- Present key findings both in text and in tables.

- Consider using a bold font or section subheading to present key statements of findings.

- Restate your key findings in your executive summary and in your conclusions.

Formatting

Formatting is a relatively easy strategy for making reports easy to read and understand. Keeping the report visually interesting, but not too "busy" can help keep readers engaged in the report. Consider the following tips when formatting your report:

■ Leave "white space" – do not crowd the page.

■ Avoid using more than 2-3 fonts within one document.

■ Use an 11-12 point font size – make sure that it is legible and easy to read.

■ Use features such as bold, italic, and underline sparingly and consistently throughout the report.

■ Consider using bullets or sidebars to emphasize key information.

Tables and graphs

Tables and graphs can be a valuable supplement to your written text. When presenting your key findings, consider whether the information will be best communicated using a table or graph, written text, or both. If you use tables or graphs, keep them as clear and simple as possible.

Language

The language used in the report not only sets the tone for the report, but also determines how understandable the report will be to your readers. Consider the following tips:

■ Use familiar words rather than jargon.

■ Use active verbs as much as possible.

■ Delete unnecessary words and phrases.

■ Keep sentences and paragraphs short.

■ Avoid using expressions that may not be familiar across cultural communities.

Objectivity

It is crucial that you report your evaluation findings objectively, including both positive and negative findings. Here are some tips for ensuring your objectivity and increasing credibility with stakeholders:

- Use disappointing results to guide recommendations for enhancing services or to address implementation barriers, rather than dismissing or hiding them.

- Discuss limitations in terms of how information was collected, so that audiences can judge the degree of confidence to place in the results. Every evaluation study has limitations, making it more difficult for stakeholders to reach definitive conclusions.

- Be clear about what is a statistical finding versus what is your interpretation. Unless you use hypothesis testing and statistics, avoid the use of the word "significance" as this implies a statistical finding that your evaluation findings may or may not support.

- Do not use emotionally charged language when describing your program or findings, like "very" or "extremely." This can make you sound like a program advocate, thus reducing your objectivity and credibility.

APPENDIX 3 – SAMPLES

Sample

3.1 Consent form

> **OVERVIEW**: In some cases, you may need to have participants indicate that they have consented to participate in the evaluation. This section provides a sample consent form that can be modified. This sample is based on Example 3, the Wellness Clinic (from the main body of the toolkit). The form is being used to obtain permission to complete brief surveys before and after patients receive one-on-one education, and to participate in a follow-up conversation by telephone three months later.

Dear Participant:

The Wellness Clinic is working on an initiative to increase the percentage of patients who get screened for colorectal cancer. The clinic staff is conducting an evaluation to learn more about patients' knowledge of screening options and willingness to be screened.

The clinic staff will ask you to complete a survey before and after your regular appointment. The survey will ask questions about your knowledge of colon cancer and screening options and your perceptions of the staff who met with today. The survey is confidential and voluntary. We would also like to call you three months after your appointment to ask a few follow-up questions.

Please note the following:
- All information collected through this project will be private. Your name will not appear in any document describing the results of this project.
- Participation is completely voluntary. Your decision to participate or not participate will have no affect on the services that you receive from the Wellness Clinic.
- Your permission is valid for the duration of the research project. However, you may revoke your permission and stop participating in the project at any time. Please see the Notice of Privacy Practices for more information.
- No specific information will be provided to anyone without your permission, unless required by law. Please see the Notice of Privacy Practices for more information.
- When information is sent to a third party, the information could be re-disclosed by the third party that receives it and may no longer be protected by state or federal privacy laws.

The list below describes the information to be collected. Please indicate your consent below. Check all that apply.

YES   NO

❏   ❏   I am willing to complete a brief survey before and after my appointment. I know that I will have the right to refuse to answer any of the questions.

❏   ❏   I am willing to complete a brief survey over the telephone three months after my appointment. I know that I will have the right to refuse to answer any of the questions.

Thank you for considering participation in this evaluation project. The information we gather will help us make changes to our program and provide the best possible service to you and future patients.

_____   _____
Patient signature   Date signed

3.2 Formulario de consentimiento

IDEA GENERAL: En algunos casos, es necesario que los participantes indiquen que dieron su consentimiento para participar en la evaluación. Esta sección proporciona una muestra del formulario de consentimiento que puede ser modificado. La muestra está basada en el Ejemplo 3, Clínica del Bienestar (*Wellness Clinic*). El formulario se está usando con el fin de obtener permiso para completar breves encuestas antes y después de que los participantes reciban educación personalizada, y para participar en un seguimiento por teléfono tres meses después.

Estimado participante:

La Clínica del Bienestar está trabajando en una iniciativa para aumentar el porcentaje de pacientes que se hacen chequeos para la detección de cáncer colorrectal. El personal de la clínica está llevando a cabo una evaluación para saber más sobre el conocimiento de los pacientes con respecto a las opciones de chequeos y sobre su disposición para ser examinados.

El personal de la clínica le pedirá que complete una encuesta antes y después de su cita regular. La encuesta incluye preguntas relacionadas con los conocimientos que usted tiene acerca del cáncer de colon opciones de chequeos, y sus percepciones sobre el personal con el que se encontró hoy. La encuesta es confidencial y voluntaria. También nos gustaría llamarlo tres meses después de su cita para hacerle algunas preguntas de seguimiento.

Tome en cuenta lo siguiente:
- Toda la información colectada mediante este proyecto será privada. Su nombre no aparecerá en ningún documento que describa los resultados de este proyecto.
- Su participación es completamente voluntaria. Su decisión de participar o no, no influirá los servicios que recibe por parte de la Clínica del Bienestar.
- Su permiso es válido para la duración del proyecto de la investigación. Sin embargo, usted puede revocar el permiso y dejar de participar en el proyecto en cualquier momento. Consulte el Aviso sobre las Prácticas de Privacidad para obtener más información.
- No se proporcionará información específica a nadie sin su permiso, a menos que la ley lo requiera. Consulte el Aviso sobre las Prácticas de Privacidad para obtener más información.
- Cuando se envíe información a una tercera persona, la información puede ser revelada de nuevo por esa tercera persona que la recibe y no sigue protegida por las leyes estatales o federales de privacidad.

La siguiente lista describe la información que se colectara. Por favor indique su consentimiento a continuación. Marque todo lo que applique.

SÍ   **NO**
❏   ❏   Estoy dispuesto a llenar una breve encuesta antes y después de mi cita. Entiendo que tengo derecho a negarme a responder a cualquiera de las preguntas.
❏   ❏   Estoy dispuesto a completar una breve encuesta por teléfono tres meses después de mi cita. Entiendo que tengo derecho a negarme a responder a cualquiera de las preguntas.

Gracias por su consideración y participación en este proyecto de evaluación. La información que colectaremos nos ayudará hacer cambios en nuestro programa y a proporcionar el mejor servicio posible a usted y a futuros pacientes.

_____   _____
Firma del paciente   Fecha de la firma

Example 1   Back to Appendix 3.3 section.

3.3 Complex logic model

INPUTS	ACTIVITY	OUTPUTS	SHORT-TERM OUTCOMES	INTERMEDIATE OUTCOMES	LONG-TERM OUTCOMES
-Staff vehicles -Telephones/ service	-Coordinate and schedule patient pick-ups/returns -Pick up and return clients from home to clinic	-Number of patients scheduled pick-ups/returns -Number of patients using driving services	-Potential patients in targeted community learn about available driving services	-More patients make appointments to be screened -Targeted community members increase	-CRC screening rates increase -CRC incidence and mortality decrease
-Staff Telephone/ service -Pamphlets/ brochures	Call patients to remind them about screening	-Number of reminder calls made to patients -Number of patients reached via phone about reminders	-Patients learn about the importance of CRC screening and available resources		
	Make and distribute pamphlets/ brochures to targeted community about importance of CRC screening	-Number of brochures/ pamphlets distributed -Number of responses to brochures/ pamphlets			

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Example 2

3.4 Weak logic model

ACTIVITY	OUTPUTS	SHORT-TERM OUTCOMES	INTERMEDIATE OUTCOMES	LONG-TERM OUTCOMES
-Coordinate and schedule patient pick-ups/returns -Pick up and return clients from home to clinic	-Number of clients scheduled	-Patients schedule screenings -Potential patients in targeted community learn about available driving services	-More patients make appointments to be screened -Targeted community members increase screening rates	CRC screening rates increase

The model lacks an "inputs" column (typically the first column in the model). An "inputs" column is important for best identifying, defining, understanding, organizing/budgeting, and coordinating the available resources for engaging in successful program activities. It is also helpful in identifying key stakeholders involved with your program.

For example, the "inputs" in this model may include staff, vehicles, and telephones.

- The "outputs" column does not adequately address or measure the activities impact on the outcomes as well as it could. It would be best to include additional outputs, such as the number of clients that actually use the driving services, not only just those who are scheduled to use it.

The phrase "number of clients scheduled" is also rather vague, leaving too much room for misinterpreting what "scheduled" is referring to (i.e. scheduled appointments, scheduled driving service appointments, etc.). It is important to be more specific and accurate with the language used in a logic model in order to have more precise measurements for evaluation.

- The short-term outcome "patients schedule screenings" is also too vague. It is important to define the types of patients being scheduled (i.e. new patients vs. existing patients), as well as the type of change in scheduled screenings (i.e. increase in screenings).

Additionally, the other short-term outcome ("Potential patients in targeted community learn about available driving services") is not adequately addressed in the "activities" column in order to be able to logically and sequentially claim that as the necessary subsequent "outcome". It would be best to add some type of activity which would logically result in that outcome.

The long-term outcome should include something additional which shows the overall goals of the program. Although the goal is to increase colorectal cancer screenings, the goal of the increased screenings is to decrease colorectal cancer mortality and incidence. It is important to include that in the long-term outcomes column as well in order to show interested stakeholders, potential donors, and staff how the activities directly result in achieving the organization's long-term goals (in this case, reducing mortality and incidence).

Sample

3.5 Survey questions

OVERVIEW: Depending on what you most need to know through your evaluation, a survey might be the right approach for gathering information. This section provides some sample survey questions that can be used or modified, addressing areas such as outcomes, process, and satisfaction. It also includes sample demographic questions, and the five core questions being recommended for consistent use in evaluations of programs seeking to increase colorectal cancer screening.

SAMPLE SURVEY INSTRUMENTS

Programs are encouraged to use the following five core questions from BRFSS in their evaluation instruments, so that they will be able to compare their findings with state and national data.

Core questions:

1. A blood stool test is a test that may use a special kit at home to determine whether the stool contains blood. Have you ever had this test using a home kit?
   ☐ Yes
   ☐ No
   ☐ Don't know / Not sure
   ☐ Refused

2. How long has it been since you had your last blood stool test using a home kit?
   ☐ Within the past year (anytime less than 12 months ago)
   ☐ Within the past 2 years (1 year but less than 2 years ago)
   ☐ Within the past 3 years (2 years but less than 3 years ago)
   ☐ Within the past 5 years (3 years but less than 5 years ago)
   ☐ 5 or more years ago
   ☐ Don't know / Not sure
   ☐ Refused

3. Sigmoidoscopy and colonoscopy are exams in which a tube is inserted in the rectum to view the colon for signs of cancer or other health problems. Have you ever had either of these exams?
   ☐ Yes
   ☐ No
   ☐ Don't know / Not sure
   ☐ Refused

4. For a sigmoidoscopy, a flexible tube is inserted into the rectum to look for problems. A colonoscopy is similar, but uses a longer tube, and you are usually given medication through a needle in your arm to make you sleepy and told to have someone else drive you home after the test. Was your most recent exam a sigmoidoscopy or a colonoscopy?
   ☐ Sigmoidoscopy
   ☐ Colonoscopy
   ☐ Don't know / Not sure
   ☐ Refused

5. How long has it been since you had your last sigmoidoscopy or colonoscopy?
   ☐ Within the past year (anytime less than 12 months ago)
   ☐ Within the past 2 years (1 year but less than 2 years ago)
   ☐ Within the past 3 years (2 years but less than 3 years ago)
   ☐ 10 or more years ago
   ☐ Don't know / Not sure
   ☐ Refused

Knowledge questions:

These questions can be asked as part of an evaluation of program outcomes. They can be used before and after program activities to assess any changes in knowledge, or can be asked after the activities have been completed. (Adapted from HINTS 2003)

At what age are most people supposed to start colorectal cancer screening? _____

Colorectal cancer can be prevented through screening.
☐ Agree   ☐ Disagree

Is colorectal cancer screening recommended for men, women, or both?
☐ Men   ☐ Women   ☐ Both

People 50 and older should be screened for colorectal cancer, even if they do not have any symptoms.
☐ Strongly agree   ☐ Agree   ☐ Disagree   ☐ Strongly disagree

Which of the following tests are recommended for colorectal cancer screening? Choose all that apply.
☐ A take-home blood stool test, such as FOBT or FIT
☐ A blood stool test performed in a health care provider's office
☐ Colonoscopy
☐ Flexible Sigmoidoscopy
☐ Digital rectal exam

In general, once people reach the age for colorectal cancer screening, if they choose the {INSERT TEST CHOSEN: FOBT home blood stool test; FIT home blood stool test; colonoscopy; flexible sigmoidoscopy} option for screening, how often should they have them done assuming results are normal? Choose only one.
☐ Every year
☐ Every 2 years
☐ Every 3 years
☐ Every 5 years
☐ Every 10 years
☐ Other, specify: _____

Intention, motivation, and pledge to screen questions:

These questions can be used in an evaluation of program outcomes to understand any changes in intention to screen after program activities. (Adapted from HINTS 2003)

In the future, would you say that…
☐ You plan to get screened for colorectal cancer
☐ You don't plan to get screened for colorectal cancer
☐ You're undecided

If you don't plan to get screened for colorectal cancer, why not? _____

If you are undecided, what would motivate you to get screened? _____

If you have not yet been screened for colorectal cancer, when do you expect to have a {colonoscopy/FOBT/FIT/flexible sigmoidoscopy}?
☐ Within 3 months from now
☐ Within 6 months from now
☐ Within the year
☐ If I have symptoms
☐ When doctor/health care provider recommends

If you have previously been screened for colorectal cancer, when do you expect to have your next colorectal cancer screening test?
☐ At the recommended interval
☐ I am not planning to have another
☐ If I have symptoms
☐ When doctor/health care provider recommends

Will you commit to get screened for colorectal cancer screening?
☐ Yes ☐ No
If no, why not? _____

Discussions with family, friends, or medical provider about colorectal cancer and screening:
These questions can be used in an evaluation of program process to understand where your participants are prior to your activities. They can also be used in an outcome evaluation to assess any changes that may have occurred as a result of the program. (Adapted from HINTS 2003)

Did a doctor, nurse, or other health professional ever advise you to get a screening test for colorectal cancer?
☐ Yes   ☐ No   ☐ Don't Know

These questions can be used in an evaluation of program outcomes. They can be used in a pre- and post-survey to understand any changes that have occurred prior to the activities, or in a survey after activities have been completed. (Adapted from WE CAN! survey)

I will talk to my health care provider about colorectal cancer screening in the next month.
☐ Yes   ☐ No   ☐ Don't Know

I will talk to friends and family about colorectal cancer screening in the next month.
☐ Yes ☐ No ☐ Don't Know

Attitude toward screening:

These questions can be used in an outcome evaluation to understand any changes in attitude toward screening. (Adapted from HINTS 2005)

Do you agree or disagree with the following statements?

There's not much you can do to lower your chances of getting colorectal cancer.
☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

Getting checked regularly for colorectal cancer increases the chances of finding the cancer when it's easy to treat.
☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

There are so many different recommendations about preventing colorectal cancer that it's hard to know which ones to follow.
☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

You are reluctant to get checked for colorectal cancer because you fear you may have it.
☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

Getting checked regularly for colorectal cancer increases the chances of preventing the cancer.
☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

You are reluctant to get checked for colorectal cancer because of the prep needed for the test.
☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

You are reluctant to get checked for colorectal cancer because the test is embarrassing.
☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

Process evaluation questions

These questions can be used in a process evaluation to understand how well activities are meeting participant needs, what challenges or barriers have been encountered, and what stakeholders would change about the way services are delivered. (Some questions adapted from the Colon Cancer Alliance Perceptions Survey)

What did you like most about the program/brochure/educational session?

What did you like least about the program/brochure/educational session?

What, if anything, would you change about the program/brochure/educational session?

Did the program/brochure/educational session meet your needs? Please explain your answer.

Did the program/brochure/educational session increase your knowledge of colorectal cancer? Please explain your answer.

Did the program/brochure/educational session increase your willingness to get screened for colorectal cancer? Please explain your answer.

Satisfaction (with program and/or program materials)

These questions can be used in an evaluation to assess satisfaction. (Adapted from WE CAN! survey and the Professional Worker Career Experience Survey, United States, 2003-2004)

The staff who presented the program were knowledgeable about colorectal cancer.
☐ Strongly agree   ☐ Agree   ☐ Disagree   ☐ Strongly disagree

The information provided by the program was useful.
☐ Strongly agree   ☐ Agree   ☐ Disagree   ☐ Strongly disagree

The materials provided by the program were easy to understand.
☐ Strongly agree   ☐ Agree   ☐ Disagree   ☐ Strongly disagree

How satisfied are you with the program [materials/staff/activities]?

Very satisfied	Satisfied	Neither satisfied nor dissatisfied	Dissatisfied	Very Dissatisfied
1	2	3	4	5

Muestra

3.6 Preguntas de la encuesta

IDEA GENERAL: Según lo que usted más necesite saber en el curso de su evaluación, una encuesta podría ser la manera correcta para reunir información. Esta sección proporciona algunas preguntas de la encuesta a modo de muestra, que pueden usarse o modificarse, aplicandolo a áreas como las de resultados, procesos y satisfacción. También incluye ejemplos de preguntas demográficas y las cinco preguntas principales recomendadas con el propósito de un uso consistente en evaluaciones de programas que buscan incrementar la cantidad de chequeos para detección de cáncer colorrectal.

Se *recomienda* que los programas usen las siguientes preguntas principales del BRFSS (siglas en inglés de Sistema de Vigilancia de Factores de Riesgo en el Comportamiento) en sus instrumentos de evaluación, para que puedan comparar sus conclusiones con la información nacional y estatal.

Preguntas principales:

1. Una prueba de sangre en materia fecal (también conocida como prueba de sangre oculta en heces) es un examen que se puede realizar con un equipo especial en casa para determinar si las heces contienen sangre. ¿Alguna vez hizo este examen utilizando un equipo en su casa?
   ☐ Sí
   ☐ No
   ☐ No sabe / No está seguro
   ☐ Rehusa

2. ¿Cuánto hace que hizo el último examen de sangre en materia fecal usando un equipo en su casa?
   ☐ Dentro del último año (en cualquier momento dentro de los últimos doce meses)
   ☐ Dentro de los últimos dos años (hace mas de un año pero hace menos de dos años)
   ☐ Dentro de los últimos tres años (hace mas de dos años pero hace menos de tres años)
   ☐ Dentro de los últimos cinco años (hace mas de tres años pero hace menos de cinco años)
   ☐ Hace cinco años o más
   ☐ No sabe / No está seguro
   ☐ Rehusa

3. La sigmoidoscopía y la colonoscopía son exámenes en los cuales se inserta una sonda por el recto para observar el colon en busca de señales de cáncer u otros problemas de salud. ¿Alguna vez se ha hecho alguno de estos exámenes?
   ☐ Sí
   ☐ No
   ☐ No sabe / No está seguro
   ☐ Rehusa

4. En una sigmoidoscopía, se inserta una sonda flexible por el recto a fin de detectar problemas. Una colonoscopía es similar, pero se usa una sonda más larga y se administra medicamento en el brazo mediante una aguja para que el paciente se adormezca; además, se le indica que alguien más lo manejé a su casa después del examen. ¿Su examen más reciente fue una sigmoidoscopía o una colonoscopía?
   ☐ Sigmoidoscopía
   ☐ Colonoscopía
   ☐ No sabe / No está seguro
   ☐ Rehusa

5. ¿Cuánto hace que le hicieron la última sigmoidoscopía o colonoscopía?
   ☐ Dentro del último año (cualquier momento en los últimos doce meses)
   ☐ Dentro de los últimos dos años (hace mas de un año pero hace menos de dos años)
   ☐ Dentro de los últimos tres años (hace mas de dos años pero hace menos de tres años)

   ☐ Hace diez años o más
   ☐ No sabe / No está seguro
   ☐ Rehusa

Preguntas de conocimiento:

Estas preguntas pueden formularse como parte de una evaluación de los resultados del programa. Pueden usarse antes y después de las actividades del programa para evaluar cambios en el conocimiento, o pueden formularse después de que se hayan completado las actividades.(Adaptado de HINTS [siglas en inglés de Encuesta Nacional de Tendencias sobre Información Relacionada con la Salud] 2003)

¿A qué edad se supone que la mayoría de las personas deben comenzar a hacerse chequeos para la detección del cáncer colorrectal?_____

El cáncer colorrectal puede prevenirse mediante chequeos.
☐ De acuerdo   ☐ En desacuerdo

¿Se recomienda el chequeo para la detección del cáncer colorrectal para hombres, mujeres o ambos?
☐ Hombres   ☐ Mujeres   ☐ Ambos

Las personas a partir de los cincuenta años deben hacerse chequeos para la detección del cáncer colorrectal aún cuando no tengan síntomas.
☐ Muy de acuerdo   ☐ De acuerdo   ☐ En desacuerdo   ☐ Muy en desacuerdo

¿Cuál de los siguientes exámenes se recomienda para la detección del cáncer colorrectal? Seleccione todo lo que corresponda.
☐ Un examen de sangre en heces fecal tomado en casa, como FOBT o FIT
☐ Un examen de sangre en heces fecal realizado en el consultorio de un proveedor (medico o enfermera) de atención médica
☐ Colonoscopía
☐ Sigmoidoscopía flexible
☐ Examen rectal Digital Tacto rectal

Por lo general, una vez que las personas llegan a la edad de realizar el chequeo para la detección de cáncer colorrectal, y si escogen la prueba de {ESCOJA LA PRUEBA QUE USTED PREFIERE: examen FOBT de sangre oculta en heces fecal tomado en casa; examen FIT de sangre oculta en heces fecal tomado en casa; colonoscopía; sigmoidoscopía flexible} para el chequeo, ¿que tan seguido debe de hacerse el chequeo que usted eligio, suponiendo que los resultados salieran normales? Elija sólo una opción.
☐ Cada año
☐ Cada dos años
☐ Cada tres años
☐ Cada cinco años
☐ Cada diez años
☐ Otro, especifique: _____

Preguntas sobre la intención, la motivación y el compromiso respecto al chequeo.

Estas preguntas pueden usarse en una evaluación de los resultados del programa para entender cualquier cambio en la intención respecto al chequeo después de las actividades del programa. (Adaptado de HINTS 2003)

Usted diría que en el futuro…
☐ Planea hacerse chequeos para detección de cáncer colorrectal.
☐ No planea hacerse chequeos para detección de cáncer colorrectal.
☐ Está indeciso.

Si no planea hacerse el chequeo para detección de cáncer colorrectal, ¿por qué no? _____

Si está indeciso, ¿qué lo motivaría a hacerse el chequeo? _____

Si aún no se ha hecho chequeos para detección de cáncer colorrectal, ¿cuándo cree que se hará una {colonoscopía/FOBT/FIT/sigmoidoscopía flexible}?

☐ De aquí a tres meses

☐ De aquí a seis meses

☐ Dentro de este año

☐ Si tengo síntomas.

☐ Cuando el médico o el proveedor de atención médica lo recomienden.

Si ya se hizo chequeos para detección de cáncer colorrectal, ¿cuándo cree que se hará el próximo?

☐ De acuerdo con el intervalo recomendado

☐ No planeo hacerme otro

☐ Si tengo síntomas

☐ Cuando el médico o el proveedor de atención médica lo recomienden

¿Se comprometea hacerse el chequeo para detección de cáncer colorrectal?

☐ Sí ☐ No

Si la respuesta es no, ¿por qué no?
_____

Platica con la familia, los amigos o el proveedor de atención médica acerca del cáncer colorrectal y el chequeo:
Estas preguntas pueden usarse para evaluar el proceso del programa con el propósito de entender el conocimiento de sus participantes antes de llevar a cabo las actividades. También pueden utilizarse en una evaluación de resultados para evaluar cambios que pudieran haber ocurrido como resultado del programa. (Adaptado de HINTS 2003).

¿Alguna vez un médico, una enfermera u otro profesional de la salud le aconsejaron que se hiciera un chequeo para detección de cáncer colorrectal?
☐ Sí ☐ No ☐ No sabe

Estas preguntas pueden usarse en una evaluación de resultados del programa. Pueden utilizarse antes y después de una encuesta, para entender cualquier cambio que haya ocurrido previamente a las actividades; o en una encuesta, luego de completar las actividades. (Adaptado de la encuesta ¡NOSOTROS PODEMOS! [*WE CAN!*]).

Platicare con mi proveedor de atención médica sobre el chequeo de detección de cáncer colorrectal en el próximo mes.
☐ Sí ☐ No ☐ No sabe

Platicare con mis amigos y familia sobre el chequeo de detección de cáncer colorrectal en el próximo mes.
☐ Sí ☐ No ☐ No sabe

Actitud hacia el chequeo del cáncer colorrectal:
Estas preguntas pueden usarse en una evaluación de resultados para entender cambios en la actitud acerca del chequeo. (Adaptado de HINTS 2005).

¿Está de acuerdo o en desacuerdo con las siguientes afirmaciones?

No es mucho lo que se puede hacer para disminuir las posibilidades de contraer cáncer colorrectal.
☐ Muy de acuerdo ☐ De acuerdo ☐ En desacuerdo ☐ Muy en desacuerdo

Hacerse chequeos para detección de cáncer colorrectal regularmente incrementa las posibilidades de encontrar el cáncer cuando todavía es fácil de tratar.
☐ Muy de acuerdo ☐ De acuerdo ☐ En desacuerdo ☐ Muy en desacuerdo

Hay tantas recomendaciones diferentes sobre la prevención del cáncer colorrectal, que es difícil saber cuáles seguir.
☐ Muy de acuerdo ☐ De acuerdo ☐ En desacuerdo ☐ Muy en desacuerdo

Usted prefiere no hacerse el chequeo de detección de cáncer colorrectal por miedo a tenerlo.
☐ Muy de acuerdo ☐ De acuerdo ☐ En desacuerdo ☐ Muy en desacuerdo

Hacerse chequeos para detección de cáncer colorrectal regularmente incrementa las posibilidades de prevenirlo.
☐ Muy de acuerdo ☐ De acuerdo ☐ En desacuerdo ☐ Muy en desacuerdo

Usted se siente renuente a hacerse el chequeo de detección de cáncer colorrectal debido a la preparación necesaria para el examen.
☐ Muy de acuerdo ☐ De acuerdo ☐ En desacuerdo ☐ Muy en desacuerdo

Usted se siente renuente a hacerse el chequeo de detección de cáncer colorrectal porque el examen es incómodo.
☐ Muy de acuerdo ☐ De acuerdo ☐ En desacuerdo ☐ Muy en desacuerdo

Preguntas sobre el proceso de evaluación

Estas preguntas pueden usarse en un proceso de evaluación para entender cuán bien las actividades están coincidiendo con las necesidades del participante, qué desafíos o barreras se han encontrado y qué cambiaría el grupo de interés acerca de la manera en que se ofrecen los servicios. (Algunas preguntas fueron adaptadas de la Encuesta de Percepciones de la Alianza contra el Cáncer de Colon [*Colon Cancer Alliance Perceptions Survey*]).

¿Qué es lo que más le gustó de la sesión educativa, del folleto, del programa?

¿Qué es lo que menos le gustó de la sesión educativa, del folleto, del programa?

Si hubiera que cambiar algo de la sesión educativa, del folleto, del programa, ¿qué cambiaría?

¿Sintio que la sesión educativa, el folleto y el programa sus necesidades? Explique su respuesta.

¿Incrementó la sesión educativa, el folleto, el programa su conocimiento sobre el cáncer colorrectal? Explique su respuesta.

¿Incrementó la sesión educativa, el folleto, el programa su disposición a hacerse el chequeo para detección de cáncer colorrectal? Explique su respuesta.

Satisfacción (con el programa y/o los materiales del programa)

Estas preguntas pueden usarse en una evaluación para evaluar la satisfacción. (Adaptado de la encuesta ¡NOSOTROS PODEMOS! y de la Encuesta de Experiencia de la Carrera de Trabajador Profesional *[Professional Worker Career Experience Survey]*, Estados Unidos, 2003-2004)

El personal que presentó el programa, ¿Tenía conocimiento acerca del cáncer colorrectal?
☐ Muy de acuerdo ☐ De acuerdo ☐ En desacuerdo ☐ Muy en desacuerdo

La información proporcionada por el programa fue útil.
☐ Muy de acuerdo ☐ De acuerdo ☐ En desacuerdo ☐ Muy en desacuerdo

Los materiales proporcionados por el programa fueron fáciles de entender.
☐ Muy de acuerdo ☐De acuerdo ☐En desacuerdo ☐ Muy en desacuerdo

¿Cuán satisfecho está usted con el programa [materiales/personal/actividades]?

Muy satisfecho	Satisfecho	Ni satisfecho ni insatisfecho	Insatisfecho	Muy insatisfecho
1	2	3	4	5

Preguntas demográficas

(Adaptado de la Encuesta de la Comunidad Estadounidense [*The American Community Survey*] y del BRFSS)

¿Cuál es su sexo?

☐ Masculino ☐ Femenino

¿Cuál es su edad y fecha de nacimiento?

Edad (en años) _____ Mes/Día/Año _____/_____/_____

¿Cuál de las siguientes opciones describe mejor su raza? Elija una.
☐ Sólo blanco
☐ Sólo negro o afroamericano
☐ Sólo asiático
☐ Sólo hawaiano nativo o de otras islas del Pacífico.
☐ Sólo indio americano/nativo de Alaska
☐ Multiracial (dos razas o más)
☐ Otra

¿Es usted de origen hispano, latino, o español?
☐ Sí ☐ No

¿Tiene usted algún tipo de cobertura médica, incluido seguro de salud; planes prepagos como HMO; o del gobierno, como Medicare?
☐ Sí
☐ No
☐ No sabe/No está seguro.

¿Cuál es el grado más alto que obtuvo o nivel escolar que completó? (Adaptado del Censo de Estados Unidos de 2000).
☐ No termino la preparatoria
☐ Termino/se graduo de la preparatoria
☐ Algunos estudios universitarios
☐ Título de Asociado de dos años *(por ejemplo: AA o AS)*
☐ Licenciatura *(por ejemplo: BA, BS)*
☐ Maestría *(por ejemplo: MA, MS, MBA, MPH)*
☐ Título profesional *(por ejemplo : MD, DDS, JD)*
☐ Doctorado *(por ejemplo: PhD, EdD)*

De acuerdo con los siguientes criterios, ¿mayor riesgo de desarrollar cáncer colorrectal? (Adaptado de la Encuesta de Percepciones de la Alianza contra el Cáncer de Colon).
Entre los factores de riesgo del cáncer colorrectal se incluyen los siguientes:
• Antecedentes personales de pólipos o enfermedad inflamatoria intestinal.
• Síndromes hereditarios como poliposis adenomatosa familiar (FAP, por sus siglas en inglés) y cáncer colorrectal no polipósico hereditario (HNPCC, por sus siglas en inglés)
• Antecedentes personales o familiares del cáncer colorrectal
• Factores de estilo de vida, como dieta, falta de ejercicio, obesidad, fumar, consumo excesivo de alcohol o diabetes tipo 2.

☐ Sí ☐ No ☐ No sabe

3.7 Focus group checklist

OVERVIEW: There are a number of logistical and organizational issues to consider when arranging a focus group. This checklist can be used as a starting point for organizing your focus group.

Name of Project:

_____

Brief Purpose of Focus Group:

_____

_____

Date of Focus Group: _____

Number of Participants: _____

Focus group checklist

- ☐ Map and/or address for destination
- ☐ Name and phone number of local contact
- ☐ Gift certificates and signature form
- ☐ Name tags or name tents
- ☐ Recording device, microphone, batteries
- ☐ Laptop
- ☐ Extension cord
- ☐ Interview guide
- ☐ Demographics forms
- ☐ Pencils and doodle pads or paper
- ☐ Sticky dots
- ☐ Flip chart and stand
- ☐ Markers
- ☐ Tape (if flip chart is not self-stick)
- ☐ Legal pad and pens/pencils for recording
- ☐ Food, refreshments (consider dietary restrictions)

3.8 Focus group protocol

OVERVIEW: When conducting a focus group, it is helpful to have your protocol ready in advance, so that you can easily facilitate the group and focus on your key questions. This section provides a sample focus group protocol. It is based on Example 2, the Metropolitan Colon Cancer Collaborative (from the main body of the toolkit). They decided to conduct focus groups with members of their target population, to determine whether their education materials were effective.

At the beginning of the focus group:

As participants enter:
1. There is food available, so please help yourself.
2. The restrooms are located _____.
3. Please turn off your cell phones.
4. Your nametags are on this table, please find your name. <u>OR</u> Please use the labels and markers to make a nametag.
5. Please look at and think about the questions on your seat.

Note: The first part of the scripts will not be read verbatim, but all the concepts will be communicated to the participants.

Introduction:
Thank you for attending today's focus group. We appreciate you taking time out of your day to share your experiences about the colorectal cancer materials provided by the Collaborative. I am [name]. I will be facilitating this focus group. [Name] will be co-facilitating and taking notes. We will also be audio recording this focus group with everyone's permission. Please let us know at this time if this is OK with everyone, keeping in mind that your names will not be associated to anything that is said in the report.

To help us capture the details of the conversation in our notes and the recording, please do not talk over anyone else. Everyone will be given the opportunity to speak and share their views. I will be asking you a number of questions during our discussion, and I encourage you to speak openly about your perspectives and opinions. There is no right or wrong answer to any of the questions I ask.

Purpose and Confidentiality:
We are here today to learn more about the experiences you have with the educational materials provided by the Collaborative. We appreciate your willingness to share your experiences. Anything you share with us will be kept confidential. All responses will be analyzed and the main themes will be included in our report. Again, we will not report anything in a way that will identify any individual.
Do you have any questions?
If there is nothing further, let's begin recording and start our discussion.

Ice Breaker: Please tell me your name, how you learned about the Collaborative, and describe a brochure or other piece of written material that you saw recently that you really liked. [NOTE: This may help you develop insights as to what is eye-catching to readers and what sorts of things stick out in their mind that may help them remember a message.]

We would like for you to take a look at these written materials.

What is your first impression of them?

What do you feel is the main message?

Are the materials understandable? [PROBE: If no, what could make them more easily understandable to you?]

Who do you think these materials are meant for? What about the materials made you believe that is the intended audience?

Does the message motivate you to get screened for colorectal cancer? What kind of messages would motivate you?

Where would be the best place to distribute the materials in order to reach people in your community?

Thank you for your time.

3.9 Protocolo para el grupo de opinión

IDEA GENERAL: Al conducir un grupo de enfoque, resulta útil tener listo el protocolo con anticipación, con el fin de poder dirigir la tarea del grupo y enfocarse en sus preguntas clave. Esta sección proporciona una muestra de protocolo para el grupo de enfoque. Se basa en el Ejemplo 2, Grupo Colaborador Metropolitano para el Cáncer de Colon (*Metropolitan Colon Cancer Collaborative*). Ellos decidieron conducir grupos de enfoque con miembros de la población a la que apuntaban, para determinar si sus materiales educativos eran efectivos.

Al comenzar el grupo de enfoque:

Cuando ingresan los participantes:
6. Hay alimentos a su disposición. Por favor, sírvanse.
7. Los baños están en _____.
8. Sus etiquetas de identificación están en esta mesa; busquen sus nombres.
9. Usen las etiquetas y los marcadores para armar una etiqueta de identificación.
1. Busquen las preguntas que están en su asiento y piensen acerca de ellas.

Nota: La primera parte del texto no se leerá palabra por palabra, pero se transmitirán todos los conceptos a los participantes.

Introducción:
Gracias por asistir al grupo de enfoque de hoy. Les agradecemos que hayan dedicado tiempo de su día para compartir sus experiencias en relación con los materiales sobre **el** cáncer colorrectal proporcionados por el grupo *Collaborative*. Mi nombre es [nombre] y seré el facilitador de este grupo de enfoque. [Nombre] será el co-facilitador y tomará notas.

También grabaremos el audio de este grupo de enfoque con el permiso de todos. Infórmennos ahora si todos están de acuerdo, teniendo en cuenta que sus nombres no serán asociados a nada que se diga en el informe.

Para ayudarnos a capturar los detalles de la conversación en nuestras notas y en la grabación, no hay que hablar sobre otra persona. Todos tendrán la oportunidad de hablar y compartir sus puntos de vista. Les haré una cantidad de preguntas durante la discusión y los animo a que hablen abiertamente sobre sus perspectivas y opiniones. No hay respuesta correcta o incorrecta a las preguntas que yo haga.

Propósito y confidencialidad:
Estamos aquí para conocer algo más sobre sus experiencias con los materiales educativos proporcionados por el grupo *Colaborador*. Les agradecemos su disposición para compartirlas. Todo lo que compartan con nosotros se mantendrá de manera confidencial. Se analizarán todas las respuestas y se incluirán los temas principales en nuestro reporte. Nuevamente, no compartiremos información que pueda identificar a ninguno de ustedes presentes.
¿Tienen alguna preguntas?
Si no hay nada más, damos comienzo a la grabación y a la plática.

Para romper el hielo: Díganme sus nombres y cómo se enteraron del grupo Colaborador y describan un folleto u otra pieza de material escrito que hayan visto recientemente que realmente les gusto/llamo la atención. [NOTA: Esto puede ayudarlo a usted a entender lo qué llama la atención de los lectores y qué tipo de cosas sobresalen en su mente, que los ayuden a recordar un mensaje].

Nos gustaría que miraran estos materiales escritos.

¿Cuál es su primera impresión acerca de ellos?

¿Que piensan que es el mensaje principal?

¿Son comprensibles los materiales? [SONDEO: Si no lo son, ¿qué los haría más comprensibles para ustedes?]

¿Quién piensan ustedes que es la audiencia objetivo? ¿Qué parte de los materiales les hicieron pensar que es la audiencia objetiva?

¿Consideran que el mensaje los motiva para hacerse el chequeo de detección de cáncer colorrectal? ¿Qué tipo de mensajes los motivarían?

¿Cuál sería el mejor lugar para distribuir los materiales para llegar a las personas de su comunidad?

Gracias por su tiempo

3.10 Case study questions

Impact of a program

▶ How did you hear about the education program?

▶ Have you made any changes to your health behaviors since working with the program? If so, what changes have you made? [PROBE: dietary changes, increased physical activity, regular medical appointments, etc.]

▶ What was most beneficial about the education classes you attended through the program?

▶ Was there information or support you needed that you did not get from the program? If yes, what else did you need?

▶ In what ways has the program helped you to be healthier? What were the most important lessons you learned through the program/staff? [PROBE: intention to get screened, etc.]

Development and implementation of a program

▶ What was the purpose of the program? What need(s) did it seek to address?

▶ What strategies or activities were included in the program?

▶ Who was(were) the population(s) that the program was trying to reach through this program? Was the program successful in reaching these population(s)? Why or why not?

▶ How did the program address the needs of patients representing diverse and/or specific populations? (e.g.. populations based on race or ethnicity, socioeconomic status, language, religion, gender identity or sexual orientation, age, or disability status)

▶ What worked well in implementing the program? What strategies or activities did you find most effective?

▶ What challenges did you encounter in implementing the program? How did you deal with any challenges you encountered? What, if anything, would you do differently?

▶ How would you describe the impact of the program? OR: What would you describe as the outcomes for the program? How did you know if you were successful in achieving these outcomes?

▶ What would you have needed for the program to be more effective?

Would you recommend this program for other health care clinics? Why or why not?

3.11 Common layperson definitions of screening tests

OVERVIEW: In creating your evaluation materials, you may need to refer to specific colorectal cancer screening tests. Some of your evaluation participants may not be familiar with these tests, however. In writing your questions, it is advisable to provide layperson definitions, rather than rely on technical definitions. This section provides layperson definitions of common screening tests. These definitions can be used as you create survey, interview, or focus group questions.

Colorectal cancer

Colon or rectal cancer. Since colon cancer and rectal cancer have many features in common, they are often referred to together as colorectal cancer.

Colorectal cancer screening

Testing done to find abnormalities early, before signs and symptoms start. This allows for earlier detection of cancer, when it is most curable. Some types of screening allow doctors to find and remove polyps, which can prevent cancer from developing. See also colonoscopy, fecal occult blood test, fecal immunochemical test, sigmoidoscopy, barium enema, DNA stool test, CT colonography (for virtual colonoscopy) and polyp.

Colonoscopy

A procedure that allows a doctor to see inside the large intestine to find polyps or cancer.

Fecal occult blood test (also referred to as FOBT or gFOBT)

A test for "hidden" blood in the feces (stool). The presence of such blood could be a sign of cancer or blood from other sources.

Fecal immunochemical test (also referred to as FIT or iFOBT)

A newer test to look for "hidden" blood in the stool, which could be a sign of cancer. The test is not affected by vitamins or foods, though it still requires 2 or 3 specimens.

Sigmoidoscopy (also referred to as flexible sigmoidoscopy)

A procedure in which a doctor can look into the rectum and the descending portion of the colon for polyps or other abnormalities.

Barium enema (also referred to as double-contrast barium enema)

A method used to help diagnose colorectal cancer. Barium sulfate, a chalky substance, is used to enlarge and partly fill the colon (large intestine). When the colon is about half-full of barium, air is pushed in to cause the colon to expand further. This allows good x-ray films to be taken. Also called a double-contrast barium enema.

CT colonography (for virtual colonoscopy)

Examination of the colon for polyps or masses using special computerized tomography (CT scans). The images are combined by a computer to make a 3-D model of the colon, which doctors can "fly-through" on a computer screen.

DNA stool test

A method to detect abnormal DNA in cells that rub off from colorectal cancers and come out in the stool.

Polyp

A growth from a mucous membrane commonly found in organs such as the rectum. Polyps may be non-cancerous (benign) or cancerous (malignant).

Reference: American Cancer Society—Cancer Glossary.
http://www.cancer.org/Cancer/CancerGlossary/index

3.12 Definiciones de los exámenes de chequeo para legos

IDEA GENERAL: Al crear los materiales de evaluación, puede ser necesario referirse a exámenes de chequeo para detección de cáncer colorrectal específicos. Sin embargo, algunos de los participantes de la evaluación pueden no estar familiarizados con estos exámenes. Es aconsejable que, al escribir sus preguntas, proporcione definiciones para legos en lugar de utilizar definiciones técnicas. Esta sección proporciona definiciones de ese tipo referidas a exámenes de chequeo comunes. Dichas definiciones pueden usarse al crear las preguntas para la encuesta, la entrevista o el grupo de opinión.

Cáncer colorrectal

Cáncer de colon o recto. Como el cáncer de colon y el rectal tienen muchas características en común, suele hacerse referencia a ellos como cáncer colorrectal.

Chequeo para detección de cáncer colorrectal

Exámenes que se realizan para detectar anomalías tempranamente, antes de que comiencen los signos y síntomas. Esto permite una detección temprana del cáncer, cuando es mayormente curable. Algunos tipos de chequeos permiten a los médicos encontrar y quitar pólipos, lo cual puede evitar que se desarrolle el cáncer. Ver también colonoscopía, examen de sangre oculta en materia fecal, examen inmunoquímico fecal, sigmoidcoscopía, enema de bario, examen de ADN en materia fecal, colonografía por CT (para colonoscopía virtual) y pólipo.

Colonoscopía

Procedimiento que permite a un médico ver dentro del intestino grueso para detectar pólipos o cáncer.

Examen de sangre oculta en materia fecal (también conocido como FOBT o gFOBT)

Examen para detectar sangre "oculta" en las heces (materia fecal). La presencia de sangre podría ser un signo de cáncer o de que proviene de otro lado.

Examen inmunoquímico fecal (también conocido como FIT o iFOBT)

Un nuevo examen para buscar sangre "oculta" en materia fecal, que podría ser un signo de cáncer. Si bien, el examen no se ve afectado por vitaminas o alimentos,se requieren dos o tres muestras.

Sigmoidoscopía (también conocida como sigmoidoscopía flexible)

Procedimiento en el cual un médico puede mirar dentro del recto y la parte inferior del colon para detectar pólipos u otras anomalías.

Enema de bario (también conocido como enema de bario de doble contraste)

Método usado para ayudar a diagnosticar el cáncer colorrectal. Se usa el sulfato de bario, una sustancia caliza, para agrandar y llenar parcialmente el colon (intestino grueso). Cuando aproximadamente la mitad del colon está llena de bario, se introduce aire para que aquél se expanda más, lo cual permite que se puedan tomar buenas radiografías. También se lo denomina "enema de bario de doble contraste".

Colonografía por CT (para colonoscopía virtual)

Examen del colon para detectar pólipos o masas mediante el uso de tomografía computada especial (escaneos CT). Las imágenes son combinadas por una computadora para hacer un modelo 3D del colon, de modo que los médicos pueden observar una vista tridimensional en una pantalla de computadora.

Examen de ADN en materia fecal

Método para detectar ADN anormal en células que provienen del cáncer colorrectal y se eliminan por la materia fecal.

Pólipo

Crecimiento de una mucosa que se encuentra comúnmente en órganos como el recto. Los pólipos pueden ser no cancerosos (benignos) o cancerosos (malignos).

Referencia: Sociedad Estadounidense contra el Cáncer (*American Cancer Society*). Glosario del cáncer (en inglés): http://www.cancer.org/Cancer/CancerGlossary/index

Note of translator: an url for references in Spanish could be http://www.cancer.org/espanol/cancer/colonyrecto/guiadetallada/index

3.13 Links of Care Sample Tools

> **OVERVIEW:** The following resources were developed by the National Colorectal Cancer Roundtable (NCCRT) as part of the Links of Care pilot project. Links of Care provided funding and technical assistance to community health centers to improve colorectal cancer screening and follow up care for uninsured and underinsured patients by strengthening relationships within the surrounding medical neighborhood.

In 2012, the Health Resources Service Administration began requiring Federally Qualified Health Centers (FQHCs) to measure and report colorectal cancer screening rates. FQHCs were concerned about securing follow up care for patients with an abnormal diagnosis, as follow-up services are often prohibitively expensive for low-income, uninsured patients.

To address this challenge, the American Cancer Society, the Centers for Disease Control and Prevention, and the NCCRT implemented the Links of Care pilot program to promote collaboration between FQHCs serving low-income patients and specialty providers to secure diagnostic services. Goals were to increase timely access to specialists after an abnormal screening, implement evidence-based strategies to increase colorectal cancer screening rates, and assess project implementation. Three FQHCs in geographically diverse locations participated in the pilot from 2015 to the present.

As a part the Links of Care evaluation, each pilot community completed the following:

- Conducted a community assessment consisting of both stakeholder interviews and a partner survey

- Tracked clinical measures through quarterly reporting of select outcome measures

- Assisted with in-depth stakeholder interviews, in which pilot leaders, navigators and GI/hospital partners were interviewed to evaluate the project processes

In this section, you'll find:

- An interview protocol and survey, adapted from the community assessment conducted as part of the Links of Care initiative. The purpose of the community assessment was to gather input from community stakeholders about how communities can improve access to specialty care in the delivery of colorectal cancer screening.

- The sample quarterly tracking form used by the Links of Care pilot clinics. The quarterly tracking form sought to collect clinical information on outcome measures

related to colorectal cancer screening rates and other clinical measures on which the pilot project hoped to see progress.

- A sample interview guide. The interview guide was one of four guides developed for a process evaluation of the program through in-depth interviews with FQHC leaders, navigators, hospital/GI partners, and ACS staff.

- You can also view a summary of one pilot's initial community assessment findings here and a poster abstract summarizing the pilot's progress after Year 3 here.

You can use and adapt these tools for your own program. The presentations of findings might give you ideas for how you might report results from your evaluation to key stakeholders.

Stakeholder Interview Protocol from the Initial Community Assessment

Introduction:

Thank you taking the time to speak with me about with about how to improve colorectal cancer screening and follow-up care for patients. Today we will be talking about the patient population served by your clinic or organization, how clinics and organizations are working together in your community to increase colorectal cancer screening rates, and the goals of your colorectal cancer screening efforts. Information from these interviews will be used to better understand what needs to be done to improve access to specialty care in the delivery of colorectal cancer screening.

Our interview should take approximately 30 minutes to complete. I will be recording this interview, and the interview will be transcribed. I am also going to take notes throughout the interview for reference later. Your responses will be kept confidential, and your name and any other personal information will be deleted after the interview. The recording of the interview will be stored for one year until the end of the Links of Care program. Your participation is completely voluntary, so if you wish, you may stop at any time.

At this time, do you agree to participate in this Links of Care interview? [*Yes/No*]

Do I have permission from you to record the interview and to take notes by hand? [*Yes/No*]

If you would like a written copy of this agreement for your records, please let me know and I will [*give you a copy now; email, mail, or fax it to you, etc.*].

Do you have any other questions before we begin?

Please briefly tell me your role at the clinic or organization.

Overview of Patient Needs & Resources for Colorectal Cancer Screening

First I'd like to learn a little bit about the patient population for this program.

What can you tell me about the patients who are uninsured or underinsured and typically access care through your clinic or organization?
    2.1 Probe as needed: language, geography, culture, attitude toward health care, no-show rates
    2.2 Probe: Is there anything that is unique or particularly challenging about serving the uninsured/underinsured community in your area?

What types of resources are currently available for people in your community who do not have insurance and need to be screened for colorectal cancer or secure needed follow-up care?
    Probe: Which clinics or health systems are providing most of the colorectal cancer-related care for the uninsured?
    Probe: How easy or difficult is it for uninsured patients to access these systems of care?

If an uninsured or underinsured patient needs a colonoscopy either as the initial screening exam or as a follow up to a positive stool blood test, what are the current barriers to care?

> Probe: If a patient receives a colorectal cancer diagnosis, what challenges would he/she face in obtaining follow up care?
>
> Probe: Are there certain components of screening or follow-up care that are harder to secure than others? If so, which ones? (Probe as needed: endoscopy, pathology, anesthesia, back-up surgery, radiology, hospital facilities, oncology)
>
> Probe: What do you think contributes to the difficulty in securing those services?

In an ideal situation, how would these barriers be overcome?

Partnering to Improve Access to Specialty Care

To what extent have members of your medical community previously attempted to improve colorectal cancer screening in your area—either among the insured or uninsured populations?

Have any of these efforts focused on increasing colorectal cancer screening among the underinsured and uninsured? What about efforts to improve access to specialty providers?

> Probe: What can other clinics or organizations learn from the successes or challenges of past efforts?
>
> Probe: Have there been any local efforts to raise funds or obtain grants to support colorectal cancer screening, provide follow-up care, or otherwise assist the underinsured? What was the outcome? Who was involved?

To what extent is there ongoing dialog or communication among health care providers in your community about the need to improve colorectal cancer screening and access to follow-up care?

In your opinion, how willing are health care providers in your community to partner with each other to jointly address colorectal cancer screening needs, such as improving access to follow-up care?
Probe: Do you have any recommendations on ways to increase the interest and engagement in collaborating among your professional colleagues/other specialists?

Which organizations do you think are best equipped or prepared to take the steps needed to make the biggest impact on this issue in your community?

Are there any other organizations you would like to see get involved in meeting this need?
[Probe: specific clinics, hospitals, faith-based, city/county agencies]

> Probe: How would you suggest engaging potential partners on this issue?
>
> Probe: What do you think would motivate an organization to commit time and resources toward addressing this need?
>
> Probe: What do you think would motivate colleagues from your profession to commit time and resources toward addressing this need?

Goals and Evaluation of Progress

If you were going to prioritize three specific actions that your organization, colleagues from your profession, or others could do to make the most progress toward increasing colorectal cancer screening for the uninsured in your community, including access to specialty care, what would those three things be?

    Probe: What kinds of resources or other support are needed to make those things happen?
    Probe: How likely is it that your organization/colleagues from your profession will be able to do these things in the near future?

If we talked again a year from now, what would you hope the program would have accomplished?

What about two years from now? What specific outcomes would you want to see for the patients in your community? How would you measure success?

Based on what you know about the pilot project, do you expect that it will be able to overcome the barriers we talked about today? Why or why not?

Summary and Wrap-Up

Many national medical professional societies are also supporting efforts to increase colorectal cancer screening rates. Do you have any suggestions for how they can work with your clinic or organization to best address this issue?

Thank the respondent for participating, and review if any follow up will take place.

Stakeholder Survey from the Initial Community Assessment

[Clinic or organization] is working to improve access to colorectal cancer screening and follow-up care and is seeking input from knowledgeable members of the community to better understand the needs of uninsured and underinsured patients.

Please take a few minutes to complete this simple survey to help [clinic or organization] gain insight from community stakeholders.

Results from the survey will be aggregated and your name will not be tied to any comments you provide.

1. Which of the following best describes your role? (Check all that apply.)
   Primary care provider (physician, RN, PA, NP, etc.)
   Specialty care provider (GI, oncologist, pathologist, etc.)
   Administrator/manager in clinical setting
   Administrator/manager in non-clinical setting
   Patient liaison (e.g., navigator, case manager, referral coordinator)
   Community member/leader
   Other (please specify):_____

2. Please rate easy or difficult it is for uninsured/underinsured patients to get the following types of services.

	Very difficult	Somewhat difficult	Somewhat easy	Very easy	I don't know
A colonoscopy for screening purposes					
A colonoscopy for diagnostic purposes					
Follow-up treatment (e.g., surgery, chemotherapy) after a colorectal cancer diagnosis					

3. Do you see differences in the level of access to colorectal cancer screening and follow-up care between uninsured, underinsured, and Medicaid patients in this community?
   Yes
   No
   I don't know
   If yes, please describe what differences you have seen.

   _____
   _____
   _____

4. Below is a list of possible barriers to delivering colorectal cancer screening to uninsured and underinsured patients in your community. Please rate how much of a challenge these barriers are from your own perspective.

	Not a challenge	A little bit of a challenge	Somewhat of a challenge	A major challenge	I don't know
Patient Related Barriers					
Patient language barriers					
Patient cultural barriers					
Poor patient prep for the colonoscopy					
Poor patient adherence to scheduled appointments					
Patients' fear of screening					
Patients' fear of a cancer diagnosis					
Poor patient understanding of the importance of colorectal cancer screening					
Cost of screening					
Cost of additional services related to screening (e.g., prep, primary care visits, pre-procedure visits with colonoscopists, transportation)					
Cost of follow-up care					
Patients' fear of incurring medical expenses, even when assured that their care will be covered					
Patients' lack of access to primary care					
Inability to set aside time for screening due to work, child care, or other commitments					
Primary Care System Related Barriers					
Colorectal cancer screening is not a priority for uninsured or underinsured patients					
Primary care providers do not offer colorectal cancer screening to uninsured patients					
Lack of reminder systems for colorectal cancer screening					
Sub-optimal utilization of fecal occult blood tests/fecal immunochemical tests by primary care system as effective alternatives to screening colonoscopy					

	Not a challenge	A little bit of a challenge	Somewhat of a challenge	A major challenge	I don't know
Lack of navigation staff to assist patients with prep					
Lack of an appointment reminder system					
Lack of access to diagnostic colonoscopies					
Primary Care System Related Barriers					
Lack of no-cost/low-cost facilities where colonoscopies can be provided					
Lack of access to colorectal cancer treatment					
Lack of awareness of existing sites that provide no cost/low cost screening/treatment in the community					
Too few specialists willing to donate their time					
Too few specialists willing to accept lower reimbursements					
Lack of local leadership/ownership of colorectal cancer screening issues					
Limited/no care coordination for community health center patients					
Absence of dialogue and cooperation or colorectal cancer screening issues among the clinical community					

5. From your perspective, what is the biggest challenge in delivering follow-up services (e.g., a colonoscopy) after a positive cancer screening test (FOBT or IFOB/FIT) to those in an underserved setting? What, if any, suggestions do you have for addressing that challenge?

6. From your perspective, what is the biggest challenge to delivering follow-up services (e.g., surgery, chemotherapy) after a positive cancer diagnosis to those in an underserved setting? What, if any, suggestions do you have for addressing that challenge?

7. What other challenges that are not listed here make it difficult for the uninsured/underinsured to access colorectal cancer screening and follow-up care? What, if any, suggestions do you have for addressing these challenges?

8. To help address the needs of the uninsured, specialty care providers in some communities have been asked to volunteer their time or accept lower reimbursements. Please indicate how likely it is that providers would do so your community.

How likely is it that specialty care providers in your community will…	Very unlikely	Somewhat unlikely	Somewhat likely	Very likely	I don't know
volunteer their time for community health center patients needing colorectal cancer screening and/or follow-up care?					
accept lower reimbursements for community health center patients needing colorectal cancer screening and/or follow-up care?					

9. Which organizations in your community do you feel are important to collaborate with to positively impact colorectal cancer screening issues? Please consider any organizations that have influence on those likely to be seen in a community health center, including health care providers, local government, social service providers, community organizations, and the faith community.

_____
_____
_____

Thank you!

Links of Care Pilots Quarterly Tracking Form

Project Name:
Organization Name/Location (City or County and State):
Lead Organization Staff Completing the form (Name/Title):
Reporting Period: □ Quarter 1   □Quarter 2   □Quarter 3   □Final Report

Baseline Information	
Baseline Number Eligible Patients for CRC Screening *(Definition: number of patients at average risk between age 50 through 75, excluding patients who have or who have had colorectal cancer or who are undergoing end of life care.)*	
Baseline Clinic Total CRC Screening Number *(Definition: total CRC screening includes number patients who have had a) colonoscopy conducted during the reporting year or previous 9 years; OR b) flexible sigmoidoscopy during reporting year or previous 4 years: OR Guaiac-based fecal occult blood test (gFOBT) or fecal immunochemical test (FIT) during the reporting year.)*	
FIT/FOBT *(Definition: if possible to distinguish number patients who have had a FIT/FOBT as their colorectal cancer screening, report here)*	
Screening Colonoscopy *(Definition: if possible to distinguish number patients who have had a screening colonoscopy as their colorectal cancer screening, report here)*	
Baseline Clinic CRC screening Rate *(Definition: number of patients screened through any type of screening test divided by the number of eligible patients for CRC screening).*	
Baseline Average Time (Number Days) from Positive/Abnormal FIT/FOBT to Follow-up Colonoscopy	

Challenges to Data Capture

Report any challenges to data capture or reporting

Colorectal Cancer Screening Rate Progress

	Target	Q1	Q2	Q3	Q4	Cumulative
Quarterly CRC Screening Rate *(i.e. Target 50%, Q1 24%, Q2 43%, Q3 50%, Q4 58% of total eligible screened population).*						N/A

Colonoscopy-based Screening Programs

	Target	Q1	Q2	Q3	Q4	Cumulative
Number of referrals for screening colonoscopies						
Number of screening colonoscopies completed						
Average total time (number days) from initial referral from provider to completion of screening colonoscopy						
Number of patients with adenomas detected during screening colonoscopy						
Percentage of patients with adenomas detected during colonoscopy *(Number of patients with adenomas detected divided by number of patients receiving a screening colonoscopy)*						
Number of colon or rectal cancers diagnosed						
Average total time (number days) from initial referral to completion of first visit with specialty provider upon cancer diagnosis						

Challenges to Data Capture

Report any challenges to data capture or reporting

FIT/FOBT-based Screening Programs

	Target	Q1	Q2	Q3	Q4	Cumulative
Number of FIT/FOBT kits distributed						
Number of FIT/FOBT tests returned						
Number of abnormal/positive FIT/FOBT						
Number of referrals for follow up colonoscopies after positive FIT/FOBT						
Number of follow up colonoscopies completed after positive FIT/FOBT						
Average total time (number days) from initial referral to completed follow-up colonoscopies after positive FIT/FOBT						
Number of patients with adenomas detected during follow-up colonoscopy for abnormal FIT/FOBT						
Percentage of patients with adenomas detected during colonoscopy after positive FIT/FOB *(Number of patients with adenomas detected divided by the number of patients receiving a follow-up colonoscopy)*						
Number of colon or rectal cancers diagnosed after follow-up colonoscopy for abnormal FIT/FOBT						
Average total time (number of days) from initial referral to completion of appointment with specialty providers upon cancer diagnosis after positive FIT/FOBT						
Challenges to Data Capture *Report any challenges to data capture or reporting*						

Optional

	Target	Q1	Q2	Q3	Q4	Cumulative
Number of colonoscopy reports received from gastroenterologists (or other endoscopists) following a colonoscopy referral						
Number of pathology reports received after biopsies done or adenomas/polyps are removed						
Challenges to Data Capture *Report any challenges to data capture or reporting*						

Stakeholder Interview Guide from the Process Evaluation of Links of Care Program

Introduction

Thank you again for agreeing to participate in this site visit. From these interviews we are hoping to learn more about what [*name of health system*] has done as part of the Links of Care program so far—how the implementation process worked, how partnerships were formed, as well as main challenges and successes of the program. I'll be asking for your perspective about the Links of Care program, the collaborative partnership, and observations you have made regarding the overall program.

Since this is a pilot project, we are trying to find out as much as possible about how our partners are implementing their Links of Care programs. We are hoping to share lessons learned among all our FQHC partners.

Our interview should take approximately 30 minutes to complete. I will be recording this interview, and the interview will be transcribed. I am also going to take notes throughout the interview for reference later. Your responses will be kept confidential, and your name and any other personal information will be deleted after the interview. The recording of the interview will be stored for one year until the end of the Links of Care program. Your participation is completely voluntary, so if you wish, you may stop at any time.

At this time, do you agree to participate in this Links of Care interview? [*Yes/No*]

Do I have permission from you to record the interview and to take notes by hand? [*Yes/No*]

If you would like a written copy of this agreement for your records, please let me know and I will [*give you a copy now; email, mail, or fax it to you, etc.*].

Do you have any other questions before we begin?

Partnering with the FQHC

1. Please describe the process of forming the partnership(s) for the Links of Care program with the FQHC.
   1.1. Probe: Who were the key stakeholders/staff involved in forming the partnership?
   1.2. Probe: How long did it take to reach a formal agreement?
   1.3. Probe: What was your relationship with the FQHC prior to the Links of Care program?
   1.4. Probe: What were the barriers to forming this collaboration?
   1.5. Probe: What was the role of ACS staff in supporting the development of the collaboration?

2. What specific services are you/your hospital providing to your FQHC partner for the Links project?
   2.1. Probe: Are you providing free colonoscopies? Reduced cost? How many per month?

3. How did you decide what services you would provide for the Links of Care program?
   3.1. Have the services you provide changed over time? If so, why?

4. Please describe the referral process for the FQHC patients.
   4.1. Probe: Have you had to change this process at all during the project period?

5. What were some of the aspects that motivated you to collaborate on the Links of Care program?
   5.1. Probe: Hospital community benefit, getting more paying patients referred by FQHC?

6. What were some of the internal challenges for you/your group to be able to provide services for this project?
   6.1. Probe: Staff time/resources? Cost?

7. How has the collaboration with the FQHC changed over time?
   7.1. Probe: What factors influenced any change in the collaboration?

EHR

8. Describe how you are using your EHR to track, analyze, and report data for the FQHC-referred patients.
   8.1. Probe: How are results from colonoscopies provided back to the FQHC? How long does it take for results to be provided back?
      8.1.1. Probe: What challenges have you experienced in using your EHR for this project? Other reporting software? (interfacing with partners' EHR or scheduling systems, other population management software)
      8.1.2. Probe: Describe any outside data sources you used as part of this project (to set baselines, assess progress).

Follow-up Care

9. Describe how you work with patients who need of follow-up care/treatment.
   9.1. Probe: Who is responsible for paying for these patients?
   9.2. Probe: What is the process for ensuring ongoing care/treatment?

Implementation

10. Did you pilot test any of your new referral processes through the use of QI processes such as PDSA prior to full implementation? Why or why not? Was it helpful?

11. How prepared has your provider team been to implement the project in terms of having all the resources, materials, or information you needed?
    11.1. Probe: What resources/materials have been particularly useful in implementing the project?
    11.2. Probe: How easy or difficult has it been to integrate the process into your existing workflow?
    11.3. Probe: To what extent has the Links of Care program been prioritized by your FQHC system?
       11.3.1. Probe: What have been (or currently are) the competing priorities that have affected implementation?

Training

12. What types of training were required to help prepare your FQHC for the Links of Care program?
    12.1.1. Probe: How helpful were these trainings?

Staff Involvement

13. Describe the roles and influence of other key project staff who have been working on Links of Care program implementation.
    13.1. Probe: Who are the champions appointed to facilitate implementation of the Links of Care program? How has(have) the champion(s) affected implementation?
    13.2. Probe: Were any incentives or rewards offered to staff as part of the project? (e.g. awards for reaching goals, performance reviews, promotions, increased respect among peers)? If so, please describe.

14. Do you have a QI team that meets regularly to implement new initiatives? How have they been involved in the Links of Care program?

15. Have you provided feedback on performance and progress toward project goals to staff (and if so, how/when)? What staff in particular have been part of performance feedback?

Patient Barriers

16. Please describe any barriers your patients have experienced with the colorectal cancer screening and follow-up referral process (e.g., transportation, co-pays, billing, colonoscopy prep).
    16.1. Probe: How did you assist patients in overcoming these barriers?

Environment

17. Has the Links of Care program been affected by any external policies such as local or state laws and practices, or FQHC accreditation policies?

18. Is your system involved in any new state-level colorectal cancer initiatives as a result of participation in the Links of Care program?
    18.1. Probe: Are you involved in a state colorectal cancer roundtable?
    18.2. Probe: Do you collaborate with other organizations for additional colorectal cancer initiatives or activities?

Sustainability, Facilitators, Barriers
19. Please describe how you feel about the sustainability of any changes you've made through Links of Care. Are these changes something that can or will continue without funding and/or ACS support?
    19.1. Probe: What are ways your program or interventions could be made more sustainable?

20. Other than what we have already discussed, were there any other key factors which served as barriers to the implementation of the Links of Care program? (Please explain.)

21. Other than what we have already discussed, were there any other key factors which facilitated the implementation of the Links of Care program? (Please explain.)

22. Is there anything else we should know or ask to fully understand your Links of Care program?

3.14 Collaboration Assessment Resource: Wilder Collaboration Factors Inventory

OVERVIEW: Designing and implementing PSE changes can often encompass many stakeholders and partners who are working together in a group, network, or formal coalition. The Wilder Collaboration Factors Inventory is designed to help groups, networks, and coalitions assess the effectiveness of their collaboration and identify areas for improvement.

The tool can be used by groups, networks, or coalitions to help assess the effectiveness of their collaboration on 20 research-tested factors, which include elements such having: shared goals and values, clear decision-making processes, effective communication strategies, a diverse representation of stakeholders and partners, and sufficient resources. An overview of the tool can be accessed by clicking here.

Organizations are free to use the inventory for noncommercial use with the following citation: Mattessich, P., Murray-Close, M., & Monsey, B. (2001). Wilder Collaboration Factors Inventory. St. Paul, MN: Wilder Research.

HOW IS THE TOOL USED?

Collaborative partners rank statements related to each of the collaboration factors on a five-point scale that ranges from "strongly disagree" to "strongly agree." When all of the collaborative partners have completed their inventory, scores for each factor are averaged, which gives an overall rating for each success factor. Here is an example from the tool measuring whether a collaborative group has a strong representation of stakeholders:

Factor	Statement	Strongly agree	Agree	Neutral, No opinion	Agree	Strongly agree
Appropriate cross section of members	The people involved in our collaboration represent a cross section of those who have a stake in what we are trying to accomplish. All the organizations that we need to be members of this collaborative group have become members of the group.	1	2	3	4	5
Favorable political and social climate	The political and social climate seems to be "right" for starting a collaborative project like this one.	1	2	3	4	5

Factor	Statement	Strongly agree	Agree	Neutral, No opinion	Agree	Strongly agree
	The time is right for this collaborative project.					
Concrete, attainable goals and objectives	I have a clear understanding of what our collaboration is trying to accomplish. People in our collaborative group have established reasonable goals.	1	2	3	4	5

The inventory can be taken as a group during a meeting or completed individually. If completed individually, it takes about 15 minutes. The score can be tallied manually or online. To access the online version of the inventory, click here. You may also download a paper copy of the inventory by clicking here.

HOW IS THE TOOL USEFUL TO PSE WORK?

When PSE change, particularly large scale change, is being planned, designed, and implemented, it is important to have in place a group or coalition to help guide and support the work. The inventory could be helpful to a collaborative group as it is starting its work or during key phases of a project to check-in with partners and make adjustments to the way the collaborative is organized and operating. The inventory could also be used at the end of a collaborative process to gauge how partners felt about the effectiveness of their work.

Collaborative groups can use the summary report of data from the inventory to inform discussions about how to build on the strengths of the group and opportunities for improvement. Here is an example of a summary report of data from the collaboration inventory:

Factor	Group score
Appropriate cross section of members	3.2
Favorable political and social climate	4.6
Concrete, attainable goals and objectives	4.2

In this example, this collaborative group may consider how to build on the favorable political and social climate to advance its work, and also review its membership to make sure that all stakeholders who should be at the table are represented.

3.15 Evaluating CRC Screening Patient Navigation Programs: Resources and sample tools

OVERVIEW: The following resources were developed by the Colorado Colorectal Screening Program (CCSP) in coordination with the University of Colorado Cancer Center. These resources provide guidance and sample tools for evaluating CRC screening patient navigation programs.

RESOURCES ON EVALUATING PATIENT NAVIGATION PROGRAMS:

While many partners are interested in evaluating CRC screening patient navigation programs, an in-depth explanation of evaluating such a program is beyond the scope of this toolkit. Having said that, excellent resources exist that provide guidance on evaluating screening navigation programs. The list below offers an excellent start. Note that the *Paying for Colorectal Cancer Screening Patient Navigation Toolkit* has an entire chapter on cost analysis, which can offer a new dimension in program evaluation not covered in this 101 toolkit:

New Hampshire Colorectal Cancer Screening Program Patient Navigation Model Replication Manual

Paying for Colorectal Cancer Screening Patient Navigation Toolkit: Strategies for Payment and Sustainability

Supplement: National Patient Navigation Leadership Summit (NPNLS): Measuring the Impact and Potential of Patient Navigation, Supplement to Cancer

Sample Tools for Evaluating Patient Navigation Programs:

The following resources were developed by the Colorado Colorectal Screening Program (CCSP) in coordination with the University of Colorado Cancer Center. The CCSP funds a screening navigation program and works with various navigators around the state to regularly evaluate efforts.

Background:

The CCSP is focused on restoring endoscopic screening throughout Colorado. It partners with federally qualified health centers, rural health clinics and critical access hospitals, and other safety net clinics to provide no cost patient navigation services for colorectal screening to the medically underserved.

CCSP, in coordination with the University of Colorado Cancer Center, has partnerships with more than 50 Colorado safety net clinics and hospitals. These participating clinics offer no-cost patient navigation services to those who qualify. The program supports comprehensive cancer screening, including navigating those who test positive from high sensitivity fecal occult blood testing (FOBT/FIT) and fosters partnerships with other chronic disease prevention programs to enhance whole-person care and comprehensive navigation services.

As a part the evaluation of the screening navigation program, each participating clinic:

- Regularly tracks and reports on a series of outcome measures and

- Assesses patient satisfaction with the program.

In this section, you'll find:

- A list of measures tracked for patients screened after working with program navigators.

- A sample patient satisfaction survey, in both English and Spanish.

These tools can be used or adapted for your own program.

Sample Evaluation Data Collection Form
Adapted from the Colorado Colorectal Screening Program

Gender
Male: _____ Female: _____

Age of Patient
<50:_____ 50-64:_____ 65+:_____

Race/Ethnicity
African American: _____
Asian: _____
Hispanic: _____
White: _____
If other, please specify: _____

Payer Source
Medicaid: _____ Medicare: _____ Private Insurance: _____ Uninsured: _____

Screen Reason
Surveillance: _____ Symptomatic: _____ Follow-up to FIT/FOBT: _____
Screening Only (Asymptomatic): _____

Family History
No Known Family History: _____
First Degree History of Adenomatous Polyps: _____
First Degree History of Colon Cancer: _____
Scheduled Screen Date: _____

Appointment Attendance (mark only one)
Appointment Kept: _____
Appointment Not Kept: _____

Prep Quality
Adequate: _____ Not adequate: _____ Not reported: _____

Cecum Reached
Yes: _____ No: _____ Not reported: _____

Screen Outcome
Client with adenoma removed: _____
Client with cancer detected: _____

Referrals
Referred to: _____
Referred to CCSP from: _____

Sample Patient Satisfaction Survey
Adapted from the Colorado Colorectal Screening Program

This survey is to see how well Patient Navigators are helping clinic patient populations with the colorectal cancer screening process of a colonoscopy. You may have received help from a Patient Navigator during your colorectal cancer screening process. A Patient Navigator could have been any clinic staff member who assisted with any of these steps:

- Education of prep for colonoscopy
- Setting appointments
- Providing a person to call for any questions you may have had or if you were diagnosed with cancer

- Reminders for appointments
- Finding transportation
- Finding someone to go with you to the appointment

1) How did you get in contact with the Patient Navigator for Colorectal Cancer Screening?

      I received a brochure in the mail
      My doctor told me about it
      Someone at the clinic called me
      I saw a TV/ radio/ newspaper ad
      Other _____

2) How useful was Patient Navigator with assisting in the following associated with Colorectal Cancer screening?

Please circle one:

	Excellent	Good	Okay	Fair	Poor	N/A
a) Explaining about Colorectal Cancer Prevention	5	4	3	2	1	0
b) Explaining the need for Colorectal Cancer screening	5	4	3	2	1	0
c) Scheduling your screening appointment	5	4	3	2	1	0
d) Explaining the screening procedure	5	4	3	2	1	0
e) Helping you prepare for the screening procedure	5	4	3	2	1	0
f) Understanding the importance of preparing	5	4	3	2	1	0
g) Finding someone for supportive care after exam	5	4	3	2	1	0
h) Who to contact if diagnosed with cancer or adverse effect	5	4	3	2	1	0

3) Did you have problems with any of the following while getting your colorectal cancer screen (colonoscopy)?

a) Finding transportation to and from your screening appointment	Yes	No
b) Getting time off from work for your screening appointment	Yes	No
c) Being able to pay for the screening procedure	Yes	No
d) Waiting a long time for your screening appointment	Yes	No
e) Finding someone to go to your appointment with you	Yes	No

4) What did the Patient Navigators do to help with the issues above?

_____

_____

5) Were the results of your screening exam given to you in an acceptable amount of time?   Yes   No   Don't know

6) Did the Patient Navigator contact you to help you understand your results after your exam?   Yes   No   Don't know

7) Did you need to have a follow-up exam?   Yes   No   Don't know

8) Did the Patient Navigator help you understand when you should have your next exam?   Yes   No   Don't know

    If **Yes**, did the Patient Navigator help you schedule your follow-up exam?   Yes   No

9) Was there a cancer found in your exam?   Yes   No   Don't know

    If **Yes,** did the Patient Navigator explain how to access additional care?   Yes   No

10) Would you recommend the Patient Navigation services to your friends and family?   Yes   No   Don't know

11) What else can be done to make the colorectal cancer screening process easier?

_____

_____

    Your Age: _____   Gender: _____ Male _____ Female

    Race/ ethnicity: ____White (not of Hispanic origin)   ____Hispanic   ____Black   ____Other:_____

Thank you for completing this questionnaire. All your answers are completely confidential. Please return the questionnaire in the enclosed envelope.

Sample Patient Satisfacation Survey – Spanish Version
Adapted from the Colorado Colorectal Screening Program

Encuesta de Satisfacción de los Pacientes

Esta encuesta es para ver qué tan bien los guías de pacientes están ayudando a los pacientes de la clínica con el proceso de las colonoscopias para la detección del cáncer de colon y recto. Quizás recibió ayuda de un guía de pacientes durante el proceso de detección del cáncer de colon. Un guía de pacientes podría haber sido cualquier empleado de la clínica quien le ayudo con cualquiera de estos pasos:

- Educación sobre la preparación para una colonoscopia
- Encontrando transportación
- Proporcionando una persona para llamarla por cualquier duda que usted haya tenido, o si fue diagnosticado/a con cáncer.

- Recordatorios para sus citas
- Haciendo citas
- Encontrar a alguien para ir con usted a la cita

1) ¿Cómo se puso en contacto con el guía de pacientes para la detección del cáncer de colon y recto?
        Recibí un folleto por correo
        Mi médico me informo
        Un empleado de la clínica me llamo
        Vi un anuncio en la televisión/radio/periódico
        Otro _____

2) ¿Qué tan útil fue el guía de pacientes con la ayuda de las siguientes cosas relacionadas con la detección del cáncer de colon?

Haga un círculo:

	Muy Bien	Bien	Justo	Mal	Muy Mal	N/A
a) Explicando la prevención del cáncer de colon y recto	5	4	3	2	1	0
b) Explicando la necesidad de detección del cáncer de colon	5	4	3	2	1	0
c) Programando su cita para su examen de colon y recto	5	4	3	2	1	0
d) Explicando el proceso de detección	5	4	3	2	1	0
e) Ayudándolo/a a prepararse para el procedimiento	5	4	3	2	1	0
f) A entender la importancia de la preparación	5	4	3	2	1	0
g) Encontrar a alguien para cuidarlo/a después del examen	5	4	3	2	1	0
h) A quien contactar si se le diagnóstico con cáncer o un efecto adverso	5	4	3	2	1	0

3) ¿Ha tenido problemas con cualquiera de las siguientes acciones durante el proceso de su examen del cáncer de colon y recto (colonoscopia)?

f) Encontrar transporte para la ida y regreso de la cita de su examen	Sí	No
g) Conseguir permiso en su trabajo para la cita	Sí	No
h) Poder pagar el procedimiento de detección	Sí	No
i) Esperar demasiado tiempo para su cita	Sí	No
j) Encontrar a alguien para ir con usted a su cita	Sí	No

4) ¿Que hizo el guía de pacientes para ayudarlo/a con las preguntas antes mencionadas?

_____

_____

5) ¿Recibió los resultados de su examen en un tiempo aceptable?	Sí	No	No se
6) ¿El guía de pacientes le ayudo a entender los resultados después de su examen?	Sí	No	No se

7) ¿Usted necesitó un siguiente examen?   Sí   No   No se

8) ¿El guía de pacientes le ayudo entender cuando debería tener su siguiente examen?   Sí   No   No se
   Si contestó **Si**, ¿El guía de pacientes le ayudo a programar su siguiente examen?   Sí   No

9) ¿Se encontró cáncer durante su examen?   Sí   No   No se
   Si contestó **Si**, ¿El guía de pacientes le explico cómo conseguir servicios adicionales?   Sí   No

10) ¿Recomendaría los servicios del guía de pacientes a sus amigos y familiares?   Sí   No   No se

11) ¿Qué otra cosa se puede hacer para que el proceso de detección del cáncer de colon y recto sea más fácil?

_____

_____

Su edad: _____   Género: _____ Hombre _____ Mujer
Raza/origen étnico: ____Blanco (no de origen Hispano)   ____Hispano   ____Negro   ____Otro:_____

Gracias por completar este cuestionario. Todas sus respuestas son completamente confidenciales. Por favor, regrese el cuestionario en el sobre adjunto.

APPENDIX 4 – WORKSHEETS

Worksheet

4.1 Developing a program theory

OVERVIEW: One of the important early steps of an evaluation is to map out your program, to identify the major activities provided and the intended outcomes of those activities. Program theories map out this alignment, as well as the evidence supporting the connection between your activities and intended impact. This worksheet can be used to organize information as you create your program theory.

In collaboration with your stakeholders, identify the major activities of your program. Then, as a group, determine the result of each activity. Use evidence from other programs or your own program to answer why you believe each activity will have that effect.

Activity	IF the activity is provided, THEN what should be the result for participants?	WHY do you believe the activity will lead to this result?	What evidence do you have that this activity will lead to this result (data from your own or other programs, published literature, etc.)?

4.2 Developing a logic model

OVERVIEW: Once you have identified your program theory, it can be helpful to illustrate that theory with the use of a logic model. This section provides a basic worksheet for creating your logic model, helping you to organize the relationships between your activities, outcomes, inputs, and output.

Consider the following

▶ Do each of these activities refer to services provided directly to participants? Administrative functions of the program, such as hiring staff or preparing budgets, are certainly an important part of providing community programming and should be reflected in your work plans. However, administrative activities that are not expected to lead directly to changes for participants should not be included in an evaluation design.

▶ Does your list contain any redundancies (e.g., same basic activity described in several different ways)? If so, eliminate duplicate activities. In designing your evaluation, consider your core activities without redundancies.

▶ Of those activities listed, which do you feel are most important in terms of either the potential for impact on the participants or the level of resources that are devoted to the activity?

LOGIC MODEL WORKSHEET

Activity	Inputs	Outputs	Short-term outcomes (changes in knowledge, attitudes)	Intermediate outcomes (changes in behaviors or practices)	Long-term outcome/ Overall Impact

Worksheet

4.3 Preparing a budget

OVERVIEW: Creating a budget is essential as you assess the resources available for your evaluation. Take time up front to brainstorm with stakeholders about these potential costs. Although it is very common to make budget adjustments as you proceed, the more accurate your original budget, the easier it will be to work with those adjustments further into the evaluation. This section provides a worksheet for filling in your project budget.

	Amount
Revenue	
a) Grant funds	
b) Government funds	
c) Fundraising funds	
Expenses	
a) Program staff time	
b) Evaluation/Data analysis/Data collection staff time	
c) Administrative support staff time	
d) Consultant time	
e) Local travel/mileage	
f) Long distance travel	
g) Postage	
h) Printing/copying	
i) Telephone (long distance, conference calls)	
j) Other (meeting expenses, office supplies, incentives, etc.)	

Worksheet

4.4 Assessing research skills

OVERVIEW: You do not need to be on your own when you conduct an evaluation. There are many professionals who might be available to help you, though often there is a fee for their service. You might also have colleagues or volunteers within your own agency that have some skills that you could draw on as you conduct your evaluation. This worksheet can be used to document staff that could be evaluation resources for you.

Think through the various stages of your evaluation and identify early on where you might need some additional training or resources to complete the evaluation. By identifying these needs up front, you can budget your money and time accordingly.

Skill	Staff with experience
Evaluation methods and design	
Evaluation planning and budgeting	
Computer and database skills	
Data analysis skills	
Qualitative and/or quantitative strategies	
Interpersonal and teamwork skills	
Writing experience/reporting	
Ideas about how to use evaluation results	
Other:	
Other:	

Worksheet

4.5 Assessing organization capacity

OVERVIEW: An important early step in conducting an evaluation is to assess your agency's readiness in order to help you to design an evaluation that aligns with your existing capacity, or to help you prioritize areas where you need to build your capacity to conduct a meaningful evaluation. This worksheet can be used to identify the existing evaluation capacity of your organization and to identify areas for improvement.

1. Who is currently responsible for overseeing program evaluation?

   _____
   _____
   _____

2. What resistance, if any, has your agency experienced from staff when engaging in evaluations? What resistance, if any, from clients?

   _____
   _____
   _____

3. How do you distribute evaluation findings? Who sees the findings? How does someone obtain a copy of the findings?

   _____
   _____
   _____

4. Have staff members put evaluation findings to use? How?

   _____
   _____
   _____

5. What changes at the organization or program have resulted from evaluation findings?

   _____
   _____
   _____

Worksheet

4.6 Data collection plan

OVERVIEW: Once you have identified your key evaluation questions, you need to develop a plan for gathering the required information. This section provides a sample data collection plan to help you align your needed information with a data collection approach.

Review the list of the outcome goals that you rated as most important to include in the evaluation design. In the first column, make a list of all the information that you will need to collect in your evaluation plan to address these outcome goals. In the second column, identify a potential data collection strategy (e.g., program records, other secondary data sources, questionnaires, interviews, observational data, etc.). In the third column, identify a potential data source for this information (e.g., medical records, participants, staff, etc.). In the fourth column, propose a plan for collecting the information, including the procedure to be used and the timing of the data collection.

Information to be collected	Data collection strategy	Data source	Data collection procedures
Sample: Participant feelings about media campaign	Focus groups	Community members	Will recruit participants at local community center, ideally would like to have three focus groups of 7 people each

Review your ideas for collecting data from the previous worksheets. Combine these strategies as appropriate to create a list of each data collection effort that would be needed.

Strategy	Evaluation issues addressed
Sample: Focus groups to understand feelings toward media campaign	Participant input on satisfaction with materials (satisfaction) Understand best media outlets to use within community (community assessment)

Worksheet

4.7 Identifying research implications

OVERVIEW: The main value of evaluation comes when you have the results and can use them to improve or expand services, inform education and advocacy efforts, etc. This worksheet can be used to help you identify key findings, implications, and recommendations using what you learned from your evaluation.

Research Question	Evaluation	Findings	Implications	Recommendations
What do we want to know?	What was done?	What was learned?	What does this mean?	Where do we go from here?

Worksheet

4.8 Action plan

OVERVIEW: The most important outcome of any evaluation is putting findings into action. This worksheet can be used to create a plan for action, using the results from your evaluation.

Domain	Finding	Follow-up action	Person responsible	Targeted completion date
Outcome evaluation				
Outcome evaluation				
Outcome evaluation				
Stakeholder satisfaction				
Stakeholder satisfaction				
Client background/ characteristics				
Service delivery				

APPENDIX 5 – SCREENING RESOURCES

Resources

5.1 Overview of Major National Colorectal Cancer Screening Data Sets

In evaluating your colorectal cancer screening program, you may want information about screening rates within your health system, a geographic area, or a specific population. Some funding sources also ask programs to track screening rates. This toolkit has provided some examples of how programs can calculate their own screening rates, but there are also a number of existing datasets you can use to track screening rates.

This section provides an overview of five national datasets that provide screening rate calculations. Each summary provides information on how rates are calculated, the populations that are included and levels of data that can be accessed, and advantages and disadvantages of each dataset. Information about accessing each dataset is also included.

The Healthcare Effectiveness Data and Information Set (HEDIS®)[16]

Description of database, including source of the data and population	The Healthcare Effectiveness and Data Information Set (HEDIS), developed and maintained by the National Committee for Quality Assurance (NCQA), evaluates the performance of health insurance plans across a variety of measures. The data are provided by more than 90 percent of the health plans in the United States (including those under Medicare and Medicaid), and cover most insured patients in the country. Currently, HEDIS includes about 80 measures across several domains of care. Colorectal cancer screening rates are included in the Effectiveness of Care domain and is one of several measures that address preventative services. Learn more at http://www.ncqa.org/HEDISQualityMeasurement.aspx.
How colorectal cancer screening rates are assessed in the dataset	HEDIS calculates colorectal cancer screening rates for commercial health care plans and Medicare Advantage plans. Colorectal cancer screening is defined as the percentage of members age 50–75 who had appropriate screening for colorectal cancer. Appropriate screening includes a fecal occult blood test (guaiac or immunochemical) within the past year, a flexible sigmoidoscopy within five years, or a colonoscopy within the past ten years. New in 2017 is that Computed Tomography Colonography within the past five years and FIT-DNA within the past three years are now numerator compliant.

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[16]   The Healthcare Effectiveness Data and Information Set (HEDIS®) is a registered trademark of the National Committee for Quality Assurance.

	Members are excluded if they have had colorectal cancer or a total colectomy in their history through the measurement year. The data set includes members who have had continuous enrollment during the measurement year and the year prior, with an allowable gap of no more than 45 days during each year of continuous enrollment. The denominator for calculating the screening rate is the total population within the health plan, age 50-75, who have been continuously enrolled during the past two years and who meet the allowable gap specifications.
Frequency of data collection and reporting	Data for HEDIS are collected and reported annually. Health plans are required to report in June from the previous year ending December 31st, and data are released publicly in September or October.
Data access	The Quality Compass® [17] tool provides access to the data across the HEDIS measures at the plan, national, state, and regional levels, with benchmarks at each of these levels. The data are available for purchase by type of plan (commercial, Medicaid, Medicare). Data can be purchased to be used by more than one user for an additional cost. Quality Compass data can be purchased here: http://store.ncqa.org/index.php/data-and-reports.html. The most recent national colorectal cancer screening rates for both commercial and Medicare plans can be accessed through the NCQA's State of Health Care Quality report, which is updated regularly and features aggregate longitudinal data since 2004 at the national level for most HEDIS measures. The report can be ordered for free here: http://www.ncqa.org/report-cards/health-plans/state-of-health-care-quality.
Geographic detail	Plan comparisons are available at the national, state, and regional level, aligned by Department of Health and Human Services regions, with benchmarks at each of these levels. Data are also available for specific health care plans.
Advantages	HEDIS has several advantages, including: • The data are collected and reported annually. • The data are based on claims, or in some cases on both claims and medical records, which are generally accurate and feasible. • The data are audited by certified auditors using a process designed by NCQA.
Disadvantages	HEDIS also has some disadvantages, including: • HEDIS only includes data on the insured population. • Differences in capacity among health care plans to track colorectal cancer screenings and patient history may lead to under-reporting of screening rates by some plans. • The chart review process required for reporting for some measures can be burdensome for health care plans. • There is a subscription fee to access the data beyond the most basic trends.

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[17] Quality Compass® is a registered trademark of the National Committee for Quality Assurance.

Behavioral Risk Factor Surveillance System (BRFSS)

Description of database, including source of the data and population	BRFSS is an annual, state-based, random-digit-dialed telephone survey of the civilian, non-institutionalized adult population age ≥18 years. The survey collects information on health risk behaviors, preventive health practices, and health care access in the U.S. State health departments use in-house interviewers or contract with call centers or universities to administer BRFSS continuously throughout the year. People with landlines and those with cellular telephones are included. BRFSS surveys more than 400,000 people each year, making it a large and robust data source. Learn more at http://www.cdc.gov/brfss/about/index.htm.

The survey has three "parts": 1) the standardized core, which is fielded in every state, 2) optional modules, which states have the option to field, and 3) state added questions. Questions about CRC screening test use are only asked of adults age ≥50 years. The questions about CRC screening are considered rotating core questions and are routinely asked only in even years (2012, 2014, etc.). States have the option of adding these questions in the odd years, however, there is a cost to this option. |
| **How colorectal cancer screening rates are assessed in the dataset** | The survey includes questions about whether the respondent has had an FOBT, a sigmoidoscopy, and/or a colonoscopy. Those respondents who say that they have had one of these tests are asked when it occurred (within the past year, past 2 years, past 3 years, past 5 years, past 10 years, or more than 10 years ago).

A statistical brief on cancer screening questions is available and provides additional information about the questions and variable calculations (http://www.cdc.gov/BRFSS/data_documentation/PDF/2014_BRFSS-statistical-brief_cancer.pdf). The brief includes instructions for calculating key variables, such as the percentage of adults age 50-75 who reported an FOBT within the past 1 year, and the percentage of adults age 50-75 who reported a colonoscopy within the past 10 years. There is also an "up-to-date" screening status, defined as the percentage of adults age 50-75 who reported FOBT within 1 year or sigmoidoscopy within 5 years with FOBT within 3 years, or colonoscopy within 10 years. |
| **Frequency of data collection, data lag and reporting** | Data are collected on an ongoing basis, but reported annually. Since CRC is a rotating core question, this means that nationwide and state-by-state CRC screening rates are available in odd numbered years (2013, 2015, 2017). Data are usually released in the summer for the prior year's results. |

Data access	State-level data are available for free and without restriction. Each year's data file is made available on the BRFSS website (http://www.cdc.gov/brfss). Extensive survey documentation is also available. The data file needs to be downloaded in its entirety – including all questions and all states – rather than allowing someone to simply download the CRC questions for their state. Once the file is downloaded, however, it is not difficult to extract the relevant data in common statistical analysis software. Because the data file includes all survey variables, it can be used to run whatever analyses are of interest, such as looking at variation in screening rates by key demographic variables.	The American Cancer Society has released an online statistics center that, among other things, draws on the BRFSS CRC screening rate to allow users to create state-based screening rate data: https://cancerstatisticscenter.cancer.org/#/
Geographic detail	Some BRFSS data are available for through the Selected Metropolitan/ Micropolitan Area Risk Trends of BRFSS (SMART BRFSS). The CDC analyzes BRFSS data for metropolitan and micropolitan statistical areas. Some SMART data are available for download through the BRFSS website. County-level data are only provided when at least 500 surveys were collected in that area, limiting data availability to major metropolitan areas. Broader county-level data may be available through the state's health department. State health department contacts for BRFSS can also be found on the BRFSS web page.	
Advantages	The BRFSS is a rigorous survey, with a large sample size, established and well-documented methodology, and a long history. It is easy to access and download data. It is a standardized survey, with questions that have been carefully researched and validated. Data are available nationwide, as well as state by state. Some county-level data is available.	
Disadvantages	There are several limitations of the BRFSS data. • It is only available at the state level and for major metropolitan areas, making it less useful in tracking data within smaller or more rural areas. • The survey's weighting methodology changed in 2011, which means that results from years prior to 2011 cannot be compared to those after 2011. This makes it impossible to look at long-term trends over time. • Only a few tests are included in the survey questions. • The survey does not distinguish between screening and diagnostic tests, resulting in over-estimates of screening prevalence. Overestimation of screening rates may also result due to the fact that respondents who have had more than one screening test are counted more than once in the percentage of the population considered "up to date" with screening.	

HRSA Uniform Data System (UDS)

Description of database, including source of the data and population	The Uniform Data System (UDS) is maintained through the Health Resources and Services Administration (HRSA), a federal agency focused on improving access to high quality health care services for people who are low income, uninsured or underinsured, isolated, or medically vulnerable. Uniform Data System data are collected from participants of the Health Center Program, which include program grantees and "look-alikes" as defined in Section 330 of the Public Health Service Act. The UDS is a reporting requirement for participating health centers of the following HRSA primary care programs: Community Health Centers, Migrant Health Centers, Health Care for the Homeless, Public Housing Primary Care, and other grantees under Section 330. Colorectal cancer screening has been a required measure for health centers since 2012.
	UDS data are used by HRSA to ensure compliance with legislative and regulatory requirements, improve health center performance and operations, and report overall program accomplishments. The data help to identify trends over time, enabling HRSA to establish or expand targeted programs and identify effective services and interventions to improve the health of underserved communities and vulnerable populations. UDS data are compared with national data to compare health care services and health outcomes between the U.S. population at large and those individuals and families who rely on the health care safety net for primary care. UDS data also inform health center programs, partners, and communities about the patients served by health centers.
How colorectal cancer screening rates are assessed in the dataset	A variety of information is collected through the UDS related to patient characteristics, health center utilization and staffing, quality of care, and other topics. As mentioned above, information related to colorectal cancer screening is one quality of care measure included in the UDS. Specifically, the UDS CRC measure documents the percentage of patients age 50-75 who had appropriate screening for colorectal cancer, and is aligned with NQF0034/CMS130 (https://ecqi.healthit.gov/ep/ecqms-2017-performance-period/colorectal-cancer-screening). In 2016, UDS specified alignment with CMS130v4. For future years, visit the UDS manual webpage (https://bphc.hrsa.gov/datareporting/reporting/) to find the current version of the eCOM numbers, as they are updated.
	As of 2016, it is calculated by dividing the number of patients age 51-74 with appropriate screening for colon cancer by the total number of patients in that age group who had at least one medical visit during the calendar year. Appropriate screening is defined as: (a) colonoscopy conducted during the measurement year or the previous 9 years; (b) flexible sigmoidoscopy conducted during the measurement year or the previous 4 years; or (c) a fecal occult blood test (FOBT), including the fecal immunochemical (FIT) test during the measurement year. Please check the UDS manual (https://bphc.hrsa.gov/datareporting/reporting/) for future updates. While age 50-75 is in the title of this measure, the detail calls for persons to be screened within a year of turning 50 and prior to reaching age 75, thus age 51-74 are used for the analysis.
	Each participating health center or other grantees submit aggregate information about this and other measures, using information extracted from electronic medical records or a sample of patient charts.

Frequency of data collection, data lag and reporting	Data are submitted by health centers an annual basis. Aggregate information for a full calendar year are submitted to HRSA by February 15 of the following year and are usually made available to the public by late summer or early fall.
Data access	UDS results are available for free to anyone and easily visible on the UDS webpage (http://bphc.hrsa.gov/datareporting/index.html). There is also a mapping tool (http://www.udsmapper.org). The mapping tool also provides free information, though you need to create a user profile to access the site. The UDS Mapper provides some estimated information about populations in specific service areas. Users can also map some other information for service areas, such as U.S. Census data and shortage areas such as Health Professional Shortage Areas (HPSAs) and Medically Underserved Areas/Populations (MUA/Ps). National data on UDS trends in the colorectal cancer screening measure can be found here: https://bphc.hrsa.gov/uds/datacenter.aspx
Geographic detail	Results for individual grantees can be accessed, as well as statewide or overall national results. These data are available from the following website: http://bphc.hrsa.gov/datareporting/index.html. See instructions below for obtaining screening rates for individual health centers.
Advantages	The UDS provides valuable information about the populations most often served through Federally Qualified Health Centers and other HRSA grantees, such as people who are uninsured or have low income. It may be especially useful for health centers themselves, to track their performance on key measures over time or to compare their performance to that of similar organizations, particularly if they have implemented interventions or systems changes to increase CRC screening rates. It may also be useful for partners, such as ACS health systems staff, state health departments, or CDC Colorectal Cancer Control grantees who are working with health centers to implement evidence-based interventions. Finally, it can serve as a surrogate marker for programs that are specifically attempting to reduce disparities in screening rates among high-risk populations.
Disadvantages	There are several limitations of the UDS data. • The data includes screening rates for patients served at HRSA-funded clinics or programs, but does not provide a comprehensive screening rate for all residents of a state or community. • Data can be examined for an individual grantee, or for an entire state, but cannot be compiled for other geographic levels such as counties. • Information is extracted from electronic medical records (EMRs) or patient charts. While this avoids challenges related to use of self-report data, there is likely to be inconsistency in how information is entered into charts and included in reports. The chart sample is small (75 charts), though plans are underway to base the measure entirely on EMRs. • Information is presented in terms of the overall percentage of the eligible population who received screening, but does not differentiate between different types of screenings. • The UDS data does not distinguish between screening and diagnostic tests, resulting in over-estimates of screening prevalence.

Instructions for obtaining UDS screening data

http://bphc.hrsa.gov/uds/datacenter.aspx?q=d&year=2014&state=AL#glist

First, click on your state:
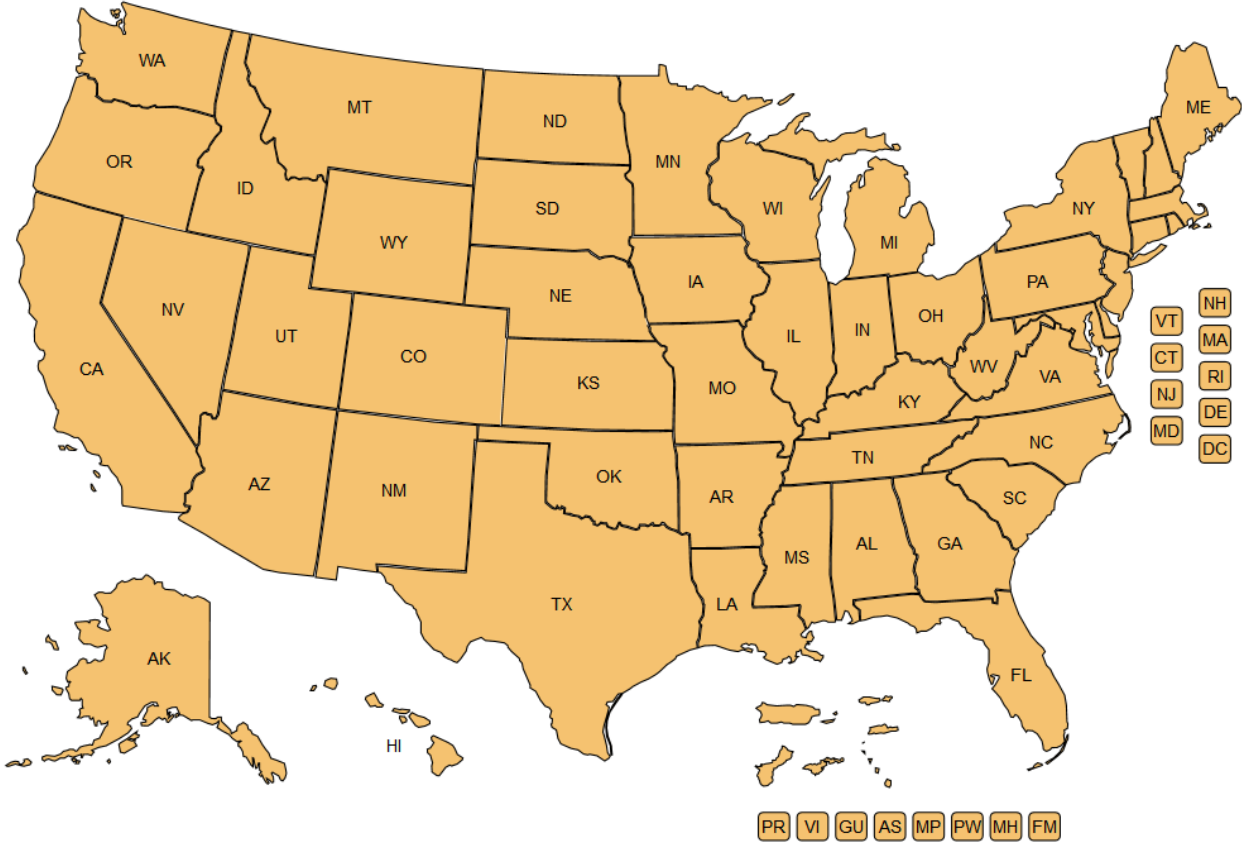
Second, click on the desired health center.

State Program Grantee Data		
California Program Grantee Data Download California Aggregated Health Center Data		
Health Center	**City**	**State**
ACHIEVABLE FOUNDATION THE	CULVER CITY	California
ALAMEDA COUNTY HEALTH CARE SERVICES AGENCY	OAKLAND	California
ALL FOR HEALTH, HEALTH FOR ALL	GLENDALE	California
ALL-INCLUSIVE COMMUNITY HEALTH CENTER	BURBANK	California
ALLIANCE MEDICAL CENTER, INC.	HEALDSBURG	California
ALTA MED HEALTH SERVICES CORPORATION	LOS ANGELES	California
AMPLA HEALTH	YUBA CITY	California
ANDERSON VALLEY HEALTH CENTER, INC	BOONVILLE	California
ANTELOPE VALLEY COMMUNITY CLINIC	LANCASTER	California
APLA HEALTH & WELLNESS	LOS ANGELES	California
ARROYO VISTA FAMILY HEALTH FOUNDATION	LOS ANGELES	California
ASIAN AMERICANS FOR COMMUNITY INVOLVEMENT OF SANTA CLARA, INC, THE	SAN JOSE	California
ASIAN HEALTH SERVICES, INC.	OAKLAND	California
ASIAN PACIFIC HEALTH CARE VENTURE	LOS ANGELES	California
AVENAL COMMUNITY HEALTH CENTER	AVENAL	California
AXIS COMMUNITY HEALTH	PLEASANTON	California

Third, open "Clinical Data" and scroll down to the CRC screening rates.

2014 Health Center Profile

ALAMEDA COUNTY HEALTH CARE SERVICES AGENCY
OAKLAND, CALIFORNIA

Service Area Map

Total Patients Served: 7,934

Select a Different Reporting Year: Select Year Go

Download CA Aggregated Health Center Data

View all California Program Grantees

View National and State Program Grantee Data

Age and Race/Ethnicity	⊕
Patient Characteristics	⊕
Services	⊕
Clinical Data	⊕
Cost Data	⊕
Program Requirements	⊕
Footnotes	⊕

The National Health Interview Survey (NHIS)

Description of database, including source of the data and population	NHIS provides information on the health of the U.S. civilian non-institutionalized population through confidential, in-person interviews conducted in households. It has been administered annually since 1957 and is one of the major data collection programs of the Centers for Disease Control and Prevention's National Center for Health Statistics (NCHS). NHIS tracks respondents' health status, access to health care, and their health care utilization.
	The NHIS sampling plan follows a multistage area probability design that allows for a nationally representative sample of households and non-institutional group quarters (e.g., college dormitories). The sampling plan is redesigned after every decennial census.
	The survey is composed of core questions and supplements, including the Cancer Control Supplement (CCS) in which questions about colorectal cancer screening tests are asked. The CCS is jointly sponsored by the National Cancer Institute and the Division of Cancer Prevention and Control at the CDC, and collects information on cancer screening and prevention behaviors. It is fielded every five years.
	Learn more at http://www.cdc.gov/nchs/nhis/about_nhis.htm and http://healthcaredelivery.cancer.gov/nhis
How colorectal cancer screening rates are assessed in the dataset	The survey includes questions about whether respondents have had a sigmoidoscopy, colonoscopy, CT colonography (asked in 2010 and 2015), blood stool or occult blood test, and/or fecal immunochemical or FIT test (the survey distinguishes between home and office testing). Those respondents who say that they have had one of the tests are asked when they most recently had it and the main reason for it (i.e., was it part of a routine exam, because of a problem, as a follow-up test of an earlier test or screening exam, or some other reason). Respondents are also asked how much they paid out of pocket for their most recent colonoscopy (2015).
	Additionally, respondents who are age 50 or older, and who are not up-to-date with their CRC screening, are asked whether in the past 12 months a doctor or other health professional recommend that they be tested to look for problems in their colon or rectum. Those who say yes, they received a recommendation to be tested, are asked which tests the doctor or other health care professional recommended they use to check for colon cancer.
	Note that NHIS is being redesigned for 2018.
Frequency of data collection and reporting	The full CCS is fielded every five years to approximately 35,000 adults. Interim supplements are fielded at the mid-point of the 5 year intervals to monitor cancer screening and new/emerging cancer control issues. CRC screening data have been collected in 2000, 2003, 2005, 2008, 2010, 2013, and 2015. Data are typically available six months after the survey field period ends.

Data access	Data are free and publically available. Each year's data file is made available on the CDC website (http://www.cdc.gov/nchs/nhis/nhis_questionnaires.htm). Extensive survey documentation is also available. The data file with all questions needs to be downloaded in its entirety. In addition, screening variables need to be created (i.e., a user cannot open the data set and look-up CRC screening rates). Sample SAS, SPSS, and STATA input statement programs are provided for each data file. Specific analysis and publication of the newly released NHIS Cancer Control Supplement data on colorectal cancer screening are typically through a collaborative effort on the part of NCI and CDC.	A brief summary of national trends in colorectal cancer screening rates according to the 2015 NHIS is available here: https://www.cdc.gov/mmwr/volumes/65/wr/mm6538a6.htm
Geographic detail	The NHIS sample data are national-level data. Obtaining state-level and urban and rural estimates requires working with the NCHS Research Data Center.	
Advantages	NHIS is the key source of population-based, self-reported health status and health care utilization data in the U.S. It has a high response rate, large sample size that yields national estimates, questions on the four major CRC screening modalities, many covariates (e.g., sociodemographics, health status measures, health care access, and health behaviors) for analyzing CRC screening use, and can look at trends over time. Additionally, NHIS is one of the few data sets that attempts to determine the "reason for the test" and distinguish between screening and diagnostic tests. In addition, the survey questions are researched and validated.	
Disadvantages	There are some limitations of the NHIS data. • NHIS is less useful for tracking data within geographic units smaller than Census regions. Accessing state-level and urban and rural estimates may be obtained by working with the NCHS Research Data Center. The center may charge for obtaining estimates. See the NCHS website for more information: http://www.cdc.gov/rdc/ • Organizing and analyzing NHIS data sets requires some skills in programming or working with a programmer, as screening and other variables need to be created by users.	

Medicare data

Description of database, including source of the data and population	This dataset looks at Medicare claims within the United States. The population is made up largely of patients over age 65, although it does include some people under age 65 who may be on both Medicaid and Medicare due to disability status.	
How colorectal cancer testing rates are assessed in the dataset	Colorectal cancer testing rates are calculated for patients age 51-75 who have had at least one office visit in the past 24 months in family medicine, internal medicine, geriatric medicine, or obstetrics/gynecology. Patients are excluded if they were in hospice or died before the end of the reporting period or have a diagnosis of colorectal cancer or have had a colectomy. When you calculate a CRC screening rate among an insured population such as Medicare patients, the denominator is the number of people 50 or older for whom screening is appropriate (and taking care to exclude those people for whom screening is not appropriate). The numerator is the number of people that have actually undergone CRC screening within the recommended timeframe. This number can be calculated by pulling dozens of codes that can indicate a person has undergone CRC screening within the recommended timeframe, meaning they are up to date with screening. To use Medicare claims data to calculate CRC screening rates, you will need to have the full list of codes and recommended frequencies that indicate a person 50 or older is up to date with CRC screening. You will also need a list of codes for conditions or procedures that would exclude someone from this pool. For instance, if a person has had colon cancer, they need surveillance, not CRC screening, and they should not counted in the pool of people for whom screening is appropriate.	When you use medical claims to calculate a CRC screening rate among an insured population (such as Medicare patients), the denominator is the number of people 50 or older for whom screening is appropriate (and excludes those people for whom screening is not appropriate). The numerator is the number of people that have actually undergone CRC screening within the recommended timeframe. This number can be calculated by searching a patient's record for any one of dozens of codes that can indicate a person has undergone CRC screening; the codes should be associated with a person's record within the recommended screening test interval, meaning they are up to date with screening. However, tests that were performed prior to the patient's current insurance coverage will not be included. For example, patients that received a colonoscopy while covered by their Anthem policy will not have a record of the colonoscopy in the Medicare dataset.
Frequency of data collection and reporting	Updates in Medicare data are released quarterly, with generally a 6-8 month lag, taking into account claims processing time.	

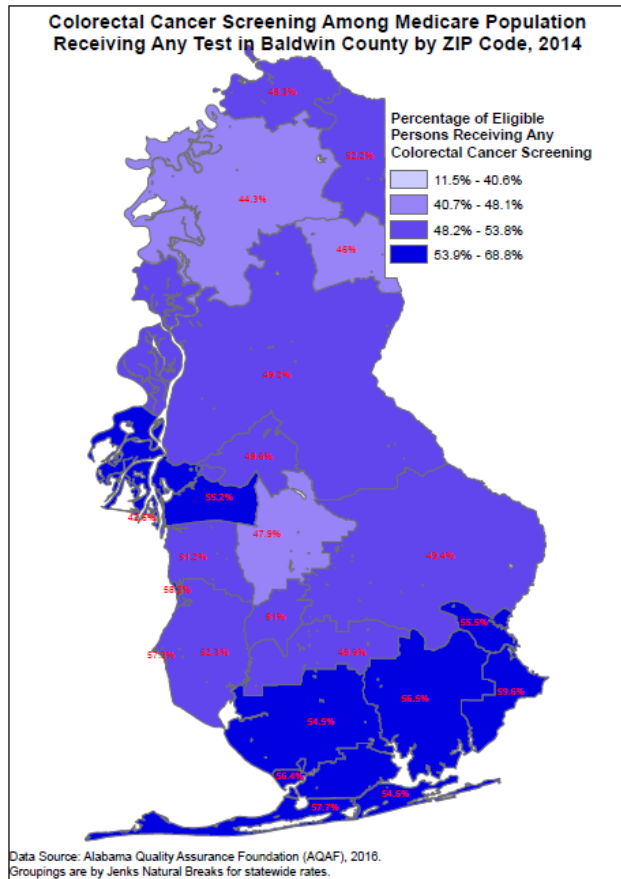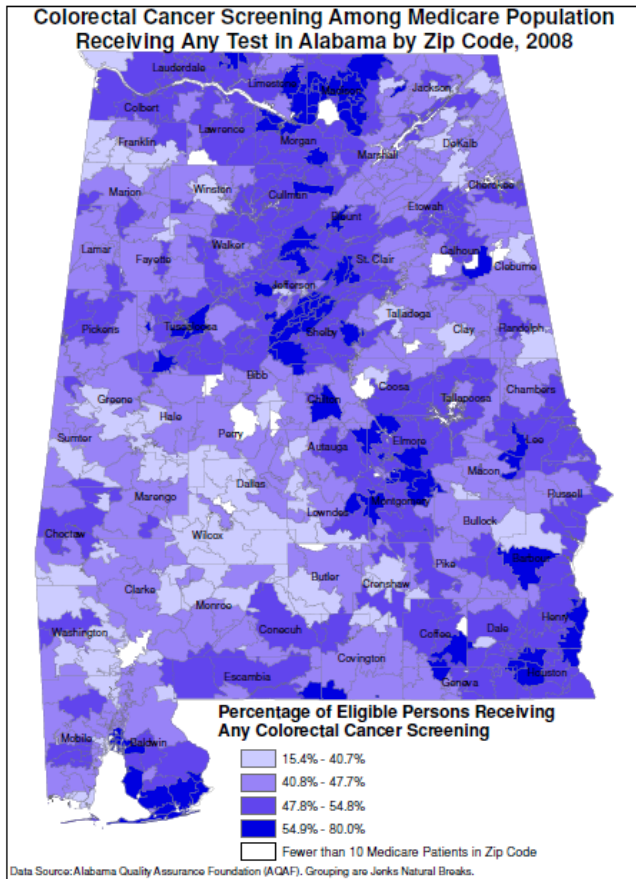|	
Data access	The data are available through the following sources: • Medicare claims data are available through the Research Data Assistance Center (ResDAC) through the Center for Medicare and Medicaid Services (CMS), which provides free support to academic, government, and nonprofit researchers interested in using Medicare or Medicaid data for their research. The data include the diagnosis (ICD-9 diagnosis), HCPCS codes, dates of service, reimbursement amount, outpatient provider number, revenue center codes, and beneficiary demographic information including zip code, gender, age, race, and ethnicity. Customizable reports are available for fees ranging from $2,000 to $15,000 depending on the size of the sample. To access the data and to create a customizable report, contact ResDAC at http://www.resdac.org/cms-data/file-family/Medicare-Claims. • Medicare claims linked to NCI's Surveillance, Epidemiology and End Results (SEER) data can be obtained for cancer cases and a 5% random control sample, which consists of Medicare beneficiaries residing in the SEER areas. A cost calculator can be accessed at: http://healthcaredelivery.cancer.gov/seermedicare/obtain/costcalc.html • Data can sometimes be accessed by contacting your state Quality Innovation Networks (QINs) free of charge. Contact information for your regional QIN can be found at http://qioprogram.org/qionews/articles/quality-innovation-network-quality-improvement-organizations-qin-qios.
Geographic detail	Data can be broken down by county, zip code, and provider, as well as by test, race, and ethnicity within these categories.
Advantages	There are several advantages of Medicare data, including: • Medicare data can be broken down by more specific metrics than some of the other datasets, including zip code, test, and race and ethnicity. • Medicare data can also be used to create provider "report cards" about testing rates. • Medicare data are available through QIOs for no cost, or through ResDAC at a lower cost than some of the other datasets.
Disadvantages	Medicare data has several disadvantages, including: • It is not possible using the Medicare claims data to accurately determine the indication (e.g., screening vs. diagnostic) for all tests. For example, if a polyp is identified and removed during a screening colonoscopy the procedure is billed as a diagnostic exam. Although a modifier code was introduced in 2011 that was supposed to be used in such situations, it is unclear if providers are routinely and accurately using this code. • It is comprised largely of patients age 65+ and excludes people not covered by Medicare. • There can be challenges in attributing patients to providers if the patient has seen more than one provider. • The data does not include records of screenings that occurred before the patient joined Medicare. • Fecal occult blood tests (FOBT) may be underreported in claims data. Although the specific CPT code (82270- e.g., Guaiac) was introduced in 2007, it is rarely reported. Additionally, although the main HCPCS code (G0328-CRC Screening FOBT) codes is present more frequently in the data, the use of either code has not been validated.

Example of level of Medicare data available by zip code, race, and procedure

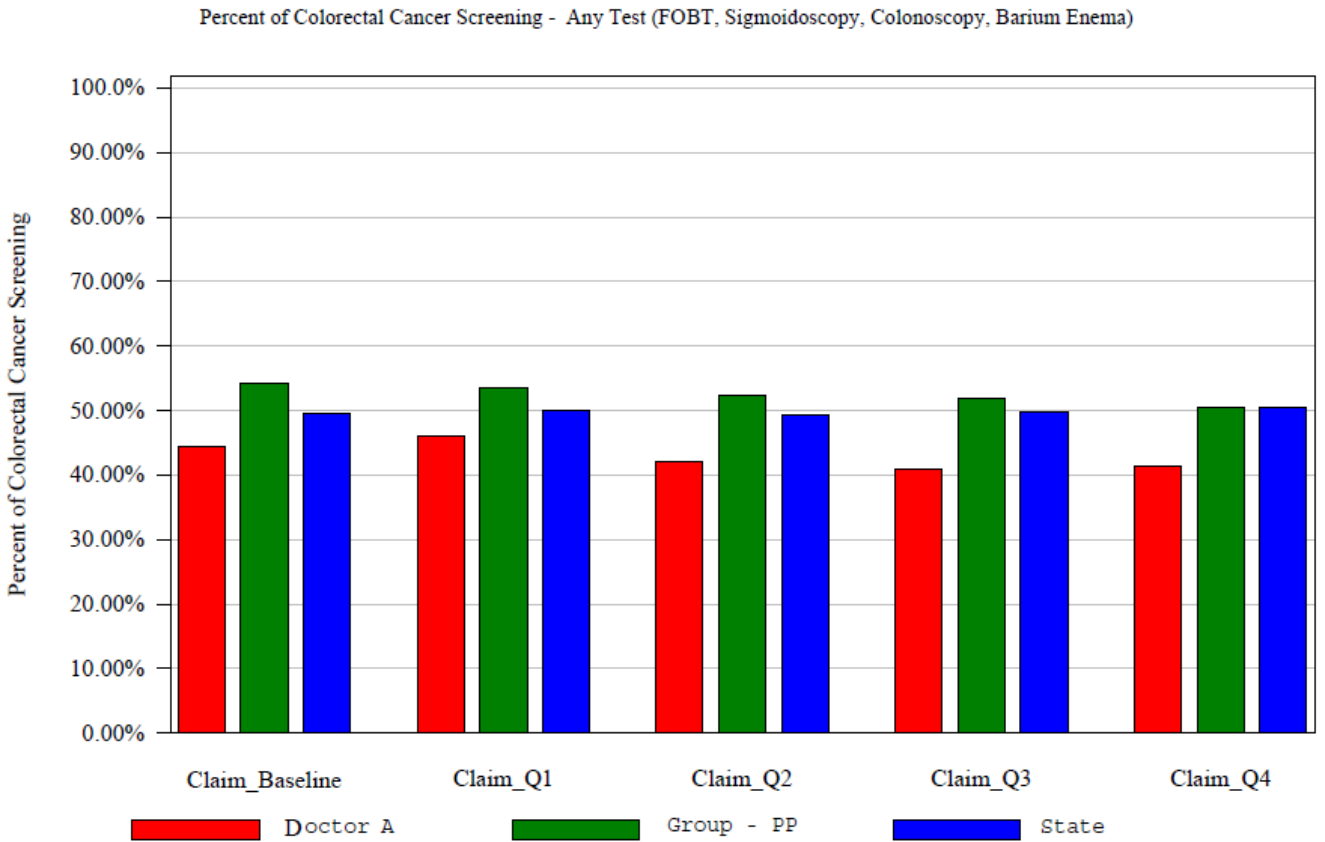*Statewide Monitoring - CRC Time Frame: 07/01/2012 - 06/30/2013*
Age: 50 - 80

Interim22		Any Test			FOBT		Colonoscopy		Sigmoidoscopy		Barium Enema	
County_Zip	Race	Den	Num	Rate	Num	Rate	Num	Rate	Num	Rate	Num	Rate
Autauga-36003	All_Race	138	77	55.80%	11	7.97%	68	49.28%	6	4.35%	5	3.62%
	Black	52	34	65.38%	3	5.77%	32	61.54%	3	5.77%	2	3.85%
	White	85	43	50.59%	8	9.41%	36	42.35%	3	3.53%	3	3.53%
Autauga-36006	All_Race	99	44	44.44%	3	3.03%	42	42.42%	0	0.00%	2	2.02%
	Black	16	7	43.75%	0	0.00%	7	43.75%	0	0.00%	0	0.00%
	White	83	37	44.58%	3	3.61%	35	42.17%	0	0.00%	2	2.41%
Autauga-36008	All_Race	9	7	77.78%	1	11.11%	7	77.78%	0	0.00%	0	0.00%
	White	8	6	75.00%	1	12.50%	6	75.00%	0	0.00%	0	0.00%
Autauga-36051	All_Race	155	74	47.74%	10	6.45%	68	43.87%	5	3.23%	5	3.23%
	Black	20	5	25.00%	0	0.00%	5	25.00%	0	0.00%	0	0.00%
	White	134	68	50.75%	10	7.46%	62	46.27%	5	3.73%	5	3.73%
Autauga-36066	All_Race	1464	826	56.42%	124	8.47%	788	53.83%	31	2.12%	16	1.09%
	Black	67	29	43.28%	5	7.46%	28	41.79%	2	2.99%	1	1.49%
	White	1377	788	57.23%	117	8.50%	752	54.61%	29	2.11%	15	1.09%
Autauga-36067	All_Race	1778	924	51.97%	123	6.92%	867	48.76%	42	2.36%	34	1.91%
	Black	223	110	49.33%	11	4.93%	103	46.19%	1	0.45%	1	0.45%
	White	1537	808	52.57%	112	7.29%	758	49.32%	41	2.67%	33	2.15%
Autauga-36068	All_Race	130	59	45.38%	7	5.38%	55	42.31%	1	0.77%	0	0.00%
	Black	21	9	42.86%	0	0.00%	9	42.86%	0	0.00%	0	0.00%
	White	107	48	44.86%	7	6.54%	44	41.12%	1	0.93%	0	0.00%
Autauga-36749	All_Race	104	45	43.27%	1	0.96%	44	42.31%	2	1.92%	5	4.81%
	Black	45	22	48.89%	1	2.22%	21	46.67%	1	2.22%	4	8.89%
	White	59	23	38.98%	0	0.00%	23	38.98%	1	1.69%	1	1.69%

Example of screening rate maps at the state and county level available through Medicare

Colorectal Cancer Screening Among Medicare Population Receiving Any Test in Alabama by Zip Code, 2008

Percentage of Eligible Persons Receiving Any Colorectal Cancer Screening
- 15.4% - 40.7%
- 40.8% - 47.7%
- 47.8% - 54.8%
- 54.9% - 80.0%
- Fewer than 10 Medicare Patients in Zip Code

Data Source: Alabama Quality Assurance Foundation (AQAF). Grouping are Jenks Natural Breaks.

Colorectal Cancer Screening Among Medicare Population Receiving Any Test in Baldwin County by ZIP Code, 2014

Percentage of Eligible Persons Receiving Any Colorectal Cancer Screening
- 11.5% - 40.6%
- 40.7% - 48.1%
- 48.2% - 53.8%
- 53.9% - 68.8%

Data Source: Alabama Quality Assurance Foundation (AQAF), 2016.
Groupings are by Jenks Natural Breaks for statewide rates.

A-250

Example of a provider scorecard data available through Medicare

Percent of Colorectal Cancer Screening - Any Test (FOBT, Sigmoidoscopy, Colonoscopy, Barium Enema)

Resources

5.2 Advice for communities on tracking colorectal cancer screening progress

OVERVIEW: The following tip sheet was developed by NCCRT to provide guidance to communities participating in 80% by 2018 efforts about how to track the progress of their community or coalition efforts to support screening.

The important thing is to pick what you are going to measure, disclose your limitations, track your progress over time, and course correct as necessary. It may also be worth setting process goals to assess your progress in the short term, and documenting CRC incidence and mortality rates to assess your progress over the long term.

When launching a community-wide effort to support colorectal cancer (CRC) screening, it is important to assess your starting point and document your progress. Having said that, it is not always easy for communities to know where to start in this initial assessment. Here are some tips provided by the NCCRT's 80% by 2018 Evaluation and Measurement subgroup on how to get started and things to consider.

Initial steps:

■ **Document who is in your coalition of stakeholders.** Some natural partners might be:

  – The American Cancer Society, a comprehensive cancer coalition, state or local health departments, a primary care association, hospitals or other large practices, payers, physicians, employers, Quality Improvement Organizations (QIOs), schools of public health, cancer centers, Federally Qualified Health Centers (FQHCs), or individual champions, such as community leaders, gastroenterologists, and survivors.

  – *Tip: Consider establishing regular meetings (e.g., quarterly, bi-annually) or other formal communication channels, to update stakeholders on progress.*

■ **Identify data that are available to you.** There are usually some groups in every state, such as the health department, comprehensive cancer programs, and/or university researchers, already collecting data about cancer screening, incidence, and mortality. Here are some ways to get started:

– Talk to the county health department to see what data they have.

– Look at Commission on Cancer hospital data (they do a community needs assessment every three years; some might collect CRC screening data).

– Ask local subject matter experts, university researchers, or state Offices of Research and Statistics for data on screening.

– Ask local health plans/QIOs for rates (Commercial, Medicare, Veterans Health Administration).

– Determine the practices and health systems that serve the most patients in the community and see if they have data about CRC screening rates, including if Electronic Medical Record (EMR) data are available.

– Identify the large insurance plans covering those in your community.

– Look at the Uniform Data Set (UDS) rates for CRC screening for the FQHCs in your community.

– Look to see if your county data are included in the Behavioral Risk Factor Surveillance System (BRFSS); a limited amount of local data is tracked through the BRFSS survey.

– Consider a survey that could be compared to another data source.

– Use demographic information from the American Community Survey to get a feel for what the population looks like in your community.

– Look at CDC Wonder or ACS Cancer Facts and Figures for trends in CRC incidence and mortality. Additionally, CRC death rates by congressional districts for 2015 are available here and CRC death rates at the county level are available here.

Note: CRC incidence and mortality rates are difficult for most communities to derive or track on their own, but still valuable to know if available through other sources. If your community is facing higher than average CRC incidence or mortality rates, that can be used to spur the community to action.

- ■ Select a measure (or a variety of measures).

  - Start with something that you will be able to track over time in a stable and consistent way (simpler is better).

  - Consider which populations are reflected in the data…the insured? The uninsured? A specific region?

  - Find out what the baseline is, and keep track of it over time.

  - Don't get stuck on finding the perfect measure. All measures are imperfect and have limitations. Pick a measure and disclose its limitations, then track it consistently over time.

  - Consider incorporating process measures to help assess short-term progress, such as:

    - ▪ Expansion of partnerships (number and type of partners involved).

    - ▪ Types of interventions launched (number, type, and connection to evidence-based recommendations).

    - ▪ Changes in awareness (simple assessment to gauge if targeted audience know more after than before, such as a pre-test/post-test survey).

- ■ Take stock of your community's previous activity promoting CRC screening to help set the path ahead.

  - Assess what CRC screening activities have happened so far.

    - ▪ Document what has been done so far to promote CRC screening.

    - ▪ Note if there has been any previous mobilization around goals, such as Healthy People 2020 goals or 80% by 2018.

    - ▪ Ask stakeholders about earlier efforts and experiences. What has worked? What community assets or programs are available? What are the common barriers to CRC screening in the community? Who/what is needed to help overcome the barriers?

  - Use the assessment to help your community/coalition know where they are now.

    - ▪ Set the right expectations.

    - ▪ Use data that can activate people; show graphs and maps.

    - ▪ Help partners use the data to understand where more help is needed.

How can communities assess if they have reached the next level?

■ **Use process measures to determine how you are doing in the short term.** How many stakeholders are participating in the effort? Has the community launched an intervention or several? Do you have a growing pool of champions who are helping with the effort? Are community relationships and collaborations strengthening?

■ **Track the CRC screening rate (or rates) you have selected.** Has there been a change in screening rates for the measures you are tracking? If some measures are going up and others are going down or plateauing, what does that tell you?

Note: The lag for many CRC screening rate measures, such as HEDIS or UDS, can be up to 18 months.

■ **Consider longer-term trends for mature efforts.** What trends over time are you seeing in mortality and incidence rates and stage of the diagnosis?

Note: Incidence and mortality rates are slow to move. Incidence usually increases initially with increased screening, then plateaus, and then drops over time.

■ Communicate about progress and use that to motivate and focus future activity.

– While change can happen slowly, it's exciting to assess and witness progress.

– Even after seeing progress, there are always areas that need improvement. Use your assessments to refocus on areas or communities in need.

– **Take the time to celebrate achievements, and say thank you.**