

# ADMINISTRATIVE LEADERSHIP

- How will research affect the operations of the center?
- How will research affect productivity?
- Are there hidden (and therefore unreimbursable) costs?
- What will be the reaction by...
  - Patients?
  - Clinicians?
  - Board?
  - Community at large?

54

Administration is responsible for the overall functioning of the health center. Top management will want to know how research fits into the grand scheme of things.

A researcher who wants to “sell” research to top management should understand the fiscal implications of research. But administration also will be concerned about the reactions of key stakeholders.

## ADMINISTRATION: OVERCOMING RESISTANCE

- Work the system
  - Go through channels
  - Propose ways around objections
- Budget review by financial director

55

There's no alternative to "working the system." Recall that we spoke earlier about needing a "marriage" between clinical and administrative people in order to build support for research. Successful marriages involve respect for different ways of doing things. There may need to be a lot of considered review by management, not only of research in general, but the specifics of any given project. Speaking of that, it's always helpful to "buy-in" if the center's financial director reviews the budget of a study.

## RESEARCH OVERSIGHT COMMITTEE

- Consider appointing committee if your center will make major commitment to research
- Committee:
  - Reviews all projects
  - Is accountable to health center leadership for overall conduct of studies

56

You should consider creating a research oversight committee (or assigning responsibility for research oversight to an existing committee, if applicable). This is particularly important if you think your center will do a lot of research. The committee can be given the responsibility for reviewing all projects.

A committee allows researchers, either from within the center or from the outside, to develop a working relationship with a small group which is accountable for the overall research effort. Over time the members of the oversight committee should become more sophisticated about research.

## SHOULD OVERSIGHT GROUP HAVE A VETO?

### ■ Pro:

- Approval can be important part of the buy-in process



### ■ Con:

- Could veto interesting and valid projects



57

If you have an oversight committee, should it have veto power over a particular project? There's no easy answer, just pros and cons on both sides.

If the committee does have the power to approve or scuttle projects, then its approval should be considered the final word. Top management should never overrule the committee except in extraordinary circumstances. On the other hand, there's the risk that the committee might be uncomfortable for reasons of its own and might turn down some interesting projects.

One solution would be for a committee to start out as an advisor to top management and later evolve into the actual approval body as the health center gains more experience with research.

## BOARD OF DIRECTORS

- Responsible for assuring that center behaves in a manner consistent with its mission
- Key question: How does research serve the center's larger purpose?

58

Boards of nonprofit organizations are always complicated, and health center boards are no exception. Boards are legally responsible for assuring that the center does what it says it does. Board members will want to know *why* the center wants to get involved in research. One way or the other, they will be asking how a research program helps the center take care of patients.

## BOARD OF DIRECTORS: OVERCOMING RESISTANCE

- Specifics vary greatly from center to center
- Take into account personalities and aspirations of individual directors
- Avoid board approval for each project
  - General approval of research
  - “Information only” agenda items
  - Directors on oversight committee

59

Every board is different, so we can't give you specific advice about how to overcome resistance at the board level to research. As Tip O'Neill once said, all politics is local. It may take some time, but it's worth the effort to get board buy-in.

You don't want a situation, though, in which the board insists on a veto for each specific research project. You want the board to endorse a research *program* so that new projects can simply be reported as information items. This is desirable for the same reason that it's always desirable for boards not to micro-manage health centers.

One route to this goal that may work for you in your center is to appoint one or more directors to the research oversight committee, if you have one.

## THE COMMUNITY AT LARGE

- Must support or at least not oppose the idea of research
- How will research affect access when I need it?
- “Guinea pigs”

60

Although boards represent the community at large, their perspectives are not identical. Your community must not actively oppose the idea of research at the health center. The whole issue of “guinea pigs” may be an important stumbling block. There may be concerns expressed about how research will affect community members’ access to health services when they need them.

Communicate, communicate, communicate -- that’s the only effective way to build community support for research. Items in a health center newsletter, presentations (where appropriate) at community meetings, flyers for the waiting room -- let your imagination go to work when you think about how to inform people and build their support.

## THE COMMUNITY AT LARGE: OVERCOMING RESISTANCE

- Allow community advisory board an opportunity to review and comment
- More intrusive studies likely to cause more problems
- Do not launch your research program with a study likely to be controversial

61

It's always a good idea to get the input of your community advisory board. As with the board of directors, in general the community board should not be asked to sign off on each specific study, unless the study is likely to be intrusive in some way.

As one would expect, more intrusive or potentially controversial research projects are more likely to stimulate community concern. Trials of an active drug versus placebo are an obvious example. But even an observational study that uses patient questionnaires can raise objections -- if the questions cover sexuality, substance abuse, or other emotionally charged topics.

It's best not to begin your research program with an intrusive study. Build some credibility through less controversial research first, tell the community how the research positively affects the quality of care its members receive, and only then take on projects that may require more advance work and community preparation.

QUESTIONS,  
THEN A BREAK



## SESSION 3:

### What You Should Ask When the Researcher Comes Calling

63

Session 3 is a long role-playing exercise and debriefing session. Participants will role-play a meeting at a health center that is thinking about doing a research project. The study idea originates with one of the staff clinicians.

Divide the participants into groups of 6 each. “Extra” participants can join one of the 6-person groups; the role-play will *not* work for groups smaller than six. You should have packets for each group that contain one copy of each role. There should be extra copies of the “board member” role. Extra participants who join an existing group will play the role of board member.

As is true in real life, each stakeholder has only a partial understanding of the project and its potential impact on health center operations. Successful small groups will discover those differences and negotiate some solutions.

Expect to spend 5-10 minutes setting up the role play. Let the small groups meet for 25-30 minutes, but be flexible: if the conversations continue and appear animated, keep things going for awhile. Be sure to leave some time for debriefing before taking a break and moving on to Session 4.

## GOALS FOR THIS SESSION

- Gain experience with starting a research program in your health center
- Test and practice skills in stakeholder analysis, persuasive communication, and negotiation

64

Now that we're back from lunch, it's time to practice some of the skills we've talked about all morning. Our next session is a role-playing exercise. You'll get to practice some key skills and explore the different issues that come up when health centers contemplate getting involved in research.

## ROLE-PLAYING EXERCISE

- Your chance to become a star!



65

This is another occasion where your positive energy will be crucial to success. Hopefully the two earlier group exercises will have gotten participants used to the idea of, well, participating!

To really learn something this afternoon, you've got to really get into the role-play. Don't be embarrassed. No one is videotaping this, and talent scouts from Hollywood are not in the room!

## THE SCENARIO

- A clinician on staff wants to conduct a research project at the center
- This is meeting #2 to discuss the details



66

One of clinicians at a community health center has gotten interested in research. There's a proposed study on the table that the clinician has already discussed the executive director and the medical director.

The agenda for today's meeting is: to review the proposal in more detail; to discuss any issues that might interfere with carrying out the study; and to settle those issues.

You should assume that there's been a prior decision by the health center's board to support research in a general way, although there was not much discussion at the board level and at the time there were no fleshed-out proposals to actually do research at the center.

## DRAMATIS PERSONAE

- The clinician who wants to do the study
- Health center medical director
- Health center clinical coordinator
- Health sciences center faculty member, consultant to the potential researcher
- Executive director
- Board member(s)

67

Describe the roles first and then divide into groups of six. Ask participants to select their roles in a brief conversation as you distribute the packet of roles to each small group. Remember that “extra” participants also are board members.

## GROUP ASSIGNMENT

- Take on a role that is *not* what you do for a living
- Read the instructions
- Meet to discuss the project
- May do anything you'd do in "real life" (caucus, etc.)
- Pay attention to issues and to group process

68

Review the instructions on this slide with participants. Do emphasize the last point, since group process is probably as important as the issues themselves.

During the role-play you might wander around the room, listening for a few minutes to each group in turn.

Give 10-minute, 5-minute, and 2-minute warnings before reassembling the group as a whole for the debriefing.

## DEBRIEFING

- What problems did you identify?
- How were differences in knowledge and experience handled?
- How were problems resolved?



69

Begin with a general question like one those on the slide, and then let the dialogue go where it goes. You should facilitate the conversation without trying to control it. As participants debrief, point out where their dialogue mirrored the points raised in the morning session about stakeholders.

If the group is slow to respond to the debriefing, try asking directly, by role play: “Okay, let’s just ask the executive directors for a moment. How did the executive directors feel about issue X...” or something like that. Whatever you can do to get people talking is fair game, although debriefing most often needs no additional prompting from you.

At the end, just before the break, thank everyone for participating fully.

QUESTIONS,  
THEN A BREAK



□

## **SESSION 4:**

Finding Friends and Other Resources

71

## GOALS FOR THIS SESSION

- Review cost and revenue implications of getting started in research
- Discuss funding sources
- Where to go for help
  - Emphasis: practice-based research networks

72

In this last session we'll touch briefly on financial matters. We're not going to discuss the mechanics of writing research grants or "ten tips to be sure your grant is funded." We will highlight a few key points and make suggestions about where your health center can get help with funding.

And we'll discuss collaboration, a way to jump-start your research program. We'll pay special attention to practice-based research networks, which may be the most appropriate way for your center to get started.

# RESEARCH BUDGET

- Revenue:
  - Line item reimbursement for direct costs
  - Indirect cost reimbursement (overhead)
- Costs:
  - Direct
  - Indirect
    - Loss of productivity

73

A typical research budget naturally will contain line item reimbursement for direct costs -- staff time, supplies, printing, and the like. Sometimes drug companies will contract for drug evaluation studies. Revenue in these projects tends to be a fixed sum for each patient enrolled.

Some, but not all, funders also allow reimbursement for indirect costs, sometimes called overhead. Typically the indirect budget item is a percentage of the overall direct budget. Indirect cost reimbursement is unusual in private foundation grants, but it's common in grants from government agencies. Those funders that do fund overhead generally tell you up front what percentage they will accept.

Obviously your costs for a study are both direct and indirect. The most important indirect cost is hard to quantify -- the loss of productivity as staff divert some fraction of their time to conducting the study.

## POTENTIAL FUNDING SOURCES

- Special interest organizations
  - American Cancer Society
  - American Heart Association
- Professional medical organizations
  - American Academy of Family Physicians Foundation
  - State AAFP research foundations or committees

74

Who might fund primary care research at health centers? Some special interest organizations -- those concerned about particular diseases or types of disease, for example -- often have research programs. Usually these are administered at the national, not the state, level. While big-dollar grants for, say, cancer research tend to go to big-name university researchers, be on the lookout for smaller initiatives for which health centers are ideal “research labs.” These might include, for example, cancer control strategies for disadvantaged populations.

Some professional medical groups have research programs. For example, the national American Academy of Family Physicians Foundations regularly makes small (\$5-\$15,000) grants to new primary care researchers. Some state chapters also have grant programs for research

## POTENTIAL FUNDING SOURCES (2)

- Private foundations with interest in health care
- State-funded initiatives
  - Arizona Disease Control Research Commission
  - California Cancer Research Program

75

Every state has numerous foundations, large and small, some of which will have a declared interest in health care, the needs of the underserved, or both. The trick is finding the list of local foundations. Libraries can help, of course. In Colorado the Junior League publishes an annual statewide directory of foundations.

Some states fund research. Arizona's Disease Control Research Commission has a competitive granting process for small grants. And California's public health department operates a Cancer Research Program that has a \$25 million budget and a large staff.

## POTENTIAL FUNDING SOURCES (3)

- Federal agencies
  - Agency for Health Care Policy and Research
    - Small grants program
  - National Institutes of Health
  - Centers for Disease Control and Prevention
- Managed care organizations

76

Certainly the various branches of the U.S. Public Health Service are well-established funders of research. Some agencies have grant programs that are targeted to small projects and new investigators -- for example, the small grants program of the Agency for Health Care Policy and Research. A full discussion of Federal research funding is well beyond the scope of this seminar, but you can get additional details by accessing the Web sites listed in our resource guide.

Don't overlook managed care organizations as potential funders of research -- although you may want to call it "pilot-testing a new clinical program" instead. MCOs are interested in innovative ways to deliver care in cost-effective ways. If your health center has an idea that, say, an intervention with high-risk pregnant women can cut the rate of premature birth, a local managed care organization might be willing to fund a trial.

## POTENTIAL FUNDING SOURCES (4)

- Industry
  - Pharmaceutical companies
  - Medical equipment manufacturers
- Individual donors (“angels”)

77

For the most part, the business world does not fund research projects that you might develop in your own center. But don't overlook the possibility of in-kind contributions. Perhaps your study concerns a particular drug or piece of medical equipment. Manufacturers may be willing to supply the drug at no cost or loan you the equipment for the duration of the study.

In-kind contributions from business can be leveraged with other funding sources. If you apply to a local foundation for research funding, for instance, your case will be enhanced if you've already secured contributions from others -- like free use of medical equipment.

And then there are angels. Some communities have individuals with means who like to fund innovative ways to deliver health care services. As with managed care organizations, it's best not to label these efforts as research studies.

## GENERAL HELP AND INFORMATION SOURCES

- Research-oriented organizations
  - North American Primary Care Research Group
  - Society for General Internal Medicine
  - American Academy of Family Physicians
    - Family medicine research initiative
- State primary care associations

78

You'll probably want help with all sorts of things, not just funding, as you launch a research program. Check out the Web site for NAPCRG (pronounced "nap-crag"), an organization that exists in order to encourage primary care research and researchers.

Some medical groups have specific research initiatives and support systems for new investigators. The Society for General Internal Medicine has developed some programs to assist new researchers. So has the American Academy of Family Physicians.

Finally, some state primary care associations are working on research issues and may offer assistance to your center.

## WHAT IS NACHC DOING?

- Teaching and research workgroup
  - Part of Clinical Practice and Program Committee
  - Reviews and recommends to NACHC and Bureau
- Annual “innovation research” award

79

NACHC is doing its part, too. Its teaching and research workgroup keeps abreast of developments and makes recommendations about primary care research in health centers both to NACHC itself and to the Bureau of Primary Health Care. NACHC gives an annual innovation award for research done in health centers.

## WHAT IS NACHC DOING? (2)

- Partnerships with like-minded advocacy groups, foundations, corporations
  - Secure funding for research relevant to C/MHC mission
    - Diabetes mellitus project involving Midwest clinician network and CDC
- Monograph
- This seminar!

80

NACHC also works to get funding for research that is relevant to the community and migrant health center mission. A recent example is a study of diabetes involving the Centers for Disease Control and Prevention and a midwest clinician network. NACHC works with a variety of partners -- advocacy groups, foundations, and corporations -- to increase available funding for projects like these.

By way of technical support, NACHC has published a monograph on starting research programs in health centers. Of course, this seminar is -- hopefully! -- another example of NACHC's support of research in health centers.

## COLLABORATION: SECRET TO SUCCESS



- Difficult to launch a research program on your own
- Working with others provides tangible benefits
  - Experience
  - Resource sharing

81

It's not easy to start a research program on your own. Collaboration offers tangible benefits.

## POTENTIAL COLLABORATORS

- Universities
  - Medical school primary care departments
    - Family Practice
    - Pediatrics
    - Internal medicine
  - Nursing researchers
  - Epidemiology departments at schools of public health
- Practice-based research networks

82

Health sciences centers are a logical place to look for collaborators. In the medical school your best bets are in the primary care departments. Here you are most likely to find researchers already developing projects that you can participate in. Faculty also may be willing to help you develop your own studies. Don't overlook researchers in nursing and public health schools, either.

We recommend that you affiliate with a practice-based research network as a way of starting your program.

## WHAT'S A PRACTICE-BASED RESEARCH NETWORK?

- The primary care office as research laboratory
- Practices study the same question and pool their data
- Not new:
  - Multi-center trials
  - Dutch "sentinel stations"

83

Networks consider the primary care office to be their laboratory. As with the examples from ASPN that we talked about earlier, in a network practices study a common question and pool their data.

This is not a new idea. After all, many of the big studies reported in JAMA or the New England Journal are multi-center trials -- the same idea on a grander scale. The Dutch have operated so-called sentinel stations for years. These are primary care practices that report principally communicable disease data to a central registry. It's been shown, for instance, that sentinel stations are an effective way to do influenza surveillance.

## "INTERNAL" AND "EXTERNAL" NETWORKS

- State primary care associations
- Clinical networks
  - Region II
  - Midwest
- Large
  - Ambulatory Sentinel Practice Network
- Small
  - Wisconsin Research Network
- Smaller
  - Upper Peninsula Research Network

84

Some existing networks can be thought of as “internal” -- that is, they exist more or less exclusively within the C/MHC movement. Some state primary care associations have started networks. Others exist within the various clinicians’ networks. Two examples of the latter are the Midwest clinicians’ network and the research sponsored by the Clinical Directors Network of Region II.

Other networks can be thought of as “external” -- they originated outside of the C/MHC movement and include a variety of practices, not just health centers. One example of a large network is ASPN. Its member practices are in the U.S. and Canada. An example of a smaller, statewide network is WREN, the Wisconsin Research Network. And networks can be even smaller. As an example, consider the Upper Peninsula Research Network, located in northern Michigan.

## WHY PRACTICE-BASED RESEARCH NETWORKS?

- Allows for recruitment of more patients than any one practice ordinarily could
  - Conclusions more likely to be valid *and* useful
- Permits generalizability of findings
  - The bigger the network, the more like the “real world” its patients and clinicians are

## HOW DO NETWORKS WORK?

- Various control and decision-making strategies
  - Example: annual meeting of all member practices that decides on studies for year
- “Opt-in/opt-out” for individual studies
- Practices collect the data, professional staff does the analysis

86

Networks vary in how they make decisions about what projects to get involved in. One typical mechanism is an annual meeting or convocation of practices that have affiliated with the network. At these sessions, the staff typically presents study ideas -- many of which originate with the participating practices -- and the members vote on what studies to do. Two of the oldest and best-established networks (the Ambulatory Sentinel Practice Network and the Dartmouth Co-op) make decisions in this way.

Naturally the ability to participate in studies depends in part on funding, and sometimes the decisions of convocations have to be modified to account for funding changes.

All networks allow individual practices to opt in or opt out of participating in any specific research project. Some practices may find that the data collection requirements for a particular study are not feasible, for example.

## A FEW ISSUES AROUND PUBLISHING AND AUTHORSHIP

- Who owns the data?
- Who gets credit for the work?
- What if you don't like the results?

87

Tell the participants that the seminar is almost over. Inform them there are just a few topics left to be covered.

## WHO OWNS THE DATA?

- In general, the principal investigator (or PI's employer) owns the data
- Health center can negotiate for copy of its own data
  - Know the format
- What else do you want?
  - Confidentiality for patients
  - Provider-specific data

88

If the study at your center is being conducted under a network, or by an investigator who is not on your staff, then you should discuss and settle issues around who owns the data. This may not appear to be important, but it can become critical if you want to slice and dice the data in different ways -- say, in support of your quality improvement program.

If the data are coming to you on a computer disk, find out the file type and special hardware needs up front. Also be sure that your other data needs are negotiated for before the study begins. For example, you may want to know how patient confidentiality is protected. Or you may want to see certain data sorted by clinician. Be sure to talk these issues over with the outside principal investigator -- and also with your own clinicians who are doing research.

## WHO GETS CREDIT FOR THE WORK?

- Authorship is coveted
- Rules about authorship from scientific journals
- Something to negotiate up front
- Networks often list participating practices separately from authors

89

Know in advance who will be listed as an author on any scientific papers to be published. Scientific journals generally state that an author is anyone who is prepared to be accountable for the work that is published. So you can be an author if you worked hard on the study, even if you didn't write a word. Conversely, if all you did was write up other people's work (a ghostwriter, more or less), you shouldn't be credited with authorship.

Practice-based research networks generally don't list every participating clinician from every participating practice as an author -- the list could have dozens of names. Instead, the names of practices and clinicians usually are listed separately at the end of the article.

## WHAT IF YOU DON'T LIKE THE RESULTS?

- Intellectual honesty can clash with institutional interests
- Should be discussed up front
- Confidentiality protections for your center
- “A quality problem is an opportunity”

90

So suppose one of your clinicians does a study at your center, and you think the results cast the center in a bad light. There are times when intellectual honesty can clash with the interests of the institution in which the intellectual earns a living! This is another example of the need for a marriage between clinicians and administrators if a research program at a health center is to succeed.

One obvious solution is to build in confidentiality protections. The paper describing the results doesn't say it was done at Community Health Center in Midsize. It says the study was done at “a community health center serving a largely indigent population in the state of Franklin” or something similar.

Do remember the adage that “a quality problem is an opportunity.” If research done at the center puts a spotlight on a quality problem, fix it! Collect data before and after the fix, and then report those data in a second scientific paper. Who says you can't kill two birds with one stone?

## WHAT WE HOPE YOU LEARNED TODAY



- Research is a good thing for health centers
- The barriers can be overcome
- The rewards are worth the work

91

Another place for your positive energy to come through. Time to make a concluding remark and send the participants on their way.

THANKS FOR COMING!



92

Obviously we hope that today's seminar "hit the bull's-eye" for the participants -- we hope it met their needs and stimulated them to get their health centers involved in research!

**NATIONAL ASSOCIATION OF COMMUNITY  
HEALTH CENTERS**

**“Getting Involved in Research”**

**SESSION 3: ROLE-PLAYING SCENARIO**

**-- Role Descriptions --**

# NATIONAL ASSOCIATION OF COMMUNITY HEALTH CENTERS

## “Getting Involved in Research”

### SESSION 3: ROLE-PLAYING SCENARIO

ROLE:            Health Center Board Member

You are a member of the board of directors of Community Health Center in Midsized, a small city. You were born in Midsized, and you live and work in the neighborhood served by the health center. You have been on the board for a number of years. In that time, you have seen many clinicians and a few administrators come and go.

Although Midsized is only 20 miles from Metropolis, the largest city in the state and home to State Health Sciences Center and University Hospital, you rarely go there. You’ve never been to the medical, dental, or nursing schools, but from time to time you have visited patients at the hospital.

You think of yourself as deeply committed to the mission of CHC. It matters a great deal to you that the health center serves the people in the community. You were one of the board members who fought for evening and Saturday morning office hours. You voted in favor of such programs as lead paint screening and parenting classes, even though funds were tight. Your commitment to community service is one reason why, frankly, you are suspicious about the whole idea of research being done in your community. You’re familiar with the infamous Tuskegee project in which African-American men with syphilis were deliberately denied treatment. You want to be sure that no one in your community is turned into an involuntary research subject.

But you’re a realist. You respect the center’s executive director, who’s helped the board understand why an affiliation with State could help the center do an even better job helping your neighbors. You know that an affiliation would include the center’s participating in research, and you’ve tried hard to remain open-minded. You and several other board members have agreed to function as board liaisons as the director and staff discuss the affiliation proposal in more detail.

The executive director, as you know, has already met once with a clinician on the CHC staff who wants to do a smoking cessation project at the center. At that meeting, the clinician described the study in general terms, and both the director and the medical director expressed support. At this point you don’t know any of the details. Apparently the Health Sciences Center has agreed to help do the study.

You’ve been invited to attend today’s meeting. The hopeful researcher will provide a more detailed description of the study and its requirements. Also in attendance will be: your executive director; the CHC clinical coordinator and medical director; and, depending on whether their schedules permit, one or more other board members in a similar liaison role.

# NATIONAL ASSOCIATION OF COMMUNITY HEALTH CENTERS

## “Getting Involved in Research”

### SESSION 3: ROLE-PLAYING SCENARIO

ROLE:            Health Center Clinical Coordinator

You are the clinical coordinator at the Community Health Center in Midsize, a small city some 20 miles from Metropolis, the largest city in the state and home to State Health Sciences Center and University Hospital. It’s a new role for you and for the center; you are its first clinical coordinator. Before this you were a member of the center’s nursing staff, doing telephone triage, patient education, and traditional “back office” tasks. Now your role is administrative, but with a patient care focus. Your job is to facilitate the care that patients receive at CHC. You handle patient complaints; perform quality assessment studies; attempt to generate interest in quality improvement projects; help coordinate patient transfers from home to hospital to skilled nursing facility and back again; and generally function as an intermediary between the clinical staff and administration. You’re judged on process measures — among them, smooth patient flow inside the health center — and, to some extent, on patient outcome measures.

The number one complaint you hear from patients — and from board members who hear from patients — is about waiting times. It takes too long for patients to register, be seen, get their lab tests and follow-up appointments, and go home. It’s not uncommon for a patient to spend two hours at the health center just to have a 15-minute appointment with a clinician.

Ever since nursing school, you’ve been interested in health promotion and disease prevention. You recognize that smoking is an important cause of health problems for your patients. In your role as a patient educator, you’ve tried various methods to help patients quit, but it’s been frustrating to see patients ignore your advice and continue to get sick from smoking-related illnesses. Despite the apparent lack of results, you remain interested in helping patients stop smoking. You think you have pretty good communication skills, but you concede that there’s always room for improvement.

Although you have no prior experience with clinical research, you’ve been interested to learn that CHC might be the site of a study on smoking cessation. Perhaps what’s learned in this research can be applied to the care of the patients for whom you feel responsible. At the same time, as a patient advocate you are resistant to anything that slows down patient flow during the course of the day. Then, too, there’s the upcoming Joint Commission site visit. It’s only a couple of months away, and you are working overtime to get everything in order.

Today the executive director has invited you to participate in a meeting about the proposed research project. You know that it concerns smoking cessation, but you have yet to hear the details.

# NATIONAL ASSOCIATION OF COMMUNITY HEALTH CENTERS

## “Getting Involved in Research”

### SESSION 3: ROLE-PLAYING SCENARIO

ROLE:            Research Consultant

You are an assistant professor at State University Health Sciences Center, located in Metropolis, the largest city in the state. You are eligible for tenure in four years. “Publish or perish” is still the norm at all three schools — medical, nursing, and dental — at the Health Sciences Center.

You’ve been approached by a clinician at Community Health Center in Midsize, a small city some 20 miles from Metropolis, who wants to conduct a smoking cessation research project at CHC. The two of you have discussed the study design in some detail. It includes three elements: (1) While in the waiting room, patients will complete a questionnaire about their general health and smoking status. It also includes some basic demographic information (age, gender, ethnicity, and so on). There are approximately 30 questions on the form. The practice’s front desk staff will distribute the questionnaires and ask patients to fill them out while they wait. (2) Clinicians will be asked to check off some items on a pocket-sized card — whether they asked about smoking, what sort of quit-smoking message they delivered, and so on. They fill in the patient’s name and chart number and then answer 6-8 questions by placing a check mark in one of several choices offered for each question. (3) Finally, patients will receive a post-visit questionnaire in the mail that will ask what they remembered about the clinician’s quit-smoking message. There are only about 10-12 questions, and a stamped, self-addressed envelope will be included. The design calls for the participating practice to make two follow-up phone calls to patients who don’t return their questionnaires. There will be statistical comparisons between what clinicians said and what patients remembered being said, and those comparisons will be related to patients’ self-reported smoking status and demographic variables.

You’ve already participated in similar studies in other health centers without too much difficulty. True, the health center staff have sometimes had to rearrange patient flow routines to accommodate the study design, and on one occasion you negotiated a slight change in the study protocol to make the study more doable in the health center environment. But for the most part, you are optimistic about the ability of health centers to make room for research.

You know that the Health Sciences Center chancellor has been talking with several health centers around the state about affiliation agreements. The chancellor hopes that health centers will become training sites for students, research “labs” for young investigators like yourself, and sources of patients to be referred to specialists at University Hospital. As part of the package, the Health Sciences Center is prepared to fund some pilot studies that might eventually qualify for larger grants.

You've been asked by the CHC "principal investigator" to attend a meeting with some key decision-makers at the center. There's been a preliminary meeting already, and your understanding is that the clinical and administrative leadership at CHC is generally supportive of the idea. Today's meeting is intended to review the details of the design and, ideally, get agreement that the on-site clinician can proceed.

# NATIONAL ASSOCIATION OF COMMUNITY HEALTH CENTERS

## “Getting Involved in Research”

### SESSION 3: ROLE-PLAYING SCENARIO

ROLE:            Health Center Executive Director

You are the executive director of Community Health Center in Midsize, a small city some 20 miles from Metropolis, the largest city in the state and home to State Medical School and University Hospital. You’ve held the job for about two years. Before this you held various administrative positions in health centers, a 50-bed hospital in a rural part of the state, and a large, multispecialty physician group practice in another state.

You know better than anyone how difficult it is to keep a health center going. Growth in patient care revenues lags behind growth in demand — a sure sign that the economic boom hasn’t affected Midsize much. You’re always being asked to do more with less. It seems you are never without some unforeseen pressure on your center’s budget. Ideally you’d like all of your clinicians to be more productive — that is, to see more patients each day and to code their encounters accurately and completely so that you can maximize reimbursement. But clinician turnover is a real problem at CHC, as it always has been at every health center with which you’ve been affiliated. You know you can only push them so far before they will start to burn out and leave.

You’ve decided, after consulting with your board, to explore several ways of improving the outlook at CHC. You’ve decided to pursue accreditation by the Joint Commission on Accreditation of Healthcare Organizations. The Joint Commission inspection is a couple of months away, and your clinical coordinator is working overtime to get ready for it. And you’ve begun discussions with State Health Sciences Center about an affiliation agreement of some kind. The chancellor has been talking with several health centers around the state, hoping to recruit them as training sites for students, research “labs” for young investigators, and sources of patients to be referred to specialists at University Hospital. Apart from the prestige of an affiliation, CHC may benefit by receiving funds allocated for education or reimbursement as part of a research grant budget.

As it happens, you’ve already had one discussion with a young clinician on your staff who wants to do a smoking cessation project at CHC. Your medical director also attended. At that meeting, the clinician described the study in general terms, and you and the medical director both expressed support. Your understanding so far is that patients and clinicians will both fill out some sort of questionnaire about smoking. You see the center’s involvement with this project as an important test case for the affiliation agreement, so you are committed to making this research project work. Today is the second meeting at CHC. The clinician/researcher has been asked to provide a more detailed description of the study and its requirements. Also in attendance will be: your medical director; the CHC clinical coordinator; one or more members of the CHC board of

directors; and a faculty member from the Health Sciences Center who's been consulting informally with your clinician about the study.

# NATIONAL ASSOCIATION OF COMMUNITY HEALTH CENTERS

## “Getting Involved in Research”

### SESSION 3: ROLE-PLAYING SCENARIO

ROLE:            Principal Investigator/Researcher

You are a clinician at the Community Health Center in Midsized, a small city some 20 miles from Metropolis, the largest city in the state and home to State Health Sciences Center and University Hospital. You went to school at State and joined the CHC staff when your clinical education was completed three years ago. You believe strongly in preventive medicine and the impact of lifestyle on health status. Some of your teachers — the ones you were most influenced by — were conducting research on prevention.

Smoking is a major cause of preventable disease and death. You’ve read the published research suggesting that messages delivered to smokers by primary care clinicians do motivate them to quit smoking. At the same time, fewer than half of smokers report that they heard a quit-smoking message from their clinicians. You’re interested in studying the difference between what clinicians say they told their patients and what the patients recall being told. This may help clinicians design more effective quit-smoking messages for their patients.

You’ve designed a study and discussed it a faculty member from the Health Sciences Center who’s done similar research. The design includes three elements: (1) While in the waiting room, patients will complete a questionnaire about their general health and smoking status. It also includes some basic demographic information (age, gender, ethnicity, and so on). There are approximately 30 questions on the form. The practice’s front desk staff will distribute the questionnaires and ask patients to fill them out while they wait. (2) Clinicians will be asked to check off some items on a pocket-sized card — whether they asked about smoking, what sort of quit-smoking message they delivered, and so on. The clinician fills in the patient’s name and chart number and then answers 6-8 questions by placing a check mark in one of several choices offered for each question. (3) Finally, patients will receive a post-visit questionnaire in the mail that will ask what they remembered about the clinician’s quit-smoking message. There are only about 10-12 questions, and you’ll include a stamped, self-addressed envelope. The design calls for the participating practice to make two follow-up phone calls to patients who don’t return their questionnaires. You’ll do statistical comparisons between what clinicians said and what patients remembered being said, and you’ll relate those comparisons to patients’ self-reported smoking status and demographic variables.

Your faculty consultant has already been involved with other studies at health centers that used similar designs. In those studies little difficulty was encountered with data collection, and the participating practices said that patient flow was not interfered with by either the waiting-room questionnaire or the clinician check-off card. As a practicing clinician at CHC, you have no reason to think that data collection for this study will be any different.

You've already met once with your medical director and executive director. You described the study in general terms, and both expressed support. This is your second meeting at CHC. You've been asked to provide a more detailed description of the study and its requirements. Additional health center staff will be present to add their perspectives. And you'll bring along the faculty member who's been advising you on your project.

# NATIONAL ASSOCIATION OF COMMUNITY HEALTH CENTERS

## “Getting Involved in Research”

### SESSION 3: ROLE-PLAYING SCENARIO

ROLE:            Health Center Medical Director

You are a clinician at the Community Health Center in Midsized, a small city some 20 miles from Metropolis, the largest city in the state and home to State Health Sciences Center and University Hospital. You completed your basic clinical education elsewhere, but you had some advanced training at University Hospital before coming to work at the health center. You’ve worked there several years and were appointed to your current leadership role about 18 months ago. Other clinicians see you as experienced — not only about patient care issues, but also about the political and social environment in which the health center operates — and they value your opinion.

You recognize that smoking is an important cause of health problems for your patients. You’ve tried various methods to help patients quit, but it’s been frustrating to see patients ignore your advice and continue to get sick from smoking-related illnesses. Despite the apparent lack of results, you remain interested in helping patients stop smoking. You think you have pretty good communication skills, but you concede that there’s always room for improvement.

Because of your seniority and position, you’re often asked to help out with recruitment and retention of clinicians. Over the years you’ve seen a number of physicians, dentists, physician assistants, and nurse practitioners come and go. Clinician turnover adversely affects the patients and the CHC staff. The departing physicians especially have sometimes mentioned the lack of intellectual stimulation as a reason for leaving (“nothing but grinding out the patients over and over again,” one physician said recently as she left the center for a faculty position at a medical school in another state). You’ve been wondering if an active research program might attract clinicians with staying power, although you personally have never participated in any kind of research study.

At the same time, your workload has steadily increased in the last couple of years. Not only are there more patients than ever — the economic boom hasn’t affected Midsized much — but you seem to be constantly in meetings. Burn-out is another often-mentioned reason for the high turnover of clinicians at CHC. The last thing anybody needs is more work on top of what they’re already doing.

Another clinician at CHC has approached you about doing a smoking cessation study. At an initial meeting, the hopeful investigator described the study in general terms, and you and your executive director both expressed support. Your understanding so far is that patients and clinicians will both fill out some sort of questionnaire about smoking.

This is the second meeting. Your colleague who wants to do the study has been asked to provide a more detailed description of the study and its requirements. Also in attendance will be: your executive director; the CHC clinical coordinator; one or more members of the CHC board of directors; and a medical school faculty member who's been advising your colleague.

# RESEARCH IN HEALTH CENTERS:

## How To Get Started

a seminar presentation of the  
National Association of Community Health Centers, Inc.

written and developed by

Ambulatory Innovations, Inc.  
Practical solutions in primary care  
6455 Dover Road  
Indianapolis, Indiana 46220  
(317) 257-5750  
(317) 253-0993 fax

supported by

Bureau of Primary Health Care  
Health Resources and Services Administration  
U.S. Department of Health and Human Services

## RESOURCE LIST

## BOOKS

An excellent and detailed introduction is “Research Methods for Primary Care,” a six-volume collection published by Sage Publications. The series editors (Moirra Stewart, Peter G. Norton, Fred Tudiver, Martin J. Bass, and Earl V. Dunn) are among the most respected names in primary care research. Particularly valuable to health centers contemplating research programs are the first (*Primary Care Research: Traditional and Innovative Approaches*) and fifth (*Strategies for Implementing Research in the Primary Care Practice Setting*) volumes in the series.

Another useful text is *Designing Clinical Research: An Epidemiologic Approach*, edited by Stephen B. Hulley and Steven R. Cummings (William & Wilkins, 1988). It contains a great of information on the specifics of study designs but also has chapters on the ethical issues of research, the implementation of studies, and the writing and funding of research proposals.

J.H. Abramson’s *Making Sense of Data: A Self-Instruction Manual on the Interpretation of Epidemiologic Data* (Oxford University Press, 1988) does what the title describes. *Epidemiology in General Practice*, edited by David Morrell and also published by Oxford (1988), has a British flavor but also contains much useful information.

A working knowledge of statistics can be helpful — not just in analyzing the results of research, but in understanding other kinds of information. Three non-technical introductory books are: *How To Think About Statistics* by John L. Phillips, Jr. (W.H. Freeman, 1988), *PDQ Statistics* by Geoffrey R. Norman and David L. Streiner (Mosby, 1986), and *The Cartoon Guide to Statistics* by Larry Gonick and Woollcott Smith (HarperPerennial, 1993).

As noted in the seminar, outcome studies can easily become research projects. *Measuring Health: A Guide to Rating Scales and Questionnaires*, 2<sup>nd</sup> edition, written by Ian McDowell and Claire Newell (Oxford University Press, 1996) is a collection of more than 80 standardized questionnaires on general health status, quality of life, pain, disability, and other outcomes. G.E. Dever’s *Improving Outcomes in Public Health Practice: Strategy and Methods* (Aspen Publications, 1997) contains information about practical, how-to-do-it assessment methods.

Not all research is about numbers and questionnaires. Some researchers employ so-called qualitative methods — long, relatively unstructured interviews that are then analyzed in non-numerical ways. A good basic text is *Introduction to Qualitative Research Methods: The Search for Meaning* by Steven J. Taylor and Robert Bogdan (John Wiley & Sons, 1984).

Finally, for information about primary care itself and the kinds of questions that need more research, see Barbara Starfield’s *Primary Care: Concept, Evaluation, and Policy* (Oxford University Press, 1992).

# SOFTWARE AND INTERNET RESOURCES

Several free software packages are available over the Internet. The most well-known is **EpiInfo** from the U.S. Centers for Disease Control and Prevention (CDC). EpiInfo is easy to learn and use. Its modules include questionnaire writing, data entry, and basic statistical analysis. Unfortunately, it is still available in DOS only (but will operate under Windows as a DOS program). EpiInfo can be downloaded from the CDC World Wide Web site at <http://www.cdc.gov/epo/epi/epiinfo.htm>.

The U.S. Census Bureau offers **IMPS**, another free data entry, statistical analysis, and reporting software package. It is particularly useful for surveys and may be downloaded at <http://www.census.gov/ipc/www/imps.html>.

The two leading commercial software packages are **SPSS** and **SAS**. Both are Windows-based, and both can handle a wide variety of data entry and statistical tasks. SPSS separately markets **QI Analyst**, an add-on module specifically designed for quality improvement projects. SAS also markets **JMP**, a more graphical statistical package that is particularly easy to use. For further information:

SPSS: (800) 543-2185  
<http://www.spss.com>

SAS: (919) 677-4444  
<http://www.sas.com>

The Internet contains numerous resources that are relevant to the development of research programs in community and migrant health centers. What follows is a *partial* listing of useful Web sites:

## Search Engines

Alta Vista	<a href="http://www.altavista.digital.com">http://www.altavista.digital.com</a>
Excite	<a href="http://www.excite.com">http://www.excite.com</a>
Infoseek	<a href="http://www.infoseek.com">http://www.infoseek.com</a>
Yahoo	<a href="http://www.yahoo.com">http://www.yahoo.com</a>

## Organizations

American Academy of Family Physicians	<a href="http://www.aafp.org">http://www.aafp.org</a>
American Dental Association	<a href="http://www.ada.org">http://www.ada.org</a>
American Medical Association	<a href="http://www.ama-assn.org">http://www.ama-assn.org</a>
American Nurses Association	<a href="http://www.nursingworld.org">http://www.nursingworld.org</a>
American Public Health Association	<a href="http://www.apha.org">http://www.apha.org</a>
Ambulatory Sentinel Practice Network	<a href="http://www.aspn.denver.co.us">http://www.aspn.denver.co.us</a>
National League for Nursing	<a href="http://www.nln.org">http://www.nln.org</a>
North American Primary Care Research Group	<a href="http://views.vcu.edu/napcrg/">http://views.vcu.edu/napcrg/</a>
Society for General Internal Medicine	<a href="http://www.sgim.org">http://www.sgim.org</a>

## **U.S. Department of Health and Human Services and Other Federal Agencies and Services**

U.S. Dept. of Health and Human Services  
Agency for Health Care Policy and Research  
Centers for Disease Control and Prevention  
National Institutes of Health

*<http://www.dhhs.gov>*  
*<http://www.ahcpr.gov>*  
*<http://www.cdc.gov>*  
*<http://www.nih.gov>*

Public health statistics, organized by county  
Entry point for all Federal statistics

*<http://wonder.cdc.gov>*  
*<http://www.fedstats.gov>*

### **Private Sector**

The Foundation Center (funding information)

*<http://www.fdncenter.org>*