

**Northwest Association for
Biomedical Research**
and the
University of Washington
present

**Sharing the
Importance of
Research**

Speaker Workshop

**UW Faculty Club
November 5, 2004**

**Northwest Association for Biomedical Research
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Sharing the Importance of Research

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How to Court an Audience

Bonnie Southcott, Director of Donor Relations, Gilda's Club

- ❖ A speech is like a courtship

- ❖ Engage your audience in the first 30 seconds
 - Approach with Enthusiasm (Dale Carnegie quote)
 - Ice Breakers
 - There is no substitute for Sincerity
 - Convey Intimacy
 - Inspire Trust

- ❖ “🎵 Getting to know you 🎵 . . .”
 - Who is your audience?
 - Size matters
 - Curious, critical or kind?

- ❖ Make them love you for your mind – but don't forget to use your body!
 - The eyes have it
 - Hands on
 - A romantic walk
 - Working the mic and using your voice

- ❖ Tell them how you feel
 - The Power of the Personal Story
 - You are the power point
 - Your best day as a researcher
 - The cancer patient who moved you
 - The reason why you work each day to fight cancer
 - Storytelling 101: Serenade your audience with orchestrated examples
 - Your speech is not about how it reads, it's how it sounds
 - Bring your world to life do your audience can relate to you
 - Paint a picture using sights, sounds, smells and feelings
 - The six elements of good storytelling (handout)
 - Embed facts and figures in interesting anecdotes
 - Tantalize with quotes

- ❖ Don't be a know-it-all
 - Do be a Human Being – dissolve the White-Coat Barrier
 - Absolutely no jargon, acronyms or technical terms (Einstein quote)
 - Use self-deprecating humor
 - Practice saying, “I don't know” and “I've drawn a blank” (Twain quote)
 - Welcome the unexpected event – every relationship has them

- ❖ It's the little things that count
 - The devil in the details
 - Ask your host for what you'll need
 - Check out the room before your speech
 - Use a checklist for props you'll need to bring
 - Check your mic before your speech

- ❖ Let's get physical
 - If possible, run, bike or workout the morning of your speech
 - Do one more run-through the night before or morning of your presentation.
 - Arrive early and walk the room; check it out.
 - Take 10-15 minutes for yourself before your speech.
 - Find a quiet corner and shake it out just before you go on.

- ❖ Your first argument
 - Interruptions, Q and A and other messy stuff
 - Feel, Felt, Found (handout)

- ❖ End upbeat
 - Hope is a patient's best friend
 - (Margaret Mead quote)

Quotes

- “Always tell the truth. This will gratify some people and astonish the rest.” – Twain

 - “There are 3 cardinal rules of public speaking:
 - 1) Speak about something you have earned the right to talk about through experience or study.
 - 2) Be excited about your subject.
 - 3) Be eager to share your talk with listeners.” – Dale Carnegie

 - “The trick of a great mind is to make things as simple as possible – but no simpler.”
~ Einstein

 - “Never doubt that a small group of committed citizens can change the world. Indeed, it is the only thing that ever has.” ~ Margaret Mead
-

Storytelling: Breathe Life Into Your Presentation¹

- **Everybody has a story to tell – many in fact!**
 - Describe the moment you knew you wanted to find a cure for cancer.
 - What happened on the most exciting day in the lab?
 - What was the biggest oversight you made in dealing with someone diagnosed with cancer? What did you learn?
 - Which patient/subject has moved you the most in your career?
 - What is your greatest hope in doing the work that you're doing?
 - How has your own life been touched by cancer?
 - Why did you decide to become a volunteer for a medical trial?

- **Everyone is a natural-born storyteller**
 - From the first hunter drawing stick figures on a cave wall to Carl Sagan describing the cosmos for 500 million television viewers around the world.
 - There are ways to create interesting stories that will engage your audience and enhance your presentation.
 - You tell stories at work, around the dinner table and at cocktail parties. What do they have in common?

- **The six elements of good storytelling**
 - Setting - Where is the story taking place?
 - Character - Who's the story about?
 - Plot - What's happening?
 - Backstory - What happened before, to create and inform the situation?
 - Details - Which specific things should your audience notice?
 - Enthusiasm - Use your own passion, excitement and wonder about the story that's unfolding to draw in your audience.

¹File: NWABR Presentation - Storytelling - © 2004
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Feel-Felt-Found²

No one cares how much you know until they know how much you care.

FEEL	FELT	FOUND
<ul style="list-style-type: none"> • I see that you feel . . . • I can understand how you might feel . . . • It sounds like you feel . . . • I think what you're saying is that you are . . . 	<ul style="list-style-type: none"> • I've spoken to others who have felt the same way. • I've felt that way myself when . . . • A patient of mine had the same concerns. • I might feel that way if I were in your shoes. 	<ul style="list-style-type: none"> • What they found was . . . • And I found that . . . • He found that . . . • What we have found, however, is that . . .

A sampling of feeling words

Adamant Adrift Affronted Alarmed Anxious Apprehensive Baffled Barraged Boxed in Clueless Committed	Conscientious Criticized Controlled Deserted Discouraged Doubtful Embarrassed Excited Fearful Fed up Forgotten	Furious Gloomy Grief stricken Hampered Hopeful Humiliated Ignored Insignificant Immobilized Impeded Insulted	Jaded Lectured to Meek Misunderstood Mised Nervous Numb Overlooked Patronized Powerless Provoked	Rattled Rebuffed Rejected Stigmatized Susceptible Terrified Trapped Uncomfortable Unappreciated Weary Worried
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WARNING: Using Feel-Felt-Found without sincerity is simple manipulation. Using this approach with empathy, however, can lead to a profound development in your relationship with your subject, patient, doctor or audience.

² File: NWABR Presentations: Feel - Felt - Found

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Computer Presentation Checklist³

- ✓ If you need special equipment, make your request ahead of time. Double-check with your host the day before your presentation.
- ✓ Is the host software compatible with your presentation?
- ✓ Is there a sound card in the host computer?
- ✓ Did you check out the sound system prior to your presentation?
- ✓ Create a back-up before leaving to give your speech, and e-mail it to yourself or your host.
- ✓ Arrange to meet the person who will be controlling your equipment during your speech. Give that person the visual or verbal cues you will use to move between slides.

No matter what

- Never let your computer presentation upstage you.
- Look at the audience, not the screen, as you speak.
- Finally, always bring your material on large index cards in the event of a technological disaster. That way you will have the information on hand.

³ File: NWABR Presentation - Computer Presentation Checklist
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Speakers' Bureau Background Materials

Presentation Planning Guide

1. How will you engage the audience in the first thirty seconds?

2. How will you ensure the presentation relates to audience members' experiences and needs?

3. Presenting the main points:
 Overall Topic:

Main Points/Key Messages	Stories to Tell (or Other Approaches to Engage)	Notes and Ideas

5. What difficult questions might arise? How will you answer them?

6. How will you summarize and bring closure?

Adult Audiences

Most people see science as difficult to understand. Research scientists can help increase scientific literacy as well as have a profound impact on the attitude of the public towards science. Adults respond best when science and medicine are discussed in terms of the *health and well being of people like themselves and their families*. Making connections between biomedical research and advances in medicine is the best way to capture the interest of a general audience and broaden understanding.

Characteristic of Adult Learners

- Adults draw upon a broad base of experience. Motivation is increased when new learning is *connected to this past experience*.
- Adults seek to learn what is really important to them rather than what others perceive is important. Personal values play a role in how much learning occurs. Adults value learning that has direct application and is *relevant to their needs*.

Presentation Tips

- Tailor your speech to the interests of your audience. If you can't survey them or find out information from them beforehand, do a quick 'show of hands' to check for level of familiarity with particular topics.
- Rehearse your material aloud. Test it on friends, family or colleagues who can give you constructive criticism from a non-scientific point of view.
- Speak slowly. Give the audience time to digest what you are saying. Remind yourself to slow down by putting slash marks between sentences in practice sessions.
- Before speaking, smile at the audience to establish rapport. Make a preliminary remark before going into your planned beginning. You might comment on some aspect of the occasion, or on a remark made by the program's host, or just say 'I'm delighted to be here'. Establish empathy with your audience; let them know you are human through an anecdote. A bit of self-deprecating humor is one way a scientist can quickly break the ice with an audience.
- Use vocal variety. Let your voice and your delivery reflect the full spectrum of emotions and points of emphasis contained in your presentation. Let your enthusiasm for your work come through. Consider your speech an 'enlarged conversation' and speak as naturally as you would to one other person.
- Use gestures that complement the expression of your ideas. Avoid distracting, meaningless movements. Maintain eye contact with listeners throughout the presentation. If the group is very large, look at listeners in a section-by-section manner.

Presentation Outline

- **Introduction**

Know your purpose. The introduction will orient listeners to that purpose and motivate them. An audience member should be able to answer these questions after hearing your introduction:

How is this information relevant to me?

Why should I bother listening?

- **Body**

The body of your talk should be organized into meaningful groupings, with all key and subordinate points illustrated with facts or anecdotes from your experience. Listeners respond well to stories. The more mental imagery you can evoke, the more memorable – and persuasive – your presentation will be. Don't use too many facts and numbers; they numb people. Use anecdotes and human examples to illustrate a few key facts. Remember that the average American has approximately an eighth grade science education. Speak simply and concisely for best communication.

- **Conclusion**

The conclusion should redirect audience attention to your purpose.

Visual Aids

- Visual aids should be used only if they significantly enhance your presentation. With a non-scientific audience, good eye contact and body language that conveys your enthusiasm for your work can be more instructive and memorable than most slides.
- If you do use slides, don't let their content dictate the course of your presentation. Decide what you want to say, and then use slides to illustrate certain points. Nothing is deadlier for a non-scientific audience than a speaker droning repeatedly, 'And this slide shows...'
- Information on the visual aid should be to the point, easy to interpret, and interesting. Try to avoid using more than four words per line and four lines per page/slide. The type should be large enough to read from the back of the room.
- Most scientific slides are too complex for the lay public. Don't use a chart or graph unless it can be quickly understood.
- Consider other types of illustrative material that might enhance your presentation: a piece of equipment, and artifact, a working model for the system about which you are speaking.
- Have the lights dimmed, but not completely out. Continue to face your audience and not the screen.

Challenges from the Audience

- If you are challenged on a statement, you can diffuse the situation by acknowledging respect for another's beliefs and values, and also by framing your statements as 'I' messages.
- Never say 'you are wrong' or any variation thereof. If it is clear that someone in your audience is making statements based on misinformation, a good way to respond is to ask 'May I tell you something more (or give you additional information) about that?' Asking permission to convey the facts is more likely to induce the person to listen.
- Control your temper. If your opponents rant and rave, you will win points for your restraint. Hold the floor by raising your voice slightly and using body language to assert your authority. Keep your head up and look at the opponent in an assertive way.
- When you have difficulty getting a word in edgewise, make a general plea by saying, 'I'd like to address that point', and then plunge right in.
- You are unlikely to convert your antagonist, so direct your energies to convincing the audience.

Responding to Audience Questions

There are two ways to set up a question and answer session following a presentation: If time is limited, you may wish to have audience members write their questions on index cards to be passed to you when you've finished speaking. Either you or someone you designate can screen the cards, selecting for those you want to answer. An open session is more difficult to control, but may be more satisfying to your audience. After you acknowledge an audience member, repeat his or her question to be sure that everyone has heard it (and give yourself time to formulate an answer).

You should be able to anticipate many questions. Write out the ones that you expect and your answers before the presentation. The session will be more interesting if you can introduce some new information in your responses.

Body language is important. Don't cling to furniture or cross your arms tightly; you want to convey an air of openness and accessibility. Even if a question is irrelevant, appear to be concerned about what the person has to say. Look at the entire audience to maintain contact when responding. If the same question is asked more than once, patiently answer it again.

When someone asks several questions at once, you are free to choose the one you would like to answer and ignore the others. If you would rather not answer the question directly, use it to lead into a point you do want to make.

If you don't know the answer to a question, say so. But cite a possible source of the information or offer to get the information for the questioner. Always finish on a high note. Don't keep answering questions when audience interest seems to have waned. You can invite those who have unanswered questions to speak to you privately at the conclusion of the program.

Group Strategies

Small group work can be very effective in promoting learning. Individuals who might not ordinarily speak up are more likely to express their ideas to a small group of their peers. In addition, discussions with peers are a good way for participants to process information and relate it to their own experiences.

Think-Pair-Share ('Think it, Ink it, Try it, Fly it')

Have participants reflect on a question individually and write down their thoughts. Circulate to monitor progress. Then, have them pair off or form small groups (no larger than 4) and discuss what they have written. Gather comments from each group to bring everyone back into a larger discussion. You may want to gather all comments in writing on the overhead or board *before* evaluating or discussing them to facilitate the sharing of information.

Problem-Solving Groups

Have each group of participants work on solving a problem together. For example, provide primary source materials that audience members must use to make inferences and draw conclusions from. Different groups may work different aspects of one problem, or all groups may work on similar materials to see if they reach the same conclusions. You may want to provide a range of options for all teams to choose from and then have each team justify their choice.

Rotating Stations

This can be used in conjunction with problem-solving groups and works well for presenting to classrooms. Cluster related materials at 'stations' and have questions associated with each station. If you are presenting to a conventional group of 32 high school students in a 50-minute period, have students work in groups of 4 and allow them 5 minutes at each of 8 stations. After each 5-minute period, use a signal to rotate them to the next station. Circulate among the groups to answer questions and check for understanding. Reserve enough time at the end of class to summarize and to help the class reach appropriate conclusions.

Cooperative Groups

Again, this strategy has wide applicability. The key is to foster 'positive interdependence' within a group. Assign, or have group members choose, various roles that are necessary for group functioning. For example, students could number off 1-4. Then perhaps the number 1's obtain all the materials, number 2's make sure that everyone's thoughts are heard, number 3's be responsible for writing down the collective ideas of the group, and number 4's be responsible for presenting them to the class. Write down the tasks associated with each number so students on the overhead or board. It is advisable to make the 'clean-up', if there is any, the responsibility of the whole group.

Jigsaw

Material to be processed is divided into four parts. Each person in the group is responsible for learning 'their' material and for summarizing its main points to share with others and for thinking of questions that will test understanding of the material. If time permits, have them meet first with others outside their group of four who are learning the same material to discuss it and come to consensus on its important features. Have participants meet back in their original groups to teach their material to the others. Each participant should take notes on the summaries of their peers and be questioned in order to ensure that they have understood the material.

Multiple 'Intelligences'

An awareness of different learning style preferences or 'intelligences' can be helpful when thinking about how to reach audience members. Most people have several areas of strength but prefer to receive information in particular ways.

Linguistic

Ability to: think in words and to use language to appreciate complex meanings

Likes to: talk, read, write, tell stories

Evident in: poets, novelists, journalists, most widely held human competence

Logical/Mathematical

Ability to: calculate, quantify, consider propositions and hypotheses, and carry out complex mathematic operations

Likes to: do experiments, figure things out, work with numbers, ask questions, explore patterns and relationships

Evident in: mathematicians, scientists, detectives

Visual/Spatial

Ability to: visualize images, think in three dimensions, to reason spatially, to manipulate images.

Likes to: draw, build, design, create, look at pictures, play with machines

Evident in: pilots, sculptors, architects

Musical

Ability to: discern pitch, rhythm, tone, and to, create, reproduce, and reflect on music

Likes to: sing, listen to music, play an instrument

Is good at: picking up sounds, remembering melodies, noticing rhythms

Evident in: composers, musicians, sensitive listeners

Bodily/Kinesthetic

Ability to: manipulate objects and use a variety of physical skills. Involves sense of timing, and perfection of skills through mind/body union.

Likes to: move around, touch and talk, use body language

Is good at: physical activities such as sports, dance, acting, hands-on projects

Evident in: dancers, surgeons, crafts people

Naturalist Intelligence

Ability to: discriminate among living things as well as sensitivity to features of the natural world.

Gardner speculates that much of consumer society exploits the naturalist intelligence, which can be mobilized in the discrimination among cars, sneakers, etc.

Evident in: botanist, chef.

Interpersonal Intelligence

Ability to: understand and interact effectively with others. Involves effective verbal and non-verbal communication, a sensitivity to moods and temperaments

Likes to: have lots of friends, share, cooperate, talk to people, join groups

Is good at: understanding people, leading others, organizing, mediating conflicts

Evident in: teachers, social workers, actors, politicians

Intrapersonal Intelligence

Ability to: understand oneself-one's thoughts and feelings and to use such knowledge in directing one's life.

Likes to: work alone, pursue own interests, reflect on feelings

Is good at: understanding self, being original, following intuition

Evident in: psychologists, spiritual leaders, and philosophers

Compiled from: Campbell, B. *The Multiple Intelligences Handbook; Lesson Plans and More*, 1994., and 'Different Child, Different Style', Kathy Faggetta and Janet Horowitz, *Instructor Magazine*, September, 1990.

<http://www.pz.harvard.edu/Pis/HG.htm>

<http://www.ascd.org/readingroom/edlead/9709/checkley.html>

Biography of Howard Gardner on Project Zero Web Site

Interview of Howard Gardner with Educational Leadership

K-12 Presentations Before Going into the Classroom

- **Partner with the teacher in preparing your presentation**

Ask the teacher about the characteristics of the class. Discuss your ideas and ask for feedback. Prepare your presentation and activity based on what the students already know. Check the enclosed learning characteristics of different age groups to determine how complex your material should be. WABR is also available to help you plan presentations. For older students, you can send some background reading material that relates to your presentation in advance.

- **Assemble resources to take to the classroom**

Bring props! Keep in mind that your goal is to arouse curiosity, excitement, eagerness, and the desire to know more. The tools of your profession may be commonplace to you, but they are fascinating to most students. Something as simple as a petri dish that you pass around can be a teaching tool. NWABR may also be able to provide some resources to support your presentation or to leave behind after you go.

- **Prepare to use terminology that is appropriate for the students**

Students are unfamiliar with terms such as ‘bench science’. If there are many words or concepts that students should know in advance, give them to the teacher beforehand and (s)he can help students learn them.

- **Think of relevant questions to pose during your presentation**

Questions are an excellent way to stimulate student thinking. Ask clear, single questions rather than multiple questions at once. Strive for questions that ask students to apply their knowledge, relate their learning to past experience, give an explanation, or draw a conclusion.

Ask the teacher to have students write questions on cards the day before and collect them at the beginning of class. You will get many more questions this way than if you simply ask for questions at the end of your presentation.

Get inspired! You can help students...

- Understand the positive and vital role of science in today’s world.
- Gain an understanding of the work scientists do.
- See scientists as real people.
- Lay the foundation for careers in science in technology.
- Understand the process of biomedical research and correct misinformation concerning the use of scientific models.

In the Classroom: Characteristics of Students

K – 3rd grade (6-9 years old)

- Curious about world around them
- Eager to learn
- Very literal
- 10-minute attention span
- 'Me' centered
- Can remember and follow only one or two directions at a time
- Like 'concrete' things, can't easily understand abstract concepts or ideas

4th –6th grade (10-12 years old)

- Interested in things they know
- Like puzzles, challenges
- Can classify items
- 20-minute attention span
- Will work in groups
- Can formulate ideas
- Like 'concrete' things

7th – 8th grade (13-14 years old)

- Attempt to be 'cool' and may appear aloof
- Make jokes or 'put downs' to save face
- Emotional
- Sensitive about self, easily embarrassed
- Will challenge authority
- Can understand some abstract concepts
- Still like to see and touch 'concrete things'

9th – 12th grade (15-18 years old)

- Able to carry on discussions
- Appreciate hearing about what you do at your job, classes you took to become qualified, etc.
- Important to have others think well of them (self-conscious)
- May not readily respond to requests for input or questions, may need some prodding
- Able to think in abstract terms, but still like to do 'hands-on' activities.

Tips for the classroom

In Washington State, teachers are required to remain with classes while there is a guest speaker. While a teacher should always be there to maintain order and attention, you might find the following suggestions helpful for establishing and maintaining your own rapport with students.

- Be yourself. Dress like you do on the job.
- Keep your plan simple.
- Bring 'stuff' to DO. Kids love hands-on learning.
- Avoid jargon. Translate your language into words students understand. Make sure that all your materials are readable.
- Make eye contact with the students and call on as many kids as possible because they love the personal attention. Circulate in the classroom.
- WAIT several seconds before calling on students to answer a question because the whole class needs time to think about the question before someone answers it.
- Tell stories and amusing anecdotes. Use appropriate analogies. Use humor. Be gross. Kids love an excuse to react.
- Explain instructions in small chunks, pausing often (15 minutes of instruction for a 2-hour lab is too long). If you MUST lecture, stop every 8 minutes and let students discuss your topic with each other.
- Organize all materials in advance, because students (especially the younger ones) sometimes have a hard time waiting.
- Wait to give handouts until it is time to read or use them because otherwise students will be distracted. Use a prearranged signal to get students' attention during activities (check with the teacher to see if one exists). Stop and wait for students to let you continue speaking if they get too noisy.
- Use student volunteers to help you set up and distribute materials, samples, pictures and handouts because students love to feel important.
- Require that students raise their hands to participate because they will probably all want to talk at once.
- Model good safety practices, because children learn by following role models.

Scientists and Teachers

Assume that scientists and teachers...

- Come from very different professional cultures
- Share the same passion for science
- Have very different demands upon their time
- Deal with the general public in very different ways
- Need and can help each other

Before you visit, consider that...

- Scientists are treated with more prestige than teachers – by parents, students, and administrators
- Science teachers might be intimidated by the specificity of your knowledge about your science specialty.
- In general, scientists are trained to be critical and teachers are taught to be nurturing.
- You might be unfamiliar with the school's complex scheduling.
- Helping teachers implement a lab with their students can be as valuable to them as any other kind of assistance.
- Working collaboratively with teachers will teach you about the school system, its issues, problems and progress.

What NOT to do...

- Don't be late! Class starts when the bell rings.
- Don't theorize. Use specific, concrete examples.
- Don't correct the teacher in front of the students.
- Don't be upset or take it personally if some students are not attentive; you don't know the full scope of their issues.

Portions modified with permission from Barbara Schulz, Science Education Partnership, Fred Hutchinson Cancer Research Center. Barb has been awarded the Presidential Award for Excellence in Teaching Science and Mathematics, the Outstanding Biology Teacher Award, and the Tandy Technology Scholar Award.

Working with the News Media

The following information is provided courtesy of Health Sciences/UW Medicine News and Community Relations:

Newspaper and magazine articles, television interviews, radio programs and talk shows are all excellent conduits for increasing the visibility of your program or practice. Working with the media can help educate the public and alert the community to advances in research, clinical care and education at the University of Washington.

The purpose of this guide is to help ensure that your contacts with the media are as successful as possible. We outline the relevant points to help you prepare for an interview, so that important information about the UW and your work is clearly and accurately communicated and makes a positive impact on your audience.

Media relations differ from advertising in that the message and the placement are not totally controlled. Advertising exposure is purchased, while media exposure is earned.

For assistance and information, call Health Sciences / UW Medicine News and Community Relations at 543-3620.

Media relations team: (206) 543-3620, 24/7

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In addition to the above, the following staff also carry our pager on a rotating schedule:

Claire Dietz
Assistant director for quality

Leila Gray
Assistant director for print and electronic publications

Justin Reedy
Science writer

Approaches to the Media

Dealing with the media should be a team effort between you and the office of Health Sciences / UW Medicine News and Community Relations. In general, there are two approaches with the media:

- Proactive media relations involve contact initiated by you or News and Community Relations. This approach keeps you and your program in the forefront of the journalist's mind as an approachable, reliable and responsive source of information
- Reactive media relations involve contact initiated by journalists. It may be an inquiry about your own work or about the work of others in your field, about which you may be an expert source.

Consider your alternatives. Chances are that your contacts with the media will be brief and positive. However, if you are approached about a controversial issue, you may wish to weigh the advantages vs. the disadvantages before granting an interview. You should assume there will be a story whether you cooperate or not, and it may be important to have your viewpoint included. In a no-win situation, consider having a written statement prepared by and issued through News and Community Relations.

Understanding the Media

The media:

- report stories in words, pictures and sounds
- often have tight deadlines to meet
- aim to stimulate, interest and even entertain their audiences; they are not only information or education services
- often look for conflict, controversy and innovation to stand out and attract an audience
- are looking for an angle that will make their story stand out from the competition
- are businesses that balance profit and loss and need to make money.

Defining "News"

Journalists must choose carefully the stories they cover, because of limited time, space and resources. Here are some general characteristics of "news." News is:

- relevant to many people
- timely
- extreme: sad, happy, serious, silly, the biggest, the worst, the best, the newest
- emotional
- educational
- different, unusual, unique
- controversial.

Before the Interview

- If time allows, give the reporter information written in lay terms (for example, an article previously written about your work, a fact sheet or backgrounder). Written background helps a reporter ask better questions, puts the story in context and clarifies difficult concepts. It also gives the reporter something to refer to back in the newsroom. If possible, keep a file of good stories that have appeared in newspapers or popular magazines on your research or your field. Do not expect the reporter to wade through technical publications or textbooks.
- In any request for an interview, remember you have rights and can **set some ground rules**, including giving yourself some time to prepare (even if it's only 10 minutes to collect your thoughts), while still accommodating the reporter's deadline.
- Prepare yourself by **anticipating questions**. If there's time, ask your colleagues or media relations specialists at Health Sciences / UW Medicine News and Community Relations (NCR) what questions would be likely. We can be reached at 543-3620.
- For most interviews, **think in terms of explaining your work to a neighbor** who knows little about your field. Your answer to a TV reporter's question will likely be more general than your answer to a print reporter for a trade magazine.
- **Know the main points** you want to make and jot them down before the interview. Keep them few, and review them immediately before the interview. The key to a successful interview is making sure you are able to convey all your messages in a positive, upbeat manner.
- Write your message in 100 words and practice it. Be concise; the more editing you do of your own verbiage, the less the reporter will have to do. **Practice:** You can learn to deliver concise statements. Interviewing isn't a natural born talent.
- Prepare **relevant, real-world examples** and analogies to help people understand. This is what viewers and readers will remember best.
- **What do you hope nobody asks you?** Write a short answer for the worst-case question, and practice it.
- **You do not have to respond immediately** if the interviewer calls without an appointment. However, be aware that reporters often have tight deadlines. Try to arrange a mutually convenient time for the interview. Don't let yourself be pressured if you are caught off guard.

Preparing for an Interview on Research Findings

If you receive notification that a study is being published, or if you are presenting research at a scientific meeting where reporters may be present, you may receive calls from reporters. It is useful (and sometimes requested by the journal publishers or meeting organizers) to have a lay summary available.

Whether you are preparing the summary yourself, or requesting the services of News and Community Relations, here are some guidelines:

- **Prepare a double-spaced summary** of the findings. Use simple English—as if you were explaining it to a grandparent or an intelligent 8th grader. Try to keep it to two double-spaced typed pages. Your points should be stated clearly and simply, as much as possible without technical jargon or abbreviations. Relate your findings to the everyday world of those who will read or hear the story.
- **Highlight the most important aspects** of the work. Answer the following in roughly this order:
 1. What has been found? Summarize the findings in an active-voiced opening sentence.
 2. Where and when is the research being published or presented?
 3. Why and how is it important, new and interesting? Clinically? Advancing basic scientific knowledge with future clinical implications?
 4. Provide important details of the research: number of subjects, how they participated in the study, what was found?
 5. What are the next steps in this research?
 6. What are the public and private sources of funding?
- **Make the most important points first.** Unlike scientific papers that present first the data and then the conclusion, news writing starts with the findings and then gives the background. This style is called the inverted pyramid, proceeding from the most important single point and then broadening out with additional detail.

During the Interview

- Don't wait for the reporter to ask the right question. **Make your key points** early and often. Don't be limited by reporters' questions or their understanding of the issue.
- To make your key points, build bridges from the reporter's question. Some good **bridge phrases**:
 - “That is an interesting thought, but in my opinion the real issue is . . .”
 - “It's important that patients know . . .”
 - “You should also know that . . . ”

"The real issue is . . ."

"I don't have a crystal ball, but I do know . . ."

- Keep your answers **short and to the point**. Try to answer the question in your first sentence, and then elaborate.
- **Don't become too chatty**. You are talking to a reporter and what you say can be on the front page tomorrow. Be wary of jokes and casual asides. They often don't come across the way you meant them.
- **Talk in a conversational manner**, rather than in a "doctor at the podium" tone. Don't use professional jargon or statistics your audience won't understand.
- **Don't be afraid to say you don't know**. Tell the reporter you'll get an answer before his or her deadline, or direct the reporter to the appropriate person to answer.
- You don't have to answer a question you don't understand. Ask the interviewer to **clarify or rephrase** it.
- **Nothing you say is "off the record."** Anything you say after "hello" and before "goodbye" is fair game for quotation. The interview includes what is said off-camera as well as on-camera. You can and will be paraphrased.

After the Interview

- Offer to check technical points, but **do not ask or expect to review the story** before it is published. This is not customary and could indicate that you were not comfortable with the information you provided.
- **Be available for fact checking**. Let the reporter know the best times and the best means to reach you. This could make the difference between a reporter succeeding in reaching you to check crucial information, or running the story with his or her best understanding of a difficult topic.
- **Evaluate your performance**. Find out when and where the interview will be printed or aired, and read it or tune in.
- If you feel mistakes have been made, **be cautious about requesting corrections**. If it is a bad-news situation, a correction rehashes the bad news. Do call the reporter to correct factual errors in a story. Even if the paper or station won't run a correction, it's worth educating the reporter so that errors aren't repeated as fact in follow-up stories.

The Newspaper Interview

- **Familiarize yourself** with the publication and reporter before the interview. Is the reporter a medical reporter? An investigative reporter? A general assignment reporter? A medical reporter, for example, will be interested in your study and its significance. An investigative reporter may want to know if you have any stake in the financial success of the product.
- **Use follow-ups** to your advantage. A reporter may follow up with a phone call a day or so later to ask an additional question or ask for clarification of a point you made. Use these follow-ups to your advantage and re-emphasize the key message points.
- **Choose your words carefully**, even before you think the interview has begun and after you think it has ended. You are always “on the record.”

The Television Interview

- **Prepare sound bites.** Rehearse pithy remarks of 15 seconds or less on your main points. In TV jargon, these are called sound bites, and they are the building blocks of broadcast news stories.
- **Hold a mock Q&A.** If possible, have a mock question and answer session ahead of time. Prepare likely questions and practice your answers. Ask for help from the media relations specialists in News and Community Relations (543-3620).
- **Repeat your messages.** Played back as a whole, your tape won't sound like a well-oiled presentation, but that's not what you're aiming for in the taped interview. You want to make sure that when the reporter goes into the editing room to tweeze out a sound bite, your messages are all over that videotape.
- **Don't be afraid of the pause.** After the question is asked, stop, relax and collect your thoughts, then state your answer. Any dead time probably will be edited out of the tape. Think of this as an opportunity to breathe.
- Unless it's a live interview, **don't be afraid to stop in mid-answer** and ask to start again. Remember, tape can be edited. However, it's up to the reporter to decide which answer to use.
- **STOP when you've finished.** It's the reporter's job to fill dead air time. Don't say more than you want to.
- **Take advantage of second chances.** Usually when broadcast reporters repeat a question or ask it in a slightly different way, they are giving you a second chance. They have realized that your first answer was not a good “bite.” Take advantage of this

opportunity. Avoid phrases like, “Well, obviously the fire did a lot of damage. Look for yourself.” A better answer is, “The fire destroyed the building. We are launching an immediate fund-raising campaign. Send your check to...”

- **Don't be trapped into saying more than you would like.** There may be times when repeated questioning is an attempt to trap you into saying more. If so, repeat the same answer or say that you believe you've already answered the question. If the exchange gets to this point:

Q: “I don't believe you've answered the real question at hand.”

A: “I've given you my answer.”

- **If you want to be quoted, speak in complete sentences:**

Q: “It is our understanding that Drs. Krebs and Fischer received a Nobel Prize for their research.”

A: “We've just received word that Drs. Krebs and Fischer have received the Nobel Prize in Medicine for their work on phosphorylation. We are extremely proud of them. Two other UW faculty have been awarded the Nobel Prize in years past.”

- **If you don't want your answer used, consider an exchange like this:**

Q: “Was the coach arrested for DWI?”

A: “That is correct.”

Physical Tips for the TV Interview

- **Think visually.** Suggest an appropriate visual setting for the interview, such as an office or conference room lined with books, or a research laboratory. Don't go on a cleaning binge; sterile settings make boring TV.
- **Avoid wardrobe extremes.** Don't wear busy patterns and shiny, noisy jewelry. If you're being interviewed in your clinical capacity, consider wearing your white coat.
- Ask the interviewer if you can **talk off-camera beforehand** for a few minutes to help yourself relax and get an idea of the type of questions he or she will ask.
- **Keep breathing.** Sometimes when we're nervous we have to remind ourselves to keep breathing. It's OK to pause occasionally to take a breath, and to talk slowly enough that you can breathe. Relax and speak in a conversational tone.
- **Look at the interviewer.** Often when nervous, we seem too stuffy or serious. Appear trustworthy by looking at the reporter – not the camera. Try not to blink too often: blinking can falsely signal that you are uncomfortable or hiding something.
- **Sit forward.** Sit with your tailbone against the back of the chair and lean slightly forward, which gives you an air of authority and involvement.

- **Use your hands.** Gesture naturally, no higher than shoulder level. If you are a hands-in-pockets person, don't jingle your change. You might want to empty your pockets beforehand.
- **Don't sit in a swivel chair.** You're likely to rock or swivel. If you cross your legs, remember not to bounce your leg.
- **Avoid side-to-side rocking.** Be aware of motion when standing.
- **Don't nod your head in anticipation of a question.** It could be perceived as a "yes" answer, when in fact your answer could be "no."

The TV Talk Show

A television talk show can be live or taped, but it differs from the taped news segment in that your remarks will air in their entirety. You still have to repeat your messages, but in a more polished way. Here are some additional tips for the talk show interview.

- **Meet with the host** before the show begins. Chat with him or her to reconfirm the topic and length of the interview. Ask a few questions to see how much the interviewer knows. Suggest a few possible angles the host can ask you about.
- **Take advantage of commercial breaks** to ask your host what questions are coming up next.
- **Assume you are always on camera**, even when you're not talking.
- **Avoid looking at the TV monitor.** Again, look at the interviewer, not the camera.

The Radio Interview

Radio interviews can be in the form of a taped segment for use in a news broadcast or in the form of a taped or live talk show. Some radio talk programs may provide the opportunity to answer questions from call-in listeners.

- **Your voice says everything.** Try to radiate warmth, enthusiasm, caring and authority.
- **Avoid the tendency to relax.** Energy disappears somewhere between the microphone and the listeners' ears ~ so increase the usual amount of energy in your speaking voice.
- **Avoid the small noises** that you are usually not aware of ~ like clearing your throat, tongue-clucking, and space-fillers like "um" and "ah."

- **If the interview is taped, you can repeat your messages again and again.** Your remarks will be edited, and you want to make sure your main message survives the cut.
- **If the interview is by telephone, you may want to have notes in front of you.** Close your door and remove any distractions.
- **Get comfortable** and remove all distractions. Have a glass of water or other drink nearby. You may want to have a lip balm nearby. Dry lips can be extremely distracting when you have to talk for an extended period of time.
- **If you're a guest on a radio talk show, listen to the show** a few days before you are scheduled to be the guest. If this is impossible, ask the station for a tape of a previous show.
- **On a listener call-in show:** Remember that the calls are being screened by a producer to reduce the likelihood of an off-beat caller. Answer the questions in a straightforward manner.

The News Conference

If you are involved in major breaking news, or if a number of reporters call requesting comment from you, News and Community Relations may organize a news conference. This allows all reporters to be accommodated at once and saves you from having to do a series of individual interviews. You can expect to see media representatives of print, television and radio.

- You may be asked to bring visual aids, such as x-rays, examples of the medical device in question, or charts. If the news conference involves a clinical research or patient care matter, you may be asked to identify a patient willing to attend and tell about his or her experience.
- You and others participating in the news conference will be introduced by the media relations coordinator, who may ask you to give an **opening statement**, which should be brief and in lay terms.
- After opening statements, the media relations coordinator opens the floor for **questions and answers from reporters**. The media relations coordinator will bring the formal news conference to a close when it appears that most reporters' questions have been answered. However, you should expect to remain in the conference room to **answer follow-up questions** from reporters who want to talk to you one-to-one.

Danger Zones

- **Correct wrong assumptions.** Don't let it slide if questions contain erroneous information. Correct it.
Q: "Many people are concerned about the large number of stolen pets used in research. What is the UW doing to prevent that?"
A: "I haven't seen any evidence that pets are being stolen and used in research, either here or at other institutions. The UW takes many precautions to guard against this: We buy cats and dogs only from animal dealers licensed by the US Department of Agriculture. We require our dealer to have people who sell their dogs sign a form acknowledging their animals may be used in research. Although we believe animals play a vital role in biomedical research, there is no place for pets in the laboratory."
- **Never repeat buzz words.** Don't echo a reporter's negative statements. Restating the negative is a form of legitimizing the reporter's assumption.
Q: "PAWS says the bone marrow transplant experiment on monkeys is tantamount to torture."
A: WRONG: "We are not torturing animals."
A: RIGHT: "Bone marrow transplants can be a lifesaver for people with deadly cancers like leukemia. In this study, monkeys are prepared for bone marrow transplants in exactly the same way that young children are prepared when they receive this treatment. We are studying the effects of enhanced bone marrow treatments on a primate model whose immune system is similar to ours."

Q: "Isn't it true that the UW is really a second-rate university?"
A: WRONG: "We are not a second-rate university."
A: RIGHT: "The facts speak for themselves. In each of the past 25 years, the UW has ranked among the top five universities in the nation in federal funds received for research. Furthermore, Money magazine lists UW as one of the nation's best buys in education."
- **Don't fall for A or B questions**
Q: "Is this a case of dishonesty or sloppy bookkeeping?" You are not limited here to A OR B.
A: "We are extremely pleased that our accountants caught this mistake early. That is the purpose of an internal audit."
- **Beware of hypothetical questions** and don't be pressured into speculating.
Q: "What if the School fails accreditation?"
A: "I would prefer not to deal with a hypothetical situation. It is our expectation that the School will pass its accreditation review and continue to produce outstanding practitioners serving every county in the state."

- **Avoid absent-party situations** and don't air spats or internal disputes in front of the media.

Q: "The state teachers' association is complaining about higher education's lack of involvement in the lobbying campaign."

A: "I plan to work closely with that association, and I am certain I will have an opportunity to discuss this issue with them personally."

You are never obligated to give an interview. As a public institution, we may be obligated to provide information, but this can be presented in the form of a prepared statement. Check with News and Community Relations, the UW Public Records Officer or the Attorney General's office to determine the necessity and advisability of releasing the information.

- **Work with News and Community Relations.** As mentioned before, in a no-win situation, consider the advantages of a prepared statement issued through News and Community Relations.
 - The information is presented in a concise manner, and you are not stating any more than you want to say.
 - It is unlikely that you will be misquoted.
 - It is likely that you will lessen the "news value" of the story since you have limited the information. This is particularly true for the television story since you have not provided the live interview so desperately needed for a lead story.
- **Remember that a "no comment" or "unavailable for comment" often makes you look worse.** It's better to explain WHY you can't respond – because of patient privacy, because your data analysis isn't finished, etc. You should assume that a story will run whether or not you grant an interview.
 - "Because the case is under investigation, the University can't comment at this time."*
 - "The case is before the courts, so I am unable to comment at this time."*
 - "I haven't seen the story/paper/study you refer to, so I'm unable to comment."*
 - "Patient privacy concerns prevent me from commenting on that."*
- **Set the record straight.** If you do grant an interview, treat it as an opportunity to set the record straight and put the situation in context.
- **Try to stay calm and pleasant** in the face of difficult questions. Getting angry with the reporter won't help you achieve your goal of conveying accurate information. Remember, your audience is the public, not the reporter. Remind yourself that part of the reporter's job is to ask the difficult questions.
- **Keep the big picture in mind.** Consider your long-term relationship with the media. It may be to your advantage to establish good rapport in this particular instance if you are going to need coverage for an event or an accomplishment in the near future.

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What You Can Do

News releases.

- Please try to give us as much advance notice as possible of news events such as a grant announcement or publication in a journal. This helps us understand the issue ourselves and come up with the best strategies to disseminate information. We respect all embargoes.
- Please also understand that not all news releases generate the same publicity. The chaos theory applies. There is no way to predict the results of any given news release or event. We are constantly trying new approaches and relying on tried and true techniques to get publicity. The sad but true fact is that for media, merit is not always the chief consideration.
- Being able to refer people to a patient - or someone directly affected by your research - is a powerful way of adding human interest to a story. It dramatically increases your ability to get coverage.

Health Beat.

- Health Beats are, in effect, a practical way of giving advice to your neighbors. They are also a proven way of attracting media interest throughout WWAMI, for several reasons and in many ways. If there is a topic that you feel comfortable discussing, let us know. We will interview you, and then produce a column for your review.

Health Source and University Week.

- Please send along all ideas. We cannot use everything, but we need to know what's going on in order to provide ideas to media and write articles for UWeek.

Experts list.

- We have an internal database, searchable by keyword, to use when reporters call us for experts in any given field. Feel free to suggest keywords and subject areas that we can use for you. Reporters work on deadlines that are so tight as to be ludicrous, and appreciate your speedy reply. Also be aware that the person who calls the reporter back first is likely going to be the most-quoted person in the story or report.

Guest editorials.

- Newspapers often welcome guest editorials. These represent an almost unique opportunity to get across a point of view without interference. However, they are short by most standards: 600 words or so. And they are most likely to be accepted if they are "pegged" to a news event, particularly an upcoming event. If you are aware of a newsworthy development that's coming up in your field – even if it is not generated by UW – it might be time to plan a guest editorial.
- We are glad to help you write the article to any degree: from ghostwriting to editing, which our office does as a matter of course. We encourage the use of as many specific details or examples as possible, to make the article more concrete and approachable to the general audience.

Engaging the Public in Clinical Research

University of Washington, April 30, 2004
Myrl Weinberg, CAE
President, National Health Council

WHY SHOULD WE ENGAGE THE PUBLIC?

I want to begin by talking about why we should engage the public in clinical research. First, it is the right thing to do. It's also the smart thing to do, and it is clearly in your own self-interest. We need the public **to participate in, and support and advocate for, clinical research.**

According to CenterWatch, about 81 percent of all clinical trials are delayed at least one to six months due to difficulties in enrolling participants, with another five percent postponed six months or more. And, as hard as it is to attract participants, it's even harder to keep them. Three million Americans do complete clinical trials each year, but so many others drop out that 90% of trials never make it to the end.

According to a 2003 HarrisInteractive poll, only 10% of the U.S. adult population has ever participated in a clinical trial. However, 77% say that if asked they would consider participating. Knowing the reasons why some people have participated and the reasons that would encourage, or inhibit, many more people from participating is useful as we work to more fully engage the public in clinical research.

It would be a mistake to ignore the many factors that encourage or discourage participation. The HarrisInteractive poll describes factors that would influence the decision of large numbers of people, like

- * Convenience
- * Having minimal side effects
- * The belief that the benefits outweigh the risk, and
- * The hope of a cure

Large numbers of potential and former participants also mention six important "rights." These are –

1. Having access to their own test results at the end of the study
2. Having their expenses paid
3. Receiving a copy of the clinical protocol
4. Being paid for their time
5. Being seen by a doctor on every visit, and
6. Having access to their test results throughout the study

In addition, a large percentage believes that participants should be able to talk to other participants. We all know there may be very valid reasons not to do some of these things, but it is our responsibility to effectively educate people so they will understand.

We also need more well informed and effective advocates for the clinical research enterprise. The truth is that public opinion drives public policy. And, as you know, public policies can support or inhibit the conduct of clinical research. Yet, many members of the research community underestimate or even dismiss the implications of this fact as it applies to the formulation of science policy and the allocation of appropriations that together provide the public framework for the conduct of research.

A Research!America poll states that 41% of scientists believe their becoming involved in public outreach makes no difference.

Another reason to engage the public is that many consumers expect ~ and sometimes demand ~ that they have a role in the formulation of the research agenda and in the design, review, and translation of the research. In addition, more consumers are aggressively accessing medical research and health information, and pushing for better translation of research into practice.

NIH Director, Dr. Elias Zerhouni, has stated that, “engaging the public in the clinical research enterprise is a strategic imperative.” The public can aid the translation of research findings into practice, help to speed up the clinical research process, and help to make the research process more efficient.

SO, WHAT DOES ENGAGING THE PUBLIC REALLY MEAN?

It means having public representatives actively participate in every aspect of the clinical research enterprise. Such engagement includes serving on IRBs, planning committees for community outreach and involvement, and as spokespersons and advocates for clinical research.

It means involving the public in setting research priorities, in improving human participant protections within your research institution, and in improving informed consent processes.

It means developing and implementing education programs to ensure that the public:

- Understands what clinical research is – what you are doing and why!
- Understands the benefits and risks of participating in clinical research, and the balance between the risks and benefits.
- Believes in and trusts the research institution as well as the researchers themselves.
- Knows where to go, what to do and how to do it to be an effective advocate for clinical research.

I strongly suggest that you involve the public in the development of your education programs. Involving the public will help you to:

- identify issues
- anticipate reactions/situations
- plan ahead about how to address the issues and reactions.

Public outreach also means reaching out to the media. It is our hope that researchers will promote an open dialogue with journalists about research and its benefits and risks. In order to establish and maintain the public's trust, it is important to be accountable and accessible to the public, and one way to do this is through the media. Your research serves the public. However, the public often is not aware of your research, or how it may ultimately benefit them and the communities in which you they live, as well as the health of our nation.

These same messages should be communicated to your elected officials. You need to tell your story. Many elected officials do not understand the connection between science and prosperity. They are not aware of the challenges you face or how scientific progress is accomplished. Meeting you, hearing from you about the specifics about your research, visiting your research institutions – all of these activities will make your research and the larger clinical research enterprise more real and personal for these policy makers who will set the framework, including funding levels, within which your research is conducted.

Combined, your outreach to the public, to patient organizations, and the communities in which you all live, can have a profound effect on the research environment in which you work. And, together, you, your institutions, patient organizations and the public at large can carry powerful messages to the media and policy makers.

CHALLENGES YOU FACE WHEN TRYING TO ENGAGE THE PUBLIC

According to a Research!America poll, 74% of you say you are too busy to conduct outreach to the public. And, it is true that involving the public in your research enterprise takes time. Add to that the fact that many scientists, about 49%, do not know how to become involved in outreach to the public, and, that there are few incentives to do so, and it is easy to understand why so many researchers are hesitant to engage with the public.

Another challenge is that the “public” is not a single entity. As you know, the public is comprised of people from many cultures, from many socioeconomic groups, with varying levels of education ~ many of whom have limited health literacy.

The Council defines health literacy to include not only an individual's reading level, but also additional factors such as cultural background, language, education level and readiness to receive health information. All of these factors can create barriers to comprehension,

and therefore to individuals' ability to take action to improve their health or the health of others, perhaps through participating in and supporting clinical research.

Health literacy is not a small or insignificant problem – it is an enormous challenge! Estimates are that 90 million people in the United States have inadequate or marginal literacy skills and that half of patients in the health care system cannot fully participate in their health care because of comprehension problems.

Another challenge is reflected in the public opinion polls conducted by Research!America, which show that 61% of the public believe that clinical research has great value, but also indicate that 76% of the public say that their major concern if deciding whether or not to participate as a volunteer in a clinical research study is the reputation of the institution. Making sure that you are doing everything possible to enhance the reputation of your institution is critical.

One way to enhance your institution's reputation is to have your human research protection program accredited. When asked, 80% of the public strongly agree that universities conducting clinical research should be certified by a national board to ensure the research meets national standards.

However, becoming an accredited research institution can also be a challenge.

HOW DO YOU ENGAGE THE PUBLIC?

First, and basic, is to have ongoing two-way communication between your research community and the public. It also is critically important to provide education about clinical research – what it is, its value, and the critical roles the public can play in helping researchers.

I suggest that you establish specific mechanisms to interact with the public, receive public input and demonstrate that such input is fully considered, whether or not it is adopted. Such mechanisms can include town meetings, presentations at community organizations, and an interactive Web site.

You could also have regular, recognized forums that will enable you to interact constructively, and, again, in a systematic and predictable way, with various public constituencies.

Such forums or other mechanisms can provide you with valuable advice on, among other things, how best to achieve the involvement of a broad representation of the public in your clinical research enterprise, how to enhance public understanding of clinical research, and how to identify and recruit participants for clinical research.

Public participation provides valuable information regarding every aspect of clinical research, from formulating a research agenda to study design, study review, oversight at all levels, and how best to disseminate and translate research into practice. We believe the public must have a seat at the table every step of the way. These public representatives will not be silent, as one of today's speakers described, if you pick the right people, make sure they receive appropriate training, if needed, and have more than one!

One final point I'd like to make relative to dialogue with the public is to encourage you to be sure to establish and maintain dialogue with responsible critics. The more they know about the facts, the more open, accountable and transparent you are about the research you are doing and its potential benefits and risks, the more likely it is that the criticism will be lessened. You may even turn a critic into an advocate!

I also want to encourage you to specifically work with the voluntary health agencies or patient organizations in your community. These organizations serve and represent people with chronic diseases and disabilities, many of whom have, or will, benefit from the research you are conducting.

Voluntary health agencies understand the role of clinical research. Some help recruit participants for clinical research through their Web sites or other communications and some maintain a database or patient registry of potential research participants. Many provide funding for research directly to researchers and research institutions. And, VHAs provide information to the public and their constituencies about research results.

They also have great advocacy training programs for the volunteers in your community. Working together, you can make sure the right messages about clinical research are included in the VHAs' work with the media and policy makers.

Locally, many VHAs are expert at reaching out and involving the community and would be prime targets for partnering with you as you seek to involve the public in your clinical research endeavors.

Also work with the churches, synagogues, Lions Clubs and other community entities. These groups can be especially helpful as you seek to involve broad and diverse communities in your clinical research enterprise.

As I said earlier, it is important to **work with the media**. Treat journalists as your allies in communicating about research to a broad audience. Share your excitement about the research you are conducting and the potential for discoveries that will treat and, perhaps, cure many chronic diseases or disabilities.

You have a major responsibility to communicate and disseminate research results, which, when done well, involves active outreach to, and involvement of the public in planning and evaluation.

Another way to use the media is to do what NIH has done.
(Refer to *Washington Post* ad, seeking participants in their clinical research studies.)

Accreditation

Another way to help establish and maintain the public's trust is, as I said earlier, to have your institutions accredited.

In 2001, the National Health Council joined six other national organizations deeply committed to the ethical conduct of human research and human participant safety in creating **the Association for the Accreditation of Human Research Protection Programs or AAHRPP**.

AAHRPP is a nonprofit entity that employs a voluntary, peer-driven educationally based model of accreditation. It was founded on the belief that ethical soundness and scientific merit in research are inextricably intertwined, and are critical to ensuring the safety of people who enroll in research.

The founders of AAHRPP strongly believe that strengthening the quality, integrity, and ethics of clinical research requires a total institutional commitment that can best be achieved through voluntary accreditation. We believe that only full participation by research organizations will preserve the public's confidence in research.

The public's trust in and support for clinical research depends, in part, on research organizations providing increased accountability. Voluntary health agencies and the communities in which many of you conduct clinical research will be able to rely on accreditation as a signal that researchers and their institutions regard human safety as a paramount concern.

In addition, AAHRPP itself models the involvement of the public by requiring that public representatives serve on its Board of Directors, its site visit teams and its Accreditation Council.

I do want to note here that it is my understanding that the University of Washington is considering accreditation by AAHRPP.

Another recommendation I have is that you **identify resources, data and trainings that will enhance your public outreach abilities**.

For example, the IOM Clinical Research Roundtable publication resulting from its workshop on engaging the public in clinical research is an excellent resource, as is the HarrisInteractive poll on the reasons why people participate, or would participate, in clinical research.

Another good resource is the book *Informed Consent: a Guide to the Risks and Benefits of Volunteering for Clinical Trials* that was sponsored by the National Health Council. This book provides an important tool to assist people to make proper decisions about volunteering for clinical research trials. As researchers, this book will help you know what it is important to communicate to any potential volunteer for clinical research, issues important to vulnerable populations, and what people are being told to do when things go wrong.

Research!America offers specific advocacy workshops for the practicing scientist to help researchers enhance their ability to communicate with nonscientists and be accessible to the public. As one radio reporter put it, “You need to make me care and understand your story in such a way that I can explain it to my listeners in 35 seconds!” It takes training for any of us to be able to respond to a challenge like this!

In closing, I want to note that it has always been important to engage the public in our discussions about research, but with the decoding of the human genome, it is more important than ever. The promise of genetics research is tempered by the risk that individuals’ genetic heritage could be used against them by employers and insurers.

Fear of these possibilities – apprehension about what could happen if a person’s genetic tendencies for particular diseases are known -require all of us to work together with the public to ensure that people continue to believe that their support for, and personal involvement in, clinical research is valued, respected, safe, kept confidential when it needs to be, and, ultimately, will lead to new treatments and cures for those with serious chronic and often, life-threatening conditions.

Selected Resources

UW Office of Clinical Research

<http://www.uwmedicine.org/Research/ClinicalResearch/>

Boston Children's Hospital: Parent's Guide to Medical Research

<http://www.bostonchild.vitalconsent.com>

Department of Health and Human Services

Office for Human Research Protections

<http://www.hhs.gov/ohrp/>

National Institutes of Health: National Cancer Institute

Clinical Trials Education Series

<http://www.cancer.gov/clinicaltrials/resources/clinical-trials-education-series>

National Institutes of Health: ClinicalTrials.gov

Information on Clinical Trials and Human Research Studies

<http://clinicaltrials.gov/>

Northwest Association for Biomedical Research

Links to information on the research process, including clinical trials

<http://www.nwabr.org/research/understanding.html>

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