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Health Research'...let's get something
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'Health Research' ...*let's get something right before the sun goes down.*

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Darwin, Northern Territory 2003



OBJECTIVE

The main objective of this article is to provide a quick reference for health researchers working in Indigenous communities. It is intended to provide a series of preliminary checkpoints which will provide an idea of community concerns and identify support mechanisms and personnel necessary for the success of the research project. It is important that the research be centred and controlled according to region or location. Some research is guided, monitored, and assessed by external forces who are not "on the ground" to see and feel the real picture. The community has an important role to play in determining how the research is to be conducted, written up, interpreted, and shared. One could think of this as a type of advisory or overseer group.

These objectives may be stated in point form thus:

1. To examine, consider and respect any concerns and misunderstandings the people/community may have concerning "research."
2. To explore the concept of *offering partnerships* as a "buy in" option.
3. To generate shared interests.
4. To promote effective geographic control.

EX-TRA CONSIDERATIONS

In considering health research with communities, there are important preliminary steps that, if taken, will foster and encourage participation.

1. Explain the practice and language of health research and vaccination trials. Answer the questions how, who, when, where, and why?
2. Explore community priorities and cultural values.
3. Extend out, rather than exclude from.
4. Expect obstacles, delays and interruptions.

MEETING THE NEEDS OF....?

Health research meets many needs. Ethical research must meet the needs of all those who participate or are affected by it. Individuals and communities as a group must give their permission for the research to be conducted. If local community people work with the health research team, community participation is increased at two levels. For maximum value, these community workers must be equals with the other team members. The challenge is often how to meet these community needs while remaining responsible for the other, equally pressing, commitments, especially those of funding agen-

cies and research institutions. A quick list of needs that must be met might look like this.

1. The People	5. Research guidelines
2. Your own	6. Academia
3. The Employer	7. The time frame
4. The Funding Body	8. Improved health

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There must be a commitment, from the beginning, to take the research findings and their impact back to the community, in forms that will be readily understood. This is particularly important when information and knowledge are either taken away or used in a manner that is not understood or approved by the community. Some considerations in this area are:

1. Impact of research: interest, response, other findings?
2. Benefits of research: the patient, community, health improvement?
3. Justification of research: to prove a point, dollars well spent?
4. Improvements resulting from research: immediate, short and long term.
5. Report on the research findings: for whom is it written, how is it interpreted and/or translated?

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Health research is usually reported to and for other health researchers and health professionals. The illustration on the next page shows how the technical information from an epidemiological study of rheumatic fever can be interpreted for communities. Instead of numbers, scientific language and graphs, a visual story conveys the necessary information.

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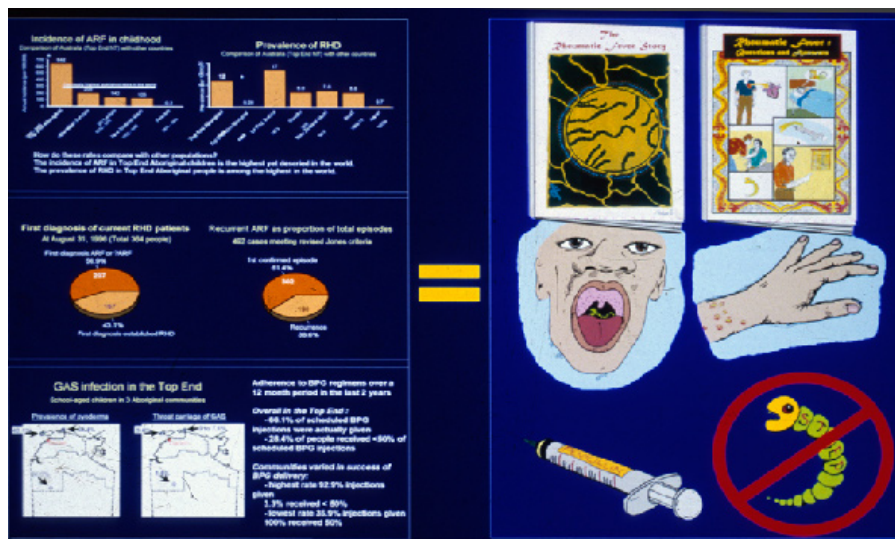
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The planning of a new “health research project” should be approached with a view to “collective collaboration.” New projects, approached and implemented in an ethical fashion, and encompassing a process of community input, have more success and are less costly in the long term. In the short term, of course, it is often considered more “efficient” to involve key selected personnel. Some ways of creating collective collaboration are:

1. Support and collation of new ideas or alternative ways.
2. Awareness of past practices in research.

3. Recognizing the opportunity to modify research methods.
4. Team selection: creating comradeship through respect and inclusion.
5. Prioritizing and fitting in with the community's agenda.
6. Strengthening of community networks.



On the left is the medical research method of presenting data visually. On the right is the same information, presented in a form more readily understood in the community.

MAJOR BENEFITS AND OUTCOMES

The benefits of any health research project need to be aligned with positive outcomes for the community. Researchers must show how the project will improve health for the community. The benefits for the people or the community must far exceed the benefits a researcher gains from completing an academic piece of research. Some of the more important community outcomes are below.

1. Employment for community people as liaison, interpreters, etc.
2. Satisfy the needs of the people and community
3. Community participation to create ownership and allow interpretation of the information, empowerment.
4. Recognition and acknowledgment for all who participate.
5. Authorship and intellectual copyright.

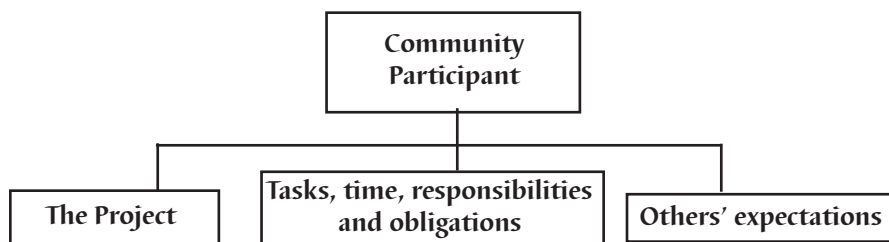
RESPECT AND PROTOCOL

The issue of respect and proper protocol applies both to the researcher in the community and the community working with the researcher. Respect comes from a willingness to be aware of and to be guided by the criteria of an individual, culture, family, community, or work commitment. It is an awareness of people's availability and input. Some elements in respect and protocol are:

1. Awareness of other responsibilities and obligations to many.
2. Awareness of the different expectations of researcher and community.
3. Awareness of culture in the form of community activities and ceremonies.
4. Awareness of the demands on other people's time, their level of interest, their normal and other duties.
5. Willingness to generate a two-way agreement in principle, perhaps for protection — to assure and ensure, possibly for guidance.
6. Awareness of and willingness to be guided by ethical and moral principles.

BEING CONSCIOUS OF WHERE THE PROJECT SHOULD FIT

In any health research project, the number of community people involved is far greater than the number of researchers. The diagram below indicates the importance of placing things where they may be more comfortable for the majority.



SO WHAT INITIATES RESEARCH?

Is it statistics which show an abnormality, hence, a reason to further investigate? Statistics speak only of numbers, not people, but they can identify health concerns which are widespread, but poorly understood.

WHAT ELSE CAN STATISTICS REVEAL?

The reporting of health statistics associated with a particular area, location, or community must be considerate and respectful. It is important to remember that the statistics can only reveal one facet of a situation unless they are placed into a fuller context. Relying on statistics to report research findings can have the following negative consequences.

1. Statistics can identify a group, area, or location as a problem.
2. Statistics can label, section off, and segregate.
3. Statistics can create negative publicity in the media.
4. Statistics can portray a story, but it is based on an outsider's understanding or interpretation.
5. Statistics can show indifference and inadequacy.
6. Statistics may be used to justify unethical research.
7. Statistics may be viewed as an opportunity to write about a problem and publish the results.

BENEFITS OF PEOPLE BECOMING SICK

One aspect of unhealthy people and communities is the creation of employment, opportunities, or areas of practice for healthy people. Health research may allow the researcher to acquire academic and professional qualifications that would otherwise be out of reach. Health care should not be viewed as a "mechanic's" job — especially the kind of mechanic who doesn't do the job right the first time in order to keep the patient coming back.

CONCLUSION

Any form of health research that directly involves humans is far more effective and achievable, if the intended recipients in the community being researched are engaged in the design, logistics and implementation of the project. This creates an appropriate representative framework. The following sections provide a quick checklist. It is important to consider community profiles and the strategies of your approach to generate interest in the research project. Be respectful of the people and their way of doing things. Ensure that protective and "opting out" measures are part of the project plan. A highly resourceful research team, which includes community members and assigned duties and roles that are appropriate and agreed to, can only generate further trust and respect. Health research which follows these protocols will benefit communities, health professionals and academic researchers.

ANNOUNCING YOUR ARRIVAL

1. The Project
2. Aims and objectives
3. Informing people
4. Connection/family
5. Commitment/Team
6. Community interest
 - a. who/how many
 - b. whose initiative
 - c. invite

ETHICALLY/MORALLY/CULTURALLY

1. Protection
2. Guidance
3. Reward
4. Insurance
5. Assurance
6. Liability
7. Methodology
8. Appropriateness
9. Protocol
10. Respect
11. Kinship issues
12. On whose country
13. Best time
14. What's in it for you — what's in it for me?

RESOURCES

1. Funding networks/submission writers
2. Research and evaluation training
3. Expertise; eg, medical, scientific
4. Indigenous support and personnel
5. Control, management and implementation; measures, strategies and appointees
6. A carefully selected team.

