

**A Guide for
consumers doing
health research**

Consumers' Health Forum

May 2001

The Consumers' Health Forum of Australia Inc (CHF), established in 1987, is Australia's leading non-government organisation representing consumers on health care issues. CHF establishes policy in consultation with its members, more than one hundred health consumer organisations, and other consumers. It provides a balance to the views of government, industry, service providers and health professionals.

The vision of CHF is to see consumers shaping health policy and health delivery systems in Australia. Our mission is to provide a respected and informed national voice for health consumers.

Matthew Blackmore
Executive Director
Consumers' Health Forum of Australia
Suite 3, 3-5 Phipps Close
DEAKIN ACT 2600

PO Box 170
CURTIN ACT 2605
AUSTRALIA

Tel: +61 2 6281 0811
Fax: +61 2 6281 0959

Email: info@chf.org.au
Website: www.chf.org.au

Publication Information

© Consumers' Health Forum of Australia Inc.
CHF Ref: 269
ISBN: 1 876034 35 1

Acknowledgments

Many people gave willingly of their time and knowledge to ensure consumers were able to share their experiences and learn from one another in undertaking consumer health research. CHF extends its appreciation to the following people and organisations:

Older Womens Network
Stillbirth and Neo-natal Death Support (Qld)
Michael Summers
George van der Heide
Alison Stanfield

1994 Manual Steering Committee

Ros Wood (Chair)
Debra O'Connor
Stephanie Short
Jackie Kearney/ Charles Livingston
Christopher Newell
Kate Moore

1995 – 6 Manual Steering Committee

Gael Walker
Kath Cape
Debra O'Connor
Stephanie Short
Kate Moore

June Ashmore
Delys Sargeant
Kate Moore

1995-6 Consumers' Research Steering Committee

Hilda Bastian
Merinda Northrop
Debra O'Connor
Denys Correll
Ros Wood
Kate Moore

1996-97 Consumers' Research Steering Committee

Hilda Bastian

Foreword

Health consumers are passionate about research. They know that research is essential to improving health outcomes and they want to make sure that research asks the questions that consumers really need answered. Consumers can often contribute better than anyone else in identifying the important questions that researchers need to ask.

Many health consumers want to work collaboratively with researchers or undertake their own research. This consumer guide aims to help consumers understand how research is carried out and assist, in a practical way, those consumers who want to undertake their own research.

This guide has been developed with the help of many people during the past 5 years. Without their enthusiasm and passion, this guide would not have been possible.

Consumers' Health Forum hopes that this will be a living tool for consumers. Future editions are planned, and a feedback sheet is included at the back to help improve future editions.

Matthew Blackmore
Executive Director
Consumers' Health Forum

May 2001

Contents

Foreword.....	ii
Introduction.....	iv
1 Introduction to consumers' research	1
1.1 The value of consumers' research	1
1.2 Barriers to undertaking research.....	4
1.3 Collaborative research	5
2 Planning a research project	14
2.1 The importance of planning.....	15
2.2 Plans always change.....	15
2.3 How much planning is needed?.....	16
2.4 Developing your research plan.....	16
2.5 Background work	24
3 Ethics	26
3.1 What are ethics and why are they important?	26
3.2 Obtaining ethics approval.....	28
3.3 Developing a research proposal	30
3.4 Informed consent	31
4 Research budgets and obtaining funding.....	33
4.1 Identifying potential funding bodies	35
4.2 Following the application guidelines	37
4.3 The funding application.....	39
4.4 The application process	44
4.5 Assessment of applications	45
4.6 What next?.....	45
5 Research methods	46
5.1 Methodologies	47
5.2 Research methods commonly used in consumers' research.....	49
5.3 Selecting a research method for your project.....	62
6 Literature reviews	64
6.1 Preparing for a literature review.....	64
6.2 Finding the literature	66
6.3 What to look for in the literature.....	68
7 Collecting and analysing data.....	70
7.1 Collecting data.....	71
7.2 Analysis	79
8 Writing the research report and communicating the findings	92
8.1 The research report.....	93
8.2 Communicating the findings	100
Abbreviations.....	108
Glossary.....	109
Bibliography	117

Introduction

Consumers' research is research undertaken from a consumer perspective, by or with consumers. It is research that arises out of consumers' needs. To date, such research has included the evaluation of a service or treatment, the gathering of data that challenged the medical acceptance of 'facts' about a condition or treatment, the exploration of consumer views and experiences, and the production of resources.

The value of consumers' research is highlighted in the following extract:¹

Consumer groups have protected their communities from environmental hazards to their health, and played a role in achieving other major public health goals, such as restricting the spread of HIV/AIDS in many communities. They have funded and initiated research, and contributed to their own body of research on consumers' views, experiences and health outcomes. They have put previously unrecognised or misunderstood health issues on the agenda, including conditions such as sudden infant death syndrome and Alzheimer's disease. They have successfully challenged health care practices, and played a key role in getting information about health and health care to the community. Consumer groups have worked to make health care services more responsive to individuals' needs, and the vast array of self-help is a vital source of mutual aid and support for many people.

This Manual has been developed with the aim of assisting consumers in carrying out research into health issues. The Manual addresses the key issues to be considered in undertaking any research project and offers advice about how consumers can overcome some of the difficulties they are likely to face during their research.

What is research?

Research is a process of finding things out, of filling in gaps in knowledge, and of understanding the world and the environment in which we live. Initially research involves having ideas and developing research questions. The subsequent research process is structured in such a way as to answer systematically the questions being asked. Successful research both answers the research question and provides useful and meaningful results.

Research is worth doing when:

- there is a clear statement of the research question and the purpose of the research;
- it is a new or innovative idea, never before studied or researched in this way or from this perspective;
- the research methods employed to undertake the research are sound;
- the research project is feasible;
- there is a clear plan to inform participants and disseminate the findings of the research; and
- there is a vision for the use or benefits of the research.

What is consumers' research?

Consumers' research differs from other research in that it involves significant control by consumers over all, or most, of the following:

- identifying the research questions;

¹ Bastian, H. 1998, 'Speaking Up For Ourselves: the evolution of consumer advocacy in health care', *International Journal of Technology Assessment in Health Care*, 14:1.

- planning the research;
- supervising research undertaken in collaboration with consultants, academics or professional groups;
- taking part in reviewing ethical aspects of research proposals;
- assisting with the implementation of recommendations arising from research;
- evaluating research projects and research programs; and
- identifying national and local research priorities, including sitting on research-funding committees.

The central issue in consumers' research is consumer involvement as participants in research rather than simply as subjects of research. Consumers' research is not market research or just research into consumers' views. Rather, it provides a way of ensuring close links between research priorities and consumers' knowledge. Consumers are in a position to ask vital and unique research questions that have immediacy and relevance because they are based on consumers' experiences with their own health and the health-care system.

Case studies

Throughout this Manual, case studies are used to illustrate various aspects of consumers' research. In particular, two case studies — the *Older Women's Health Project* and *General Practice Care after Miscarriage: Consumer and Provider Views* — are used to illustrate the process of consumers' research and consumers' experiences of undertaking research.

Older Women's Health Project

The Older Women's Network is a community-based organisation run for and by older women. It was established to provide a means for older women to meet others with similar interests and to challenge the stereotyped images of the older woman. The Network aims to:

- provide enrichment, support and friendship to older women;
- lobby for a fairer deal for older women;
- encourage discussion about ageism and sexism;
- promote appropriate policy in the area of older women's health, income security, housing, home support services and transport;
- assist older women to develop skills; and
- provide information to older women.

The *Older Women's Health Project*, undertaken in 1993, was driven by the Network, funded through the National Women's Health Program and commissioned by the Women's Health Unit of the NSW Department of Health.² The Project looked at health for older women, its meaning, importance and maintenance. It also examined women's perceptions and use of health services and health promotion initiatives.

General Practice Care Following Miscarriage Project

In 1996, Stillbirth and Neonatal Death Support (Qld) Inc (SANDS) and the University of Queensland (UQ) were successful in obtaining a seeding grant from the General Practice

² Older Women's Network 1993, *Well-Being: For and By Older Women*, Older Women's Network Inc: Sydney.

Evaluation Program (GPEP)³ to undertake research into *General Practice Care Following Miscarriage: Consumer and Provider Views*.⁴ This project aimed to:

- investigate women's perceptions of quality general practice care following miscarriage;
- examine general practitioners' attitudes to the psychological aspects of miscarriage and their role in miscarriage support;
- determine whether a need exists among general practitioners for further informational resources relevant to miscarriage support; and
- identify possible strategies to meet this need.

Structure of the Manual

This Manual provides a step-by-step description of how you and your consumer group can undertake your own research.

- Chapter 1 discusses issues for consideration before a research project is started, including the value of consumers' research, potential barriers, and collaboration.
- Chapter 2 focuses on the importance of planning a research project and details how to develop a research plan.
- Chapter 3 discusses the important topic of ethics including what to consider in planning your research, and how to obtain ethics approval for your research project.
- Chapter 4 focuses on the issue of research budgets and how to get your research funded. It discusses the funding application and the application process, through to the assessment of applications.
- Chapter 5 outlines some commonly used methods in consumers' research and discusses how to select a research method for your research project.
- Chapter 6 discusses the literature review in detail. (Discussion of the literature review is also included in Chapters 2 and 5 and, in reality, the literature review may have been conducted at the planning stage of the research.)
- Chapter 7 provides an introduction to collecting and analysing data. The concepts of collecting and analysing are discussed together as an understanding of how the data will be analysed is essential before setting out to collect the data.
- Chapter 8 provides a framework for preparing your research report and describes ways of communicating your research findings.

At the end of the Manual you will find a list of abbreviations used within the Manual, a glossary of research terms, and a bibliography which outlines suggested further reading and resources.

³ The GPEP is a part of the General Practice Branch of the Commonwealth Department of Health and Aged Care.

⁴ Boyle F, Chapman R, Hancox J (1998) *General Practice Care After Miscarriage: Consumer and Provider Views*. Stillbirth and Neonatal Death Support (SANDS) (Qld) Inc and Department of Social and Preventive Medicine University of Queensland.

1 Introduction to consumers' research

Once you have decided to undertake research, there are a number of issues to be considered. It is helpful to understand why your research will be of value to yourself, your consumer group and potentially to policy makers and other researchers. It is also useful to be aware of barriers to your research and of means of collaboration which may help you to overcome the barriers.

Summary — Introduction to consumers' research

The value of consumers' research

- Consumers' experiences of the health system, their social environment and their physical environment provide them with a broad understanding allowing them to identify research issues of relevance to themselves and other consumers.
- Undertaking their own research provides the opportunity for consumers to increase their understanding of health issues and their control over their lives and their health.
- Research driven by consumers can help shape the structures that affect consumers' health.

Barriers to undertaking research

- There are both practical and structural barriers to conducting consumers' research including:
 - lack of funds;
 - lack of equipment/resources/personnel;
 - lack of time;
 - lack of research expertise; and
 - difficulty complying with funding requirements/obligations and controversial outcomes.

Collaborative research

- Collaboration is often essential to the success of the research project as consumer and self-help groups frequently do not have all of the skills necessary to design and undertake a good quality research project without help.
- The involvement of consultants, academics and professional groups, other consumer groups, and students in the research can be an effective way of accessing vital skills and increasing the quality of the research.

1.1 The value of consumers' research

There are many good reasons for undertaking consumers' research including:

- ensuring the relevance of research to the people whose health is the ultimate purpose of the research;
- increasing consumers' understanding and control over their own health; and
- informing and providing support for people who shape the structures and decisions that affect people's health.

Research that is relevant

Health is an important part of any person's everyday experience. It is affected by the social environment (income security, employment, education, friends and family) and by the physical environment (housing, safe food and water, transportation and the ozone layer). If research into health issues is going to be of relevance to people, they should have a significant degree of control

over that research — the idea, the design, the conducting of the research, the analysis and discussion of research findings, and the dissemination of the findings. The people doing the research shape the research; it is informed by their background, beliefs and experiences.

Consumers are in a unique position as they experience the whole of the health-care system while health-care professionals, medical researchers and public servants may only focus on certain aspects of health. This provides consumers with the understanding and experience to identify key research issues and questions that are relevant to their lives in a way that may not be possible for professional researchers. The view that research will more adequately address people's needs if it is controlled to a significant extent by the people whose lives are the subject of the research has spawned a school of research called participatory action research (see Chapter 5).

Historically, much of the research that has been done has been of limited value and relevance to many groups within society. Two groups that have found much research of less relevance to them are women and Aboriginal and Torres Strait Islander peoples. The feminist methodology discussed in Chapter 5 attempts to address the perceived imbalance resulting from the masculine viewpoint used in standard research. Over the years, conclusions and generalisations have been drawn from research that has unquestioningly assumed that the male experience was the 'norm'.

Similarly, Aboriginal and Torres Strait Islander communities and groups have been the subjects of much research but have not necessarily benefited from the research. In some cases, these peoples have suffered exploitation and cultural damage from their experience as research 'subjects'.

Chapter 3 discusses the ethics of research and comments on the Australian National Health and Medical Research Council (NHMRC) *National Statement on Ethical Conduct in Research*

*Involving Humans*¹ and the *Guidelines for Health Research and Aboriginal and Torres Strait Islander Communities*² both of which seek to protect the rights and dignity of research subjects.

The Northcote Self Help Hydrotherapy Massage Group is an example of what can be achieved simply, cheaply and with relevance through cooperative and sensitive consumers' research.³

The Northcote Self Help Hydrotherapy and Massage Group formed because of a common bond of pain and loss of mobility. The Northcote Community Health Centre's physiotherapist, with the consumers, decided that hydrotherapy was a possibility to improve treatment of consumers' mobility problems and pain.

Over time, and with funding from various sources, the consumers acquired the skills to 'treat' and work with each other. For example, one of the members of the Group takes the 'happy swim and exercise' class with suitable qualifications gained as a school teacher, and under the tuition of the physiotherapist for medical exercises.

The Group told the story of their research using photographs in a book. Funds to develop the book were provided by the Consumers' Health Forum of Australia.

¹ NHMRC 1999, *National Statement on Ethical Conduct in Research Involving Humans*, NHMRC: Canberra. <http://www.health.gov.au/nhmrc/publicat/synopses/e35syn.htm>

² NHMRC 1995, *Guidelines for Health Research and Aboriginal and Torres Strait Islander Communities*, NHMRC: Canberra. <http://www.health.gov.au/nhmrc/publicat/synopses/e11syn.htm>

³ From Matrice, D., Brown, V. 1990, *Widening the Research Focus: Consumer Roles in Public Health Research*, Consumers' Health Forum: Canberra, pp.22–25.

Increased understanding and control

Consumers' research also provides the opportunity for consumers to exercise and build on their skills, judgement and knowledge in a practical way around issues that are of concern and importance to them. These skills and knowledge can be shared within consumer and self-help groups. Ultimately, this involvement and development has the capacity to increase feelings of self-esteem and self-actualisation, with individuals reclaiming some degree of control over their lives and their health. Completing even the smallest research project increases a person's understanding of research, as well as providing them with the knowledge gained from the research. Knowledge, skills and information are power. Those with some power over their lives have better health than those without.⁴

Research can provide a way of placing consumer concerns on the public agenda. Arguments for change have a better chance of being heard and being persuasive if they are based on good quality research. Through consumers' research, both the individuals and the self-help group can become recognised 'experts' with increased credibility and greater likelihood of influencing public policy decisions that affect health.

Consumer-based research methods were used in Alzheimer's Disease Research (a research project funded by the Consumers' Health Forum of Australia between 1987 and 1989).⁵

Through the process of information exchange in a trusting environment, consumers and carers were able to become informed about their own disease and its management, and to go on to share this information in teaching videos and a Carer's Handbook. Through developing a comprehensive knowledge base, their self-help activities have been more effective. Consumers have been able to develop creative ways of bringing about changes and improvements in services so that they better meet their needs for a minimum cost.

The Older Women's Network found that both the research and the experience of doing research were empowering to older women. They noted that the empowerment arose from:

- *the pride that the research 'is something we have done';*
- *the affirmation through research of the beliefs of the older women;*
- *the realisation that their research balanced, and was on a par with, academic research;*
- *proving the capabilities of older women to funders and others; and*
- *the older women's now justified claims to partnerships in research.*

The Network encourages all consumers to 'have a go' at their own research and to consider their own knowledge and experience as valuable. Consumers' research is one way that this knowledge and experience can be acknowledged in society.

⁴ Marmot M.G., Kogevinas, M., Elston, M.A. 1987, 'Social/economic status and disease', *Annual Review of Public Health*, 8: 111–35.

⁵ From Matrice, D., Brown, V. 1990, *Widening the Research Focus: Consumer Roles in Public Health Research*, Consumers' Health Forum: Canberra, pp.12–17.

Shaping the structures that affect consumers' health

As part of the national and international consumer movement there has been increasing recognition of the need to involve consumers in health-care decision-making processes within governments and services. Consumers have a stake in these decisions, both as receivers of health services and, ultimately, as funders of health services. Good quality research is essential to making informed policy decisions. Research driven by consumers can provide policy makers with a balanced framework in which to make decisions.

As a consequence of its close ties to people's everyday lives, consumers' research can pick up health issues many months, or even years, before they are recognised as such by other researchers. Consumers' research is also a valuable way for self-help groups to build links with other people and organisations, and provides professional researchers an opportunity to work in what is often a very rewarding context. In some instances, consumers' research can work as a community-based strategy for identifying, researching and addressing local health needs. It can be sensitive to the cultural and social context of the people being researched because these people have a role in developing and conducting the research.

1.2 Barriers to undertaking research

There are both practical and structural barriers to conducting consumers' research. In a survey conducted by the Consumers' Health Forum of Australia in 1996,⁶ the major difficulties faced by consumers in undertaking research were found to be:

- lack of funds/money;
- lack of equipment/resources/personnel;
- lack of time;
- lack of research expertise;
- difficulty complying with funding requirements/obligations; and
- controversial outcomes.

Despite these barriers, 81 per cent of consumer groups in the survey had been involved in research, and over 60 per cent of all consumer groups that responded to the survey would like to do research, or would like to do more research in the future. Workshops and manuals like this one can assist consumers in overcoming such barriers and developing research skills. Workshops can also provide the initial forum for consumers to develop networks.

At a practical level, it is difficult to apply for research funds when your group:

- is not incorporated (and cannot therefore receive funds from government);
- has difficulty finding someone with a computer or typewriter to type up an application;
- finds that the grant application forms are of limited relevance to your group; and
- has no access to an ethics committee.

Limited resources is another common problem for researchers. While people working in institutions and universities are likely to have access to resources (ie computers and library), it is common for members of health-related self-help groups to be without access to minimal resources. Undertaking research is a balancing act — you need to weigh up the pros and cons of using the time and energy

⁶ Consumers' Health Forum of Australia Inc. 1997 *Consumers' Research Project Member Survey*, Unpublished.

of members. If your group is to embark upon research there must be commitment from the group of time, energy and other internal resources. For the research to be successful, members must support the group's journey into research.

Difficulties in undertaking consumers' research also come from outside the group. The limited understanding of consumers' research in academic, medical, and social arenas is a problem at a number of levels:

- at the consumer level, research may be seen as something only done by people with doctorates (PhDs);
- experienced researchers often find it difficult to set aside their own preconceptions of what are the important research questions; and
- the organisation and structure of major research funding bodies often makes them seem inaccessible and inhospitable to people wishing to undertake consumers' research.

While there is no instant solution to these issues, this Manual contains practical guidance and suggestions for minimising the difficulties, and maximising the quality and impact of consumers' research. The result is not so much a recipe for research, but rather a road-map of the research process, with many different ways of getting from here to there. A journey is a good metaphor for research, with the unexpected detours, wrong turns, intriguing discoveries, and the inevitability of learning as you go. A map cannot take you to your final destination, but it can increase your chances of getting there.

1.3 Collaborative research

Self-help groups often involve other people in developing and undertaking a research project. This is collaborative research. Collaboration is often essential to the success of the research project since consumer and self-help groups may not have all of the skills necessary to design and undertake a good quality research project. The involvement of consultants, academics and professional groups, other consumer groups, and students in the research can be an effective way of accessing vital skills and increasing the quality of the research.

Collaboration can also improve your access to resources such as computers and libraries. Collaboration with an academic can help to get the results published in an academic journal. Assistance in identifying and securing funding for the research can also be valuable. This includes collaborating with people or organisations that are eligible for funding where your group is ineligible.

Access to skills and resources are not the only advantages of collaboration. By involving other people, you can avoid common research problems and save a lot of time. Collaboration can also provide another point of view that will help you in covering all arguments in your ultimate discussion of the research.

Collaboration between your group and others provides a strong foundation for action based on the research in several ways:

- by producing a high quality research project — good quality research has the credibility essential to underpin any recommendations arising from the research;
- by increasing legitimacy of the research — if more than one stakeholder is involved in the research it is often seen as less parochial and less biased and the research is less likely to be seen as self-serving; and

- by sharing the ‘ownership’ of the research — this is especially useful if one of the purposes of the research is changing the behaviour, practices or attitudes of the other group involved in the research (eg collaborative research with the Royal Australian College of General Practitioners is more likely to have recommendations about the training of general practitioners seriously considered than the same research done without their involvement).

Some of the tasks that self-help groups commonly seek assistance with include:

- developing the aims and objectives of the research;
- designing the research project to meet the aims and objectives;
- developing a questionnaire or interview schedule; and
- analysing the results.

Although there are many advantages to working collaboratively, there are also a few disadvantages:

- extensive involvement of consultants often costs money;
- collaboration requires giving up some control over the research;
- working with other people can create difficulties, particularly if everyone involved has different views about the research;
- professionals unused to working with consumers may unintentionally undermine consumers’ confidence and take over; and
- the needs of professionals for academic or professional advancement may conflict with the goals of a consumer group.

The risks of getting involved in a disastrous collaboration can be minimised, and the following sections give some hints in this regard.

Consultants, academics, and professionals

There are several factors involved in working successfully with consultants, academics and professional groups. These include:

- knowing what you want from them;
- finding the right people;
- negotiating the work to be done; and
- knowing how to work constructively with them.

Determining what you need

What you need from a consultant, academic or professional group depends on the nature of the research project and the skills of members of your self-help group. You need to decide what work you want the consultant to do. From this, you can determine the level of experience and the range of skills you are looking for in a consultant. In addition to experience and skills, you should also consider other resources that the research requires, such as a driver’s licence, access to a computer, and the use of libraries.

The consultant, academic or member(s) of a professional group will also need to be people that you can work with. Ideally you want someone who has done, or believes in, consumers’ research and who has worked with a self-help group before. At the very least, however, you need a consultant, academic or professional who is flexible, listens to you and takes directions from you. You need

someone who can work on a research project that is driven by your priorities and needs rather than theirs, or whose own goals are at least compatible with yours.

A brief summary of your proposed research project and what you need from research partners will help you focus on exactly what you are looking for in a consultant or academic. A ‘consultancy brief’ should be written in consultation with other group members who have an interest and understanding of the research project. The consultancy brief should include:

- the background of the project;
- its purpose, aims and objectives (see Chapter 2);
- what will be done with the research data at the end of the project;
- possible timeline (see Chapter 2); and
- the skills and experience you want in a consultant or other research partner.

Finding the consultant, academic or professional

The consultancy brief should be distributed to your group members and other relevant people as part of your search for a consultant, academic or professional group. Use your group’s networks to find out about consultants who have worked with other self-help groups. You might also telephone some of the large or well-known groups or organisations in your area to see if they know someone who might be suitable.

Ideally, any consultant, academic or professional should be involved in the research project from the very beginning. This gives you the opportunity to draw on their expertise from the start.

However, this is not always possible as some researchers may not work with you until funding for their work is secured. Also, sometimes it is only when a problem arises that the need for assistance is recognised.

Choosing the right consultant, academic, or professional is important. If you get the wrong person for the job it can be very difficult to redeem the project at a later date. It may take some time and a lot of chasing around to find the right person. Check the person’s reputation (particularly their ability to work with other people), and make sure that you get copies of previous research reports he or she has worked on. You may not be able to be as choosy as you would like to be, particularly if you are offering little or no money. However, you need to be sure that you can work with them and that they have the skills for the job.

Negotiating the work

When you think you have found a consultant, academic or professional who seems appropriate, the first step is to negotiate their role in the research project. This is also the first real test of your ability to work together. A central issue in negotiating the work with a consultant, academic or professional is whether or not you are expected to pay for their help. However, this is closely related to how much assistance you require, and whether your research will be funded or not. Outlined below are some tips for negotiating unpaid and paid work.

You can get some help with little or no money to pay. If you have an idea for a research project but do not really know where to begin you could talk to a consultant, academic, or professional about it. One possibility is to suggest that you develop a research proposal together and submit it for possible funding. Even if you do not get the funding, you have received some help in developing a plan for doing the research. Make it clear to the consultant whether or not they can expect to be employed to do some of the research if the funding proposal is successful.

With a little bit of money (between \$500 and \$1,000) you can work with a consultant on ways that this limited budget can be stretched as far as possible. The best way to do this is to do as much of

the work as you can yourself, and use the consultant, academic, or professional as a teacher, guide and adviser. This could mean that you use the consultant to help you with critical parts of the research. These might include:

- reviewing the aims and objectives of the research;
- advising on the appropriate research methods and sampling;
- helping you construct a questionnaire;
- teaching you how to analyse your data; and
- reading and commenting on drafts of your research report.

Not everyone you might use as a consultant will need to be paid for his or her work. Some people are happy to put in a lot of work on the research project if they can see that there is value for the community or something in it for them. This is often the case with academics who might be able to use the research as the basis for publishing one or more articles in academic journals. However, you do need to be careful with this and make sure that their needs are compatible with yours. In particular you must sort out who will ‘own’ the research, and be certain that how they will use it is acceptable to you and your group. Sorting out who can publish what, and who can claim authorship of the work, are areas which can become fraught.

You should not underestimate how important publication and credit can be to academics and professionals, and you should always appropriately acknowledge the assistance provided. Similarly, you should ensure that your group and its members receive the level of credit and acknowledgment to which they are entitled. It is also important that you consider what will happen if your research findings are controversial.

If you are paying someone to work on the research project you should have a written contract. For smaller projects this does not have to be either difficult nor complicated. The main issues that you should consider in a contract are:

- who the contract is between;
- a clear description of the work to be done;
- a timeline or deadline for completion;
- a schedule of payments, usually linked to the completion of particular tasks;
- how disputes will be settled;
- how any changes will be negotiated;
- frequency of meetings with the consultant;
- who owns the research and research reports;
- who the consultant is accountable to; and
- how the contract can be terminated.

Working with the consultant, academic, or professional

A good working relationship with a consultant, academic, or professional involves many of the same issues as any other working relationship. Good communication skills are essential. This includes listening to each other; being clear about expectations; establishing communication links; and dealing with problems early. Research projects rarely work out as planned, so be prepared to negotiate changes with the consultant and work together to solve problems that are encountered.

Hopefully, you will engage someone who listens to you — make sure that you also listen to them. Be careful not to let their research expertise overwhelm you. Ask questions to make sure you understand what is being said. It is unlikely that a consultant will be able to write a report that you can understand if they cannot answer questions in ways that you can understand.

From the very beginning of your work together, you need to understand what each other's expectations are regarding good communication. The self-help group needs to be clear about the aspects of the research in which it expects to be involved, and how often and what form of regular reporting the consultant should provide. You need to find a balance between the need to maintain adequate links between the group and the consultant, and the time that this takes up. Too many meetings, too many written reports, or too many telephone calls can mean that the consultant spends more time communicating than actually working on the project. Talk to the consultant about what they have found has worked well in the past.

The General Practice Care Following Miscarriage project is an example of collaborative research between the consumer group SANDS (Qld) and an academic from the Department of Social and Preventive Medicine at the University of Queensland (UQ). SANDS had been interested in carrying out research into the experiences of women following miscarriage for some time as the importance of this issue had become apparent through feedback from the membership of SANDS. The academic from UQ had been involved with SANDS at a personal level for some years, but the possibility of collaborative research into this issue had not arisen until the coordinator of SANDS and the researcher from UQ realised, in informal conversation, that a need existed for systematic research in the area.

The SANDS coordinator then raised with the SANDS committee the possibility of undertaking collaborative research into miscarriage. The committee agreed that the project should go ahead in collaboration with the academic from UQ and agreed that they were happy for the coordinator and the researcher from UQ to be joint researchers on the proposed project. Feedback to the group would occur at regular intervals.

Other consumer groups

The 1996 *Consumers' Research Project Member Survey*⁷ found that consumers are most likely to have partnerships with other consumer groups for the purpose of undertaking research or for providing consumer representatives to others' research projects. Partnerships with other consumer organisations occurred almost three times more often than any other partnership.

Collaboration with other consumer groups in undertaking research can improve the quality of the research and may create a stronger foundation for action based on the research. Self-help groups also involve other groups or organisations in their research as part of a broader agenda of strengthening links with these groups. A collaborative research project can be a good way of finding some common ground and getting to know each other better.

Collaboration between groups can improve the quality of the research through:

- the sharing of both resources (networks, members, computers) and the workload;
- access to a wider range of research skills and experience;
- bringing other views and ideas into the research process; and

⁷ Consumers' Health Forum of Australia Inc. 1997 *Consumers' Research Project Member Survey*, Unpublished.

- increased access to funding — the other group may have access to funding that yours does not (eg if funding is only available to incorporated applicants, an incorporated consumer group may be willing to auspice your project if your group is not incorporated).

There are many consumer or self-help groups in the community that might be interested in working with you and your group on a research project. Potential groups or organisations for collaborating on research projects are those whose members have an interest or a stake in the issue being researched.

Deciding to work together

Decisions about working with another group on a research project are often complex. Before deciding to collaborate in research, both groups need to be clear about:

- what each group wants from the research;
- what the roles of groups and group members will be; and
- whether or not you can work with each other.

When approaching another group or organisation about working together it is necessary to have an outline of your research ideas. Initial discussions about what each group wants to get out of the research should lead into negotiations to determine the aims and objectives for a joint project. Look carefully at whether or not the proposed research project is meeting your needs. You do not want to get halfway through a research project only to find that you are feeling used or dominated by the other group. Make sure that both groups' interests and commitment to the research are compatible before deciding to collaborate. Together with the other group, set a date for making a final commitment to proceed with a joint research project.

Once the groups have decided to collaborate in the research, it is essential to establish a solid foundation for the collaboration as soon as possible. You need to spend some time building the relationships between the groups and between group members. This will help to generate the necessary trust, goodwill and commitment to the collaboration that will be essential to working out problems and conflicts that may occur when you work together.

Jointly developing the research proposal is one of the best ways to develop your relationship. This joint development gives both groups the opportunity to ensure that the proposal reflects their interests. It is also an effective way to find out if you can, and want to, work together.

Part of finalising and agreeing on a research plan is deciding who will do which research tasks. This is a relatively simple task if you are hiring a consultant or engaging a student to do the research. However, if most of the work is to be done by the members of both groups, decisions should be made based on what needs to be done and people's skills, interests, time and ability. It is important to find roles for everyone who wants to contribute, and to acknowledge the time and effort each person contributes. The roles and responsibilities of everyone involved need to be clearly articulated.

Supporting the research and the collaboration

If the collaboration between two consumer groups is to work effectively, a number of issues must be sorted out. The most important of these are:

- how decisions will be made; and
- how problems and conflicts will be resolved.

Your group may already have clear and effective decision-making processes. It is worth considering using these as the basis for setting up ways for the two groups to make decisions about the research project. This usually means establishing a research sub-committee, if one does not already exist, or

making the research the responsibility of an already existing committee. It is important to have effective ways of keeping all the group members regularly informed about negotiations with the other group and the progress of the research. You must also decide which decisions about the research should be made by committees (single or joint committees), and which by individuals or the whole group.

An important issue related to supporting the collaboration between two consumer groups is the matter of who owns the research. To maintain each group's commitment to the project and goodwill to each other, it is vital that you reach a fair and clear decision about this. Joint or equal ownership is appropriate if the effort and responsibilities of doing the research are equally divided. You may need to negotiate something other than equal ownership if one group has considerably more involvement than the other.

A related and often identical issue is authorship — that is, whose name(s) will go on the report and other publications as author(s). Agreements vary considerably on this, with choices usually being the individuals responsible for most of the work or the groups involved. Whatever decisions are made, make sure that all relevant people are involved in the decision and are aware of the outcome.

Students

Collaborating with a student can be an excellent way of getting a small research project done. It is a particularly good option if there is no funding available to pay a consultant. Research projects appropriate for students are those that are small and suitable to the developing skills of students.

Student projects need to fulfil the student's course requirements. This often requires you to be flexible and willing to negotiate project details. Student projects must be complete projects in themselves — involving a literature review, collecting and analysing data and writing a research report. It is sometimes possible for a student to do a literature review as a complete research project as long as it includes some analysis and is written up as a research report.

The quality of student research varies. Consequently, your expectations should not be too high. Remember that students are still learning how to do research. The quality of student research projects is dependent to a large extent on the interest the student has in the project and the importance they attach to it.

Finding student researchers

Many university courses require students to undertake research projects. It is worth using your group's networks and the telephone directory to find teachers who have students that are looking for research projects. The best places to find students who are looking for research projects that are of benefit to consumers include:

- social work courses and departments;
- health education or health science courses and departments;
- social or behavioural science courses and departments;
- nursing schools (especially postgraduate courses); and
- medical schools.

It might take time and quite a few telephone calls to contact someone who can help you, but if you are persistent it will be worth it. Once you have contacts you will find that getting students to work on future projects is likely to be easier.

You might also find that students will approach your group wanting to do a research project. Student approaches to a consumer group vary from expecting you to distribute and collect a

questionnaire (that they have developed without consulting your group), to offering their services to work on a project that meets your research needs and their course requirements. When deciding whether to collaborate with a student researcher you will need to carefully consider the costs (particularly your members' time) and the benefits (possible links with a university and potentially useful research).

Working with student researchers

As with the other possibilities in collaborative research, good communication is essential to working successfully with students. Discuss each other's needs and expectations, and try to find some common ground. One way of doing this is to talk about how each of you would gauge the success of the collaboration and the research. With some common ground and good communication, your different needs, skills and interests can strengthen rather than weaken the collaboration. Some of the issues that you and any prospective student researchers need to discuss include:

- details of the research to be done;
- why the research is being done and how it fulfils each of your needs;
- what the student is expected to do, and what the consumer group is expected to do;
- the level of support and involvement you can expect from the student's supervisor;
- any formal assessment or comment on the student's work that is required of you;
- regular meetings; and
- timeline.

After agreeing, in principle, to work together, the first task is to define and refine the research proposal. This proposal should include such things as the aims and objectives of the research, the research methods and the timeline. Ideally, the student will develop the research proposal in close consultation with the consumer group. When negotiating the timeline, take into account the student's other commitments, such as exams, lectures, or holidays. Developing the research proposal may involve meetings with several members of the group, or the whole group. However, there should be one person within the group who acts as the main contact person for the student.

You will need to deal promptly with any concerns or problems as they arise. One of the most frequent complaints about student researchers is that they do not keep consumer groups adequately informed about the research. To prevent this, make sure that your expectations about regular reporting and meetings are clear from the start.

You have much less control over the work of a student than over the work of a paid consultant. Therefore, success is even more dependent on negotiation and good will. Working with students is essentially a three-way contract:

- you provide the student with the opportunity to do interesting and valuable research;
- the student provides you with a useful piece of research.
- the student's supervisor provides them with a mark towards completion of the course.

Because of this arrangement, you rarely have any direct control over the student. Your strength in this three-way contract is dependent on stimulating and maintaining the student's interest and enthusiasm. It is also worth developing your relationship with the student's supervisor or teacher. The supervisor is usually readily available to provide advice on the student research project and can help you to get the most out of your collaboration with the student. A good relationship with the supervisor can result in a steady supply of students for your future research projects. It can also

result in easy access to advice or assistance with other research projects, including research projects that do not involve students.

2 Planning a research project

Once you have determined whether your group is ready to undertake research and decided whether you will do so in collaboration with other groups or individuals, it is time to look more closely at the research project. Planning a research project requires making decisions regarding:

- the nature of the research;
- how the research will be carried out;
- the resources required; and
- the ethical implications of the research.

The end product of the planning process is a research plan that will be used to provide clear directions to those conducting the project.

Although the focus of this chapter is on planning, it would be advisable to read the entire manual before you begin to plan your project. This will enable you to be more aware of the many things that you need to think about during the planning process.

Summary — Planning a research project

The importance of planning

- Good planning can help to ensure that all members of the group understand and agree upon the nature of the research, why it is being done, and how it will be done. If you are collaborating with individuals or another group, planning can also be a useful way of clarifying the expectations and defining the roles of each partner in the project.

Plans always change

- A balance must be sought between the need to keep to the original plan and the need to make changes. Making too many changes to a research project removes the structure that is essential to supporting the people doing the research, consumes extra research resources and energy, and can ultimately destroy a research project. However, not making necessary changes can reduce a project's value and impact.

How much planning is needed?

- The amount of planning undertaken should match the size and scope of the project. It is advisable to start with smaller projects or to carry out a pilot project to test whether your research plan is feasible.

Developing your research plan

- The **purpose** (see page 17) of a research project needs to be agreed upon by all members of the group. The purpose can be expressed in one or two sentences which should outline what the researchers want to achieve and why they want to do it.
- Consideration of your **audience** (see page 18), that is who you want to read the research report and who you want to be informed and influenced by the findings of your research, should influence almost every aspect of your research plan.
- Clearly stated **aims and objectives** (see page 19) are essential to developing and maintaining a well-focused and manageable research project. Each aim of a project should be a simple statement in one or two sentences specifying what the project intends to do. Objectives are specific statements about what will be done to achieve the aim.
- Achieving your research aims and objectives requires collecting information using various research methods. You will need to decide on the type or **types of information** (see page 22) your research requires and appropriate research methods to gather this information.

- A **timeline** (see page 22) is a schedule that outlines the tasks that need to be done in order to complete the research project. It indicates when each task will be done, or the estimated length of time needed to complete the task. Timelines are essential for keeping track of what has been done and what still needs to be done.
- An essential part of the planning of any research project is to work out all the resources that will be needed to complete it. The resources needed and an associated **budget** must be determined for the entire duration of the project.
- **Ethical issues** (see page 24 and Chapter 3) should inform and shape the whole research process. Consequently, their consideration in the planning stage and throughout the duration of the research project is vital.

Background work

- In preparing to undertake research, you need to know what research has already been done in the area, and what others' main debates or areas of concern are in relation to the proposed research topic. You will also need to know who the key people are, and which organisations are interested in your topic.
- Background work to help you determine the most appropriate way of doing your research includes looking at how other research has been done; reading about the research methods you are considering; and talking over your ideas with experienced researchers.

2.1 The importance of planning

Planning is essential to completing any good quality research project, particularly if resources are tight or experience in research is limited. Planning forces you to consider the entire research process, not just the parts that interest you.

Thinking through the whole research process can help inexperienced researchers to minimise potential problems. Good planning can help to ensure that all members of the group understand and agree upon the nature of the research, why it is being done, and how it will be done. As discussed in Chapter 1, planning can be a useful way of clarifying the expectations and defining the roles of collaborators in the project. A well developed research plan with clearly stated and agreed upon purposes, aims and objectives can also enhance the possibility of receiving funding; keep the research on track; and provide continuity if the people involved in supervising and undertaking the research change.

Careful consideration of each stage of the research process may also help to minimise the number of problems that develop during the project itself. For example, if you do not think about how you are going to analyse the information that you collect before you start collecting it, you may find that it is in a form that is difficult to analyse. This could mean that a lot of extra time will be spent in the latter stages of the project trying to analyse the data or that the results of your project may not be as useful as you had intended.

2.2 Plans always change

Although planning is vital, you can be certain that the research will not go precisely according to the plan:

- situations change over time;
- information uncovered in the research might suggest or require modifications of the research aims and objectives; and/or
- aspects of the planned research may turn out to be impractical, not possible or unnecessary.

A balance must be sought between the need to keep to the original plan and the need to make changes. Making too many changes to a research project removes the structure that is essential to supporting the people doing the research, consumes extra research resources and energy, and can ultimately destroy a research project. However, not making necessary changes can reduce a project's value and impact.

Where a funding body has funded research, particular care must be taken in making changes. Since the funding body has approved your research as originally intended, they need to be notified of significant changes to the research plan. At times, the research process should be delayed while the funding body approves your modified design. At other times, the research may need to be re-submitted to an ethics committee for approval. Even small changes between the original research and the final project should be recorded in the report to the funding body or in the final report of the project.

When modifying a research project, care must also be taken to account for the 'flow-on' effects of any changes that are made. For example, if you alter the locations from where you choose your research participants, you will need to ensure that your sample is still representative enough to make the generalisations you seek (see Chapter 5 for discussion of sampling and generalisability).

2.3 How much planning is needed?

The amount of planning undertaken should match the size and scope of the project. A small research project that seeks to find out what the 20 members of your group want to do for the next 12 months may not require extensive planning. However, a larger and more complex project, such as identifying particular health needs and concerns of people in your local government area, would require much more detailed and extensive planning.

In order to keep within your limitations it is advisable to start with a small project. This will enable you to learn about and gain experience of the whole research process while keeping the process manageable and achievable. Once you have successfully completed one project you can use the experience gained to competently tackle increasingly complex projects.

If the project you really want to do is a large one, you can start by doing a pilot project. A pilot project is a small-scale exploratory version of the full project. Pilot projects enable you to test whether your research ideas are feasible and whether your research method gives you the desired data. They can also help to identify problems and potential solutions before you do the larger project. Results from a pilot study can be used in proposals to convince funding bodies of the value and need for the project.

2.4 Developing your research plan

The process of planning a research project is painstaking and may take months to complete. However, it is worth persevering. Although the level of detail and the time spent in planning the research will vary with the size and complexity of the project, the components that should be considered in the plan are essentially the same. These components are as follows.

Conceptual issues

- *Purpose* —What do you want the research to achieve and why do you want to do it?
- *Audience* — Who is the research intended to inform or influence?

Practical issues

- *Aims and objectives* — What, specifically, will the research do? What will it tell us?
 - *Type of information required and research methods* — How will the research be done?
-

- *Timeline* — What are the specific tasks involved and how long will they take?
- *Budget* — What resources will be needed and how much will these resources cost? How can you expect to get the resources you need?

Ethical issues

- *Ethics* — Does the research infringe on people's rights or privacy, or is it likely to do them harm?

The components of a research plan are presented here in the order in which they are most often considered. However, developing a research plan cannot be done by simply answering one question and moving onto the next. All the components are inter-related, and each answer or component must take into account all the others. For example, identifying the purpose of the research cannot be done without also identifying the audience. Consequently, as the research plan progresses, earlier work must often be modified, and sometimes radically changed. Three processes are commonly used to answer these questions and answering each question usually involves a combination of these:

- brainstorming;
- discussions; and
- work done by individuals.

Brainstorming involves a group discussion in which everybody has a chance to put forward their ideas without any discussion of the merits or otherwise of the ideas being raised. Brainstorming is particularly useful in the early stages of planning a project because it allows a wide spectrum of ideas to be put forward. It can result in some very original and innovative ideas. Ideally, brainstorming should involve as many interested members of the group as possible to ensure that the project reflects the interests of the entire group.

Group discussions are more focused discussions and will generally be more appropriate for the long process of refining the research plan. Although, it would be ideal if the entire group were involved in these discussions, in practice they are likely to involve a core group of interested people. It is important that this group keeps the whole group informed of progress to make sure that what they are doing reflects the views and interests of the broader group.

In addition to the group work, it is essential that a core group of individuals do some additional background work. This is particularly so for those parts of the research plan that require investigation and attention to detail (ie literature review, budget). However, these individuals will still benefit from guidance and ideas from the wider group before they start their investigations. In addition, they need to be able to discuss and refine their ideas with the wider group on a regular basis.

Which ever processes are used, the aim in developing a research plan is to address all the questions outlined in the research plan. The components of a research plan are discussed more fully below.

Purpose

The purpose of a research project is of great importance as it outlines what you want the research to achieve and why you want to do it. It is vital that the purpose be thoroughly understood and agreed upon by the entire group as any misunderstandings or disagreements at this stage can grow and haunt the project for its entire duration. When the purpose has been agreed upon it should be recorded clearly and concisely in one or two sentences.

In deciding upon the purpose of your research, you need to consider how the research fits in with the group's overall purposes and other activities. The issue of who takes the lead in the group, the

dynamics, planning, and research experience of members of the group need to be discussed and resolved. The goals and reasons for undertaking the research, and the context within which the research is undertaken, need to be clarified before specific planning is undertaken. Without a clear and strong connection between the purpose of the research and the group's purposes there is no point in proceeding. Given the limited resources (time, energy and money) available to consumer and self-help groups, it is essential that your research efforts are carefully targeted.

The purpose of the General Practice Care after Miscarriage project was clearly expressed in the stated research hypotheses/questions to be tested:

- *are general practitioners' attitudes and perceptions of miscarriage congruent with women's perceptions of quality care following miscarriage?*
- *what, if any, informational resources or other strategies are needed to enhance the capacity of general practitioners to provide quality care to women who have experienced miscarriage?*

The ultimate purpose of the project was to improve the care of women after miscarriage. It was believed that the magnitude of loss following miscarriage was not widely articulated either by women themselves or by members of the medical profession and that the impact of miscarriage was not well understood within the community. It was felt that many women were not receiving adequate care after miscarriage as general practitioners were not aware of the support needed or its availability.

The Older Women's Health Project arose from the evaluation of the National Women's Health Program. Although older women were identified as a priority issue in the Program, the Older Women's Network felt that the needs of older woman had not received adequate attention during the implementation phase.

The needs of the older woman had been particularly well articulated at a conference initiated by the Older Women's Network that had looked at older women's issues and differences in health. Following this conference, the health committee of the Older Women's Network met to discuss practical ways to deal with the issues that had arisen.

Informal discussions with the Women's Health Unit, NSW Department of Health, led to a formal submission to the National Women's Health Program for research funds. The Older Women's Network worked collaboratively with the NSW Women's Health Unit to develop their research proposal.

Audience

From the very beginning of the planning process, you must be clear about who you want to read the research report, and who you want to be informed and influenced by the findings of your research. These people make up your audience. Consideration of your audience should influence almost every aspect of the research plan.

Because your research must be credible and accessible to your audience, your audience will influence your choice of research methods, the language, style and content of your research report and how you disseminate the findings. Potential audiences include the group itself, medical or other health practitioners, public servants, news media, educators, other researchers and the general public. Each of these audiences has different requirements regarding what they will accept as credible research and how that information should be presented. For example, medical practitioners

tend to give more credibility to statistical-based research that has been published in a well-known medical journal. In contrast, the general public is not as concerned with the way that the research was done as with the actual results of the research. They are more likely to find out about the research if the results are reported in a newspaper or on the radio.

Research can be aimed at several audiences. However, it is often useful to identify primary and secondary audiences because reporting and dissemination requirements can vary widely, and the limited resources available for the research may mean that it will be most effective to focus on only one or two audiences.

The Older Women's Network identified four audiences for their findings:

- *Commonwealth funders or funding authorities of women's health — the Network's philosophical position drove them to carry out research that would promote the concept of self-help and partnerships in health; the Network challenged the traditional concepts of health programs;*
- *State/Territory funders — the Network sought to influence health policies and programs at the State/Territory level to incorporate the concerns and issues of older women;*
- *local and regional area health services — the Network sought to gain respect for the concept of consulting with consumers at local and regional levels;*
- *older women — above all, the Network sought to empower older women to identify with the aims and philosophies of the network, and to become involved with and take up the issues articulated through the Project at their own level.*

The group's research report, Well-Being: For and By Older Women, was disseminated to all the research project's audiences.

SANDS and the UQ had three audiences for the findings of their research:

- *general practitioners — to provide general practitioners with information about the psychological impact of miscarriage on women;*
- *women who have experienced miscarriage — to validate their experiences; and*
- *women who will have miscarriages in the future — to indicate what they might expect.*

Aims and objectives

The aims and objectives of your research will define the scale, scope and type of research that will be done and determine the research boundaries. In stating what will be done, it will become clear what will not be done in this piece of research. The general issues outlined by the purpose and audience are made specific and concrete through the aims and objectives.

Clearly stated aims and objectives are essential to developing and maintaining a well-focused and manageable research project. They provide strong guidance to those conducting the project and minimise the possibility that the researchers will go off on a tangent.

Each aim of a project should be a simple statement in one or two sentences specifying what the project intends to do. They should be clearly formulated (even if they are modified in the latter stages of planning) and worthwhile. It is important to make sure that it is feasible to collect the

necessary information to meet your aims. The aims and objectives connect what you want to research with how you are going to go about your research.

The aim of the Older Women's Health Project was to document the health issues and needs of older women as stated by older women. The Project looked at health for older women, its meaning, importance and maintenance. It also examined women's perceptions and use of health services and health promotion initiatives.

Aims can also be expressed as research questions. For example, the aim of the Older Women's Health Project when expressed as a research question would be:

What are the health issues and needs of older women as stated by older women?

A project's objectives are specific statements about what will need to be done to achieve the aim. To develop the objectives, you need to think about the level of detail and what information you need to meet the aim of the project.

The objectives of the Older Women's Health Project were to document the barriers:

- *in access to health services for women aged over 60;*
- *to independent living and the pursuit of optimal healthy lifestyles for women aged over 60;*
- *to participation in health service decision making; and*
- *to older women's self-advocacy within the health system.*

Again, research objectives can also be stated as research questions, based on what sub-questions need to be answered to achieve the research aim or answer the primary research question. In the case of the Older Women's Health Project, the sub-questions to the research were as follows.

- **What are the barriers in access to health services for women aged over 60?**
- **What are the barriers to independent living and the pursuit of optimal healthy lifestyles for women aged over 60?**
- **What are the barriers to participation in health service decision-making?; and**
- **What are the barriers to older women's self-advocacy within the health system?**

While there is no single 'right' way to state aims and objectives, and while the level of detail can vary considerably, it is important that they provide an adequate framework and boundaries to guide the researcher. Hence, it is important that aims and objectives lend themselves to operationally definable concepts and to measurable outcomes. For example, a research project that aims 'to encourage people to think more sensibly about AIDS' is not easily defined, and is certainly not measurable. Encouragement means different things to different people, measurements of 'thinking' are difficult, and what constitutes 'more sensibly' cannot be defined. An alternative research aim would be 'to change attitudes to AIDS among the target group (of...)'.

Aims should incorporate specific active verbs that imply an outcome.

Verbs that imply an outcome	Verbs that do not imply an outcome
To describe, to delineate, to document	To explore
To assess	To find out all we can
To measure	To encourage
To show similarities and differences	To research
To evaluate	
To show changes associated with...	
To develop and trial	

The General Practice Care after Miscarriage project did not make distinctions between aims and objectives. Rather, the ultimate aim, or purpose, of the project was broken down into the following aims and objectives:

- *to investigate women's perceptions of quality general practice care following miscarriage;*
- *to examine general practitioners' attitudes to the psychological aspects of miscarriage and their role in miscarriage support;*
- *to determine whether a need exists among general practitioners for further informational resources relevant to miscarriage support and, if so;*
- *to identify possible strategies to meet this need.*

The aims and objectives should clearly lead you to possible methods to be used to achieve them. You need to have at least one strategy in your research method to meet each of the aims and objectives.

Several types of information were required in the General Practice Care after Miscarriage project. In order to investigate women's perceptions of quality general practice care following miscarriage (first aim), the researchers employed a research assistant who undertook focus group meetings and interviews with women who had experienced miscarriage. From this data a questionnaire was developed that incorporated the themes (i) that had been raised through the qualitative stage or (ii) that were supported in the literature.

The questionnaire was developed in order to fulfil the second and third research aims: to examine general practitioners' attitudes to the psychological aspects of miscarriage and their role in miscarriage support; and to determine whether a need exists among general practitioners for further informational resources relevant to miscarriage support. The questionnaire was sent to general practitioners and provided quantitative data about their attitudes to the psychological aspects of miscarriage and their role in miscarriage support.

During the project it is worthwhile keeping a copy of your aims and objectives where you can see them clearly. Constantly referring to them is a great way to keep you and the research on track. They are the basis for deciding what needs to be done and what should not be done on a day-to-day, month-by-month basis. It is surprisingly easy to lose the plot halfway through a research project when you find yourself immersed in new and interesting information.

Types of information required and research methods

Achieving your particular research aims and objectives requires collecting information using various research methods (or techniques). You will need to decide on the type or types of information your research requires and appropriate research methods to gather this information. Together the purpose, audience, aims and objectives will help to determine the type of information that you need.

Your choice of research method will be determined by a number of factors. The most important of these are the purpose, the audience, and the aims and objectives of your research. In undertaking consumers' research, you are also likely to be constrained in your choice of research method by how much time you have, your available resources, and from whom you want to collect the information — your research participants. Choosing the most appropriate method or combination of methods for your project can be difficult. Selecting methods appropriate for your project is discussed in Chapter 5. It may also be advisable to seek the advice of one or more experienced researchers (see Chapter 1) before making your final decision.

The two most commonly used and discussed types of information are quantitative and qualitative. Quantitative research aims to measure and count things, recording the findings using numbers and statistics. Qualitative research aims to collect people's interpretations of things, and people's reasons for actions, recording and analysing the findings using themes, language and words of the research participants. Having said this, the qualitative / quantitative divide is not this clear cut. Research is also done which records both quantitative and qualitative findings. Qualitative findings can be recorded with numbers, and quantitative findings can be recorded with themes to explain the findings.

As the information sought was about perceptions and meanings, the Older Women's Network chose a qualitative methodology for the Older Women's Health Project, using focus groups to gather material.

The General Practice Care after Miscarriage project used more than one research method for collecting information.

Timelines

Once you know what you are going to do (aims and objectives) and how you are going to do it (methods), you need to develop a timeline. A timeline is a schedule that outlines the tasks that need to be done in order to complete the research project. It also indicates when each task will be done, or the estimated length of time needed to complete the task. Once the project has begun, timelines are essential for keeping track of what has been done and what still needs to be done. They are also often required for funding applications and are therefore further discussed in Chapter 4 (see page 40).

Timelines for consumer and self-help groups are often quite different from the timelines used by professional researchers. Generally, members of consumer groups must fit their research work around the rest of their lives; unlike professional researchers they may be unable to siphon off large blocks of time to undertake the research. Hence, the time taken to complete the research may be quite extended compared with the time taken to perform similar tasks by a professional researcher.

Developing a timeline requires careful consideration of each task necessary for completing the research, and estimation of how long each task will take. Doing this will give you an indication of

whether or not the aims of the project are realistic. This is the point at which many research plans are dramatically scaled down.

It is often difficult to estimate just how long each task will take, and usually the actual time taken will be longer than estimated. For example, in estimating how long it will take to do 50 one-hour face-to-face interviews, you need to work out all the components of each interview and then estimate the time necessary for each component. For example, on the assumption that the interviewee is available as arranged, each face-to-face interview could take a total of 150 minutes, or two and a half hours, broken down as follows.

For each face-to-face interview:

- arrange interview 15 minutes
- conduct interview 60 minutes
- review and complete interview 15 minutes
- travel to and from interview 60 minutes

Hence, it will take at least a total of 125 hours to complete all 50 interviews.

A common but not foolproof method for estimating how long each major stage of the research process will take is to determine as closely as possible how long it will take to collect the information. This is approximately how long it will take to do each of the other major stages of the research.

Time taken for each major stage of the research:

- 125 hours to do the preparatory work, such as the literature review, preparing and trialing the interview questions, and choosing the sample;
- 125 hours to do the interviews;
- 125 hours to analyse the interviews and discuss the findings with group members;
- 125 hours to write up the research report; and
- 125 hours to disseminate the results.

In developing timelines, it is essential that you include plenty of extra time, especially if you are inexperienced researchers. Things will go wrong, and some things will be harder and more time consuming than you anticipated. It is reasonable to add at least 10 to 20 per cent of the total time estimated by the above method to derive a total estimation of the time needed to complete the project. This would bring the estimated number of hours above to 750 hours.

Budget

An essential part of the planning of any research project is to work out all the resources that will be needed to complete it. The resources needed and an associated budget must be determined for the entire duration of the project from the planning stage right through to the dissemination of the results. Preparing a research budget is usually a very sobering experience and often results in significant scaling down of the project to fit within the available resources.

Your previously developed timeline should provide the basis for determining the resources needed as it already lists each of the necessary research tasks. Using your timeline, systematically go through each task and carefully work out all the possible resources that will be needed to complete the project.

After identifying the resources, you need to determine to what extent you have, or can easily obtain, the necessary resources. These resources can then be removed from your list and the costs of the remaining resources become your budget.

If you are applying for funding for your research (see Chapter 4) you will probably work with two versions of your budget. The first will be your ‘working budget’ which will be a very detailed list that documents every single resource needed and their costs. The second will be a ‘summary budget’ that will be in a format that conforms to the broad categories used by your funding body. It is worth keeping the ‘working budget’ so that you can refer to it during the project, or if the funding body queries any of your proposed budget items.

If you are not applying for funding for your research and your proposal is beyond the resources readily available to your group, you have the option of scaling down the project, or breaking it up into several smaller projects. Doing several smaller projects that are each part of a larger project has many advantages for consumer groups. Small projects are more easily finished. This can give you the sense of satisfaction and accomplishment necessary to move onto the next project, and can also provide a stronger foundation for seeking funding for the next project.

Ethics

Ethical issues should inform and shape the whole research process. Consequently, their consideration in the planning stage and throughout the duration of the research project is vital. Ethical research and ethical research practices are achieved by thoroughly considering the impact of the research on those involved. Many ethical issues are centred on how you treat the research participants. Other ethical issues relate to the quality of the research and the integrity of the researchers. The importance of ethical research and obtaining ethics clearance are discussed in Chapter 3.

2.5 Background work

The main areas of background work that need to be carried out in order to complete a research plan are:

- developing a good understanding of your research topic;
- identifying the best ways of doing your research;
- developing the timeline; and
- working out the resources that you will need to complete the project.

While the latter three have been discussed already in this chapter, this section deals with the importance of developing a good understanding of your research topic.

For many self-help and consumer groups, the understanding of the research topic derives from people’s own experience. However, in preparing to undertake research, you need to know what research has already been done in the area, and what others’ main debates or areas of concern are in relation to the proposed research topic. You will also need to know who the key people are, and which organisations are interested in your topic.

In any research one finds out about the proposed research topic by reading relevant articles and books. If any material has been published on your topic you should try to read it and review it. Further information about finding and assessing the literature is given in Chapter 6.

It is not always possible to review existing research because at times the topics to be researched are so new that no previous research has been done. If this is the case, you should try to find any related material that helps to support your argument for the need for the project, or that puts your proposed

topic in the context of other related research that has been done. For example, if you wanted to carry out research into a rare blood disorder, you might look up the readily available literature on haemophilia. If you were wanting to research the social impact of a rare or newly defined disease that primarily affects people physically, you might look up the readily available literature on the social impact of other diseases that affect people in this way.

Background work to help you determine the most appropriate way of doing your research includes looking at how other research has been done; reading about the research methods you are considering; and talking over your ideas with experienced researchers, as discussed in Chapter 1. Looking at how previous research has been undertaken can give you some ideas on how to (or how not to) carry out your own research. It can also be useful to look at books that discuss in detail the research methods you are considering using. A number of useful references can be found in the Bibliography.

One of the most effective ways of identifying the key articles and books on your topic, as well as the main debates in the area, is to talk to one or two experts working in the area. It is extremely beneficial to spend some time identifying these people as they will often save you much time and energy. They will usually be able to direct you quickly to the relevant literature and they may be able to help you with other aspects of your research. Finding people to assist in your research has been discussed in Chapter 1.

Experts in the area can usually be found through reading. Contact details, or at least the author's institution, are often included in the publication. Otherwise, the editor of the journal or publisher of the book should be contacted for the author's contact information. In addition, specialists treating people with a particular illness or condition can be good expert contacts, or can refer you to other experts or other literature in the area.

You may be hoping to undertake research that challenges views held by health care professionals, academics and public servants. In these instances, and contrary to your 'hunch', it is possible that you will be told that what you are trying to do is wrong, will not work or is pointless. It is important, nevertheless, to listen to what they say and to evaluate their comments based on your knowledge of your research topic, and what you know about their perspective. Their arguments may provide you with an indication of what to expect when your research is completed. In this case, you have the opportunity to strengthen your research design against such critics. Above all, do not lose sight of why and for whom you are doing the research.

3 Ethics

Throughout the development of your research plan and collection and analysis of information, it is important to work within ethical boundaries. Ethics are of foremost importance in all research. The term ‘ethics’ refers to standards of conduct and moral judgement. In research, ethics is about protecting the rights, health and lives of the participants in the research.

Summary — Ethics

What are ethics and why are they important?

- Ethical research and ethical research practices are achieved by always and thoroughly considering the impact of your research on those involved.
- An ethical appraisal of research will consider the integrity of the researcher, whether respect for persons is shown, how the research benefits the participants and social justice in relation to the informant(s), the community, the profession and/or society in general.

Obtaining ethics approval

- Research proposals involving human participants must have obtained ethics must be reviewed and approved by a Human Research Ethics Committee before any research is undertaken or research funds are paid.
- Institutions or organisations conducting research into humans are required to set up **Human Research Ethics Committees** (see page 28). These were initially established to assess the ethics of biomedical or experimental research but now have an expanded role which includes assessment of the ethics of research in other areas.

Developing a research proposal

- In preparing a research proposal, it is important to consider what effect your research will have on the participants.

Informed consent

- **Informed consent** (see page 31) involves providing participants with information at their level of understanding and the exercise of voluntary choice to participate. Consent should usually be obtained in writing.
- Many Human Research Ethics Committees require researchers to prepare an **information sheet for participants** (see page 30), which describes the research in language readily understandable to the proposed participants in the research.
- In some circumstances it is ethically appropriate or necessary to **follow-up** (see page 32) the research participants after their involvement in the research.

3.1 What are ethics and why are they important?

Ethical research, whether biomedical, experimental or qualitative, is fundamentally dependent upon the ethical behaviour of researchers; while guidelines have been set, they, in themselves, cannot make ethical research happen.¹ Ethics in research is about balancing the right of the researcher to acquire knowledge and insight that will be of value to society with the right of the research

¹ van der Heide, G. 1995, *Ethics, Consumers and Research*, The 1995 General Practice Evaluation Conference Proceedings, National Information Service: Adelaide, p.95.

participants to maintain privacy, dignity, and self-determination.² Ethical research and ethical research practices are achieved through thorough consideration of the impact of your research on those involved.

Ethics is about not causing harm. As such, ethics is about asking whether what you are doing is right and fair, and whether the things you are doing are being done in the right way, respecting the people involved and their rights. An ethical appraisal of research will look at:

- the *integrity*, both personal and professional, of the researcher as expressed in the honest and ethical conduct of research and dissemination and communication of results;
- the researcher's *respect for persons* as shown by their regard for the welfare, rights, beliefs, perceptions, customs and cultural heritage of persons involved in the research;
- how the research *benefits the participants* and the researcher's efforts to minimise the risks of harm or discomfort to participants in the research project; and
- social *justice* in relation to the informant(s), the community, the profession and/or the society at large.³

Researching ethically goes beyond gathering data in an ethical manner; it is research that is of high quality, is worthwhile, has an ultimate purpose and has the potential to elicit change. Ethical research considers the ethical implications throughout the research, including:

- choosing methods that respect privacy, anonymity and confidentiality;
- approaching research with an open mind and making every attempt to be fair in treatment of the topic;
- treating people appropriately and with respect during the research;
- storing the research data safely; and de-identifying the information to preserve anonymity and confidentiality (de-identifying the information in qualitative research is particularly important since care must be taken when using anecdotes or case studies that the person cannot be identified from the information given);
- ensuring that participants have easy access to the results; and
- reporting processes and results honestly.

The NHMRC *Guidelines for Health Research and Aboriginal and Torres Strait Islander Communities*⁴ may be useful in considering consumers' research as they address many of the issues of consumers' research — issues of community participation in research design, questions of ownership of the data and objects collected during the course of the project, and the publication of the results.⁵

² Minichiello, V., Aroni, R., Timewell, E., Alexander, L. 1995, *In-Depth Interviewing* (2nd Edition), Longman: Melbourne, p.194.

³ Minichiello, V., Aroni, R., Timewell, E., Alexander, L. 1995, *In-Depth Interviewing* (2nd Edition), Longman: Melbourne, p.192.

⁴ NHMRC 1995 *Guidelines for Health Research and Aboriginal and Torres Strait Islander Communities*, NHMRC: Canberra. <http://www.health.gov.au/nhmrc/publicat/synopses/e11syn.htm>

⁵ Albury, R., Dodds, S., Thomson, C., Secomb, L. 1996, *Ethical Research: Issues for Institutional Ethics Committees*, University of Wollongong: Wollongong, p.5.

3.2 Obtaining ethics approval

In Australia, the NHMRC has set the standards for ethical research through the *National Statement on Ethical Conduct in Research Involving Humans*.⁶ Under the Statement, research proposals involving human participants must be reviewed and approved by a Human Research Ethics Committee (formerly referred to as an Institutional Ethics Committee; see below) and the research must not be undertaken or funded unless or until approval has been granted.⁷ Research using data in which an aspect of health is involved, held by a Commonwealth department or instrumentality, and not normally available also needs to be reviewed by an Human Research Ethics Committee.

Sometimes a research project is carried out in a number of institutions and in these cases ethics approval should be sought from Committees at all participating institutions except where the responsibility for ethics has been formally delegated to one Human Research Ethics Committee.

Human Research Ethics Committees

Since the 1960s,⁸ many institutions, including hospitals, universities, and Commonwealth and State/Territory health departments, have set up Human Research Ethics Committees. While these were initially established to assess the ethics of biomedical or experimental research, the role of such committees has expanded to encompass assessment of the ethics of the various qualitative and mixed or complex methods. Under the NHMRC's *National Statement on Ethical Conduct in Research Involving Humans* all institutions and organisations in which research involving humans is undertaken must individually or jointly establish a Human Research Ethics Committee.

Researchers without affiliation to an institution or organisation with a committee must ensure that the project is approved by an established HREC.⁹

A Human Research Ethics Committee must include as a minimum¹⁰: a chairperson; two members who are lay people with no affiliation with the institution or organisation; a member currently involved in the professional care, counselling or treatment of people; a minister of religion or a person who performs a similar role in a community; and a lawyer.

Although there is some debate about how effectively they do so,¹¹ ethics committees are primarily concerned with protecting the welfare and rights of participants in research. In doing so, they check how much the research will impose a burden on participants. They assess the research proposal for the methods of recruitment, consent, privacy and confidentiality, and the reporting of the findings.

Experience by consumers serving on Human Research Ethics Committees (as 'laypersons') suggests that some researchers, including those undertaking consumers' research, may overlook the needs of research participants. For example, one consumer researcher was surprised when it was suggested that the project she was working on required ethical approval since it was being done on

⁶ NHMRC 1999 *National Statement on Ethical Conduct in Research Involving Humans*, NHMRC: Canberra. <http://www.health.gov.au/nhmrc/publicat/synopses/e35syn.htm>

⁷ NHMRC 1999, *National Statement on Ethical Conduct in Research Involving Humans*. NHMRC: Canberra, p.13.

⁸ Daly, J., McDonald, I. 'Ethics, Responsibility and Health Research', in J. Daly (ed) 1996, *Ethical Intersections: Health Research, Methods and Researcher Responsibility*, Allen & Unwin, St. Leonards, p.xv.

⁹ NHMRC 1999, *National Statement on Ethical Conduct in Research Involving Humans*. NHMRC: Canberra, p.15.

¹⁰ NHMRC 1999, *National Statement on Ethical Conduct in Research Involving Humans*, NHMRC: Canberra, pp.15–16.

¹¹ See, for example, McNeill, P.M., 'Research Ethics Committees: Is the tail wagging the dog?' in Daly J. (ed) 1996, *Ethical Intersections: Health Research, Methods and Researcher Responsibility*, Allen & Unwin, St. Leonards, pp.15-23, and Minichiello, V., Aroni, R., Timewell, E., Alexander, L. 1995, *In-Depth Interviewing* (2nd Edition), Longman: Melbourne, pp.196-197.

behalf of consumers; in fact the research project concerned had a considerable participant burden in terms of long interviews and keeping a diary of relevant events.

Many consumers face difficulties in accessing Human Research Ethics Committees. If your research has enlisted the help of someone who is attached to an institution, it is preferable to seek ethics clearance from their Human Research Ethics Committee. However, if this is not possible, other ethics committees like the Departmental Ethics Committee attached to the Commonwealth Department of Health and Aged Care or the Royal Australian College of General Practitioners Ethics Committee may assess your research proposal. If all else fails, you might like to discuss your problems in accessing an ethics committee with the potential funding body.

Ethical approval for the General Practice Care after Miscarriage project was obtained through the University of Queensland's Behavioural and Social Sciences Ethical Review Committee. The academic involved in the project was familiar with the process for making applications to this committee. Issues relating to privacy and confidentiality were identified and addressed at an early stage in the process so that ethical approval could be sought and obtained well before the project was due to commence.

Applying for ethics approval

Human Research Ethics Committees have forms that you need to fill out when you are applying to them for ethics clearance. Unfortunately, the forms are not standard although some issues are always covered. These include:

- details about all of the researchers;
- a brief summary of the research in everyday language;
- a description of the risks (if any), how they will be minimised and managed if any occur (for example, an interview about sexual health may include the risk of an individual's becoming distressed during or after discussion about sexual abuse and the researchers need to have help available for those who need it);
- a description of the benefits;
- who the participants in the research will be;
- if any will be minors under 18 years of age;
- how participants will be contacted initially;
- how they will be asked to participate in the study (a copy of the participant's information sheet must be attached; see below);
- how informed consent (see below) will be obtained from them (a copy of the consent form must be attached);
- how confidentiality will be protected in terms of data collection and storage (for example, all interviews are usually allocated a number and a document which matches the number with name and other identifiers is stored separately from other research information); and
- how participants can get access to the results of the research.

Most ethics committees will also want the research proposal attached to the ethics application or at least a description of the methodology and a literature review. If you are using an interview

schedule, questionnaire or survey, most Human Research Ethics Committees will want to see a copy because of their concern about the burden on the participants.

Ethics committees will assess the research application for how well the privacy, confidentiality and anonymity of participants is protected. This will include an assessment of the sampling and analysis techniques to be used, the storage of data, and the dissemination of the research findings. Where interviews are to be conducted, it is of critical importance that the venue promotes the confidentiality and safety of participants. For example, conducting interviews in a person's home may promote the comfort of the participant, but it could also arouse socially damaging suspicion and unwanted enquiry from the participant's neighbours. In addition, the privacy considerations within the house, and the impact of other family members on the person's ability to respond honestly, confidentially, and with ease, may also be impeded by the setting. The participant could feel very uncomfortable being interviewed in their own home, depending on the research subject.

Ethics committees may also include in their ethical assessment of the research proposal an analysis of the project's value for money. Where the research funds come from the public purse, there is an almost unspoken requirement that the research should reflect value for money. Value for money also relates to the use of resources, for example, that participants are not interviewed in excess of that required to gather sufficient information to meet the project's aims and objectives. Ultimately, however, the assessment of value for money is a subjective analysis that will be influenced by the values of the people on the ethics committee. Nevertheless, the research should be fully justified — from the background and aims to the methods and through to the research budget, as outlined in Chapter 4.

Ethics committees should also assess the project for the suggested and potential benefits to society. Although not mandated, included in this should be an assessment of the adequacy of the dissemination process. The dissemination process is discussed in Section 8.2.

3.3 Developing a research proposal

In preparing the research proposal, it is necessary to focus on the results but an ethical approach to the research is also required. Although not a definitive list, to assess whether your research proposal meets ethical guidelines it helps to think about your proposal:

- for its potential impact to effect change rather than doing research just because it is 'interesting';
- to check that the research method is the most appropriate to address the research problem;
- to check that the research methods intrude as little as possible into the lives of the participants in the research. The research method should minimise harm to the research participants;
- to conduct research that collects and analyses data as rigorously as possible. Only valid and substantiated conclusions should be drawn;
- to disseminate the research results appropriately. Researchers are ethically obliged to ensure the correct reporting and interpretation of their research findings, although this is not usually mandated in print.¹²

In preparing your proposal, consider what it would be like for a person to take part in the research as a participant. How would he/she be contacted? What explanations about the research would need to be made? What assurances about confidentiality would the person require? What sequence of

¹² Daly, J., McDonald, I. 'Ethics, Responsibility and Health Research', in J. Daly (ed) 1996, *Ethical Intersections: Health Research, Methods and Researcher Responsibility*, Allen & Unwin, St. Leonards, pp. xviii–xix.

activities would he/she need to take part in? In short, this involves ‘getting inside the shoes’ of participants.

It is also advisable to consider the ethics in regard to the funding of the research. Researchers accepting funding from, for example, industry may feel constrained regarding the release and publication of their findings. However, ethically, the funder cannot influence the findings to suit their purposes or interests. In accepting funding for your research, it is vital that you agree with the funder on the terms and conditions of the funding. All parties are responsible for disclosing all potential conflicts of interest, including on publication of the findings.

3.4 Informed consent

Before research is undertaken, the consent of the participants must be obtained. Obtaining informed consent should involve:¹³

- providing participants with information at their level of comprehension about the purpose, methods, demands, risk, inconveniences, discomforts and possible outcomes of research; and
- the exercise of voluntary choice to participate.

Consent should usually be obtained in writing unless there are good reasons why not and these reasons will need to be carefully explained. There might be occasions, for example, where it would be culturally inappropriate to ask people to give their written consent when their experiences in their country of origin would cause this to elicit high levels of anxiety and distress.

For minors (usually considered to be people younger than 18 years of age) and for people with some level of temporary or permanent intellectual incapacity their consent as well as that of a parent or guardian may be required depending on their age, level of understanding and the nature of the research.

A consent form would normally include the following information:

- names and contact details of the researchers;
- title of the research;
- language readily understandable by the research participants;
- a description of any possible material risks;
- a description of the benefit to the participant or to others;
- how confidentiality of information will be maintained;
- a statement that participation is voluntary, that declining to take part will result in no penalty or loss of benefits (where appropriate), and that the participant may decide at any time to discontinue participation without comment or penalty;
- a statement that participants can contact the Chief/Principal Investigator at any time to discuss any matter concerning them (increasingly, Human Research Ethics Committees nominate one of their number or another independent person to receive any complaints from research participants);
- an undertaking to provide feedback if participants wish it; and
- space for participants (and parent/guardian where appropriate) to sign and date the form.

¹³ NHMRC 1999, *National Statement on Ethical Conduct in Research Involving Humans*, NHMRC: Canberra, p.12.

Participants should be given a copy of the signed form.

Participant's information sheet

Many Human Research Ethics Committees require researchers to prepare an information sheet for participants, which describes the research in language readily understandable to the proposed participants in the research. It may also contain some of the information included on the consent form such as the risks and benefits of participation. However, Human Research Ethics Committees differ in their requirements for what should be contained in the information sheet.

Follow-up

In some circumstances it is ethically appropriate or necessary to follow-up the research participants after their involvement in the research. For example, if a study of teenagers revealed that a number of young men were suicidal, there is a moral and ethical obligation to follow up the young men and to offer to refer them to counselling or other support. Information given to the ethics committee should address these considerations.

In the General Practice Care after Miscarriage project, women who were interviewed in the qualitative stage of the project were offered ongoing support from SANDS.

4 Research budgets and obtaining funding

Even small research projects are likely to strain the limited resources of self-help groups. More groups would be able to undertake good quality research projects if they could attract some funding for their projects. Funding enables the group to conduct their research without compromising the core activities of the group.

Funding is particularly important for consumer groups for whom research is not a normal part of their core activities. Despite the best of intentions, most consumers are simply not able to devote the amount of time necessary to undertake a good quality research project unless they receive some recompense for their time. Obtaining funding to enable the members of the group conducting the project to be paid greatly increases the chance that they will be able to devote the necessary time to the project. Funding also allows the group to employ experienced researchers who can then conduct all, or parts, of the project if they are needed.

Seeking funding for a research project is a gamble. It can take time and effort to find possible funding sources and to complete application forms, and there are no guarantees that you will be successful. A sound research proposal and some funding ‘know how’ can assist you in your attempts to obtain research funding. This chapter provides some suggestions about where to look for funding sources and how to apply for funds.

Summary — Research budgets and obtaining funding

Identifying potential funding bodies

- Research funding sources in the **Commonwealth Government** (see page 35) include the General Practice Evaluation Program; Pharmaceuticals and the Rational Use of Medicines; the National Health and Medical Research Council; and the Commonwealth Department of Health and Aged Care.
- If seeking funding from the **State/Territory Government** (see page 36), approach relevant government departments and check major newspapers for notices of funding programs.
- **Local governments** (see page 36) rarely have formal funding programs for research. However, they can often provide a small amount of financial support or access to council facilities.
- **Trusts and foundations** (see page 36) are an important source of research funds.
- **Service clubs** (see page 37), such as Rotary, Lions, and the Returned Services League, can often provide a small amount of funding for projects.
- **Commercial sponsorship** (see page 37) is sometimes available for research that is relevant to the funding corporation’s business.

Following the application guidelines

- A good research application will avoid excessive jargon and be easy to read quickly; be typed; be presented to the funder with the correct number of copies; be presented to the funder on or before the due date; and answer all the questions/provide responses in all the required sections of the application form.

The funding application

- The **title** for your proposal should clearly state what the proposal is considering and the description of your research (see page 39) should summarise the aims, objectives, methodology and expected outcomes of the research.
- The **background and justification** section (see page 40) should show how the idea for the project came about and what research has already been done on the topic.

- The section on **research design and methods** (see page 40) should include a clear and moderately detailed description of what you propose to do. This is where you include your strategies for meeting each aim/objective and how they will be implemented.
- The **timeline** (see page 40) should take into account every major step in the research plan. It should include a start date, the total number of months that the project will run and the proposed completion date.
- Your **budget** for the project (see page 41) should be cost-effective; the outcomes to be gained by conducting the research should justify the amount of support you are requesting. Budgets should include estimated costs for labour, on-costs, overheads and other costs.
- You will need to follow guidelines regarding seeking **ethical approval** for your research proposal. You may need to have gained this approval before you submit the application.
- Applications for research funds usually include a request for brief **Curriculum Vitae** (see page 43) from each of the people who will play a major role in the research. The Curriculum Vitae, or resume, should outline all relevant experience, qualifications, training, previous research, and publications.
- Nominate **referees** (see page 43) who will comment positively and authoritatively but independently on your application.
- Most funding bodies will insist that a group be in some way legally incorporated before they will hand over research funds. If your group is not incorporated under one of the Incorporation Acts you will usually need to find a 'parent' organisation that is prepared to act as an **auspicing body** (see page 44).

The application process

- Most research applications follow a fairly standard assessment process. The process may take between three and nine months.

Assessment of applications

- Criteria for reviewing funding applications may include originality and relevance of the research topic; appropriateness of the proposed research methods; evidence of your familiarity with the research topic and of work done in developing your ideas; your ability to do the research, and complete it in the proposed timeframe; and the proposal's value for money.

What next?

- If you are successful in obtaining your research funds you will fairly quickly need to start dealing with the practicalities of the project, including obtaining ethics approval; organising a reference group; determining who is responsible for financial administration of the project; and employing any staff specified in the funding application.
- If you are unsuccessful in your attempt to gain funding, you may wish to consider contacting the funding body to find out why you were unsuccessful and obtaining a list of projects that were successful to inform future funding applications with that organisation; modifying your application and submitting it to a different funding body; doing all or part of the project using voluntary labour and resources of the group; or having the project completed by a student (see Chapter 1).

4.1 Identifying potential funding bodies

There are at least two approaches to developing proposals for research projects:

- having an idea, developing it and then finding a source of funding to suit the aims and objectives of the research — look for common ground between what you want to research and what research the funding source wants to support; and
- knowing where the funding application will be submitted and developing the research proposal around the requirements of the funding body — viewing a list of grants previously made by the funding body may help you in structuring your proposal to meet requirements and to ensure that there is no duplication.

There are numerous funding sources and programs. Funding sources and the research they want to support are constantly changing. This section aims to give an overview of where to look, rather than listing specific funding sources.

Some research funding bodies have programs specifically for inexperienced researchers. These programs are often referred to as ‘seeding grants’ or ‘small grants’. They generally involve relatively small amounts of money, usually \$10,000 to \$15,000 or less. It is worth starting with a seeding grant if you are not an experienced researcher.

The process of seeking funds for the Older Women’s Health Project started quite informally, with an offer from the Women’s Health Unit of the NSW Department of Health to work collaboratively on the Project.

The Network made a written submission to the National Women’s Health Program for \$10,000 of funding to undertake the Project. The process of submission was supported and encouraged by the Women’s Health Unit.

Commonwealth government

Commonwealth departments and offices are major research funding sources and a number of Commonwealth funding programs have expressed an interest in funding research by or with consumer groups. Specifically in the health area some of the major funding programs include:

- the NHMRC — a national body which funds both medical and public health research;
- the PHARM committee and the Quality use of Medicines Education Program —national bodies which fund research into pharmaceuticals and their use; and
- GPEP — a national funding body which funds research into general practice evaluation.

In addition, sections of the Department of Health and Aged Care may offer funds for research or commission research into particular areas. Such funding may be advertised but generally it is preferable to be on a Departmental mailing list and/or have contacts with relevant people in the Department.

Funds for research from the national funding bodies are usually advertised once a year and in the national media. It pays to regularly check newspapers, particularly *The Weekend Australian*, for these notices. Information on these and other Commonwealth research funds can be obtained by contacting the relevant section of the Commonwealth Department of Health and Aged Care.¹

¹ Contact the Department on (02) 6289 1555 or 1800 289 1555. The website is at www.health.gov.au.

National funding bodies tend to fund research that is of national significance. That is, the research findings should be generalisable to other areas of Australia even if, for example, you have only used a sample of people from your State/Territory. In this instance you would need to show the funding body in your research proposal that there are no confounding factors that relate only to your State/Territory or area.

At the time that the research idea crystallised for the General Practice Care After Miscarriage project, the researchers knew something of the General Practice Evaluation Program (GPEP). Their research idea closely matched the funding body's requirements. The researchers paid close attention to the objectives of the funding body and to the guidelines on preparing a submission. The researchers were able to make minor modifications to their proposal so that their research project fitted within the guidelines of the funding body. Their application was reviewed in the annual funding round of the GPEP.

State and Territory governments

Like the Commonwealth Government, State/Territory government departments frequently have funds available for research into issues that they are interested in investigating. Think broadly when deciding which department(s) to approach as your project may be relevant to a number of areas.

State and Territory governments vary widely in how they provide funds for research. To determine whether funding is available:

- check with the departments that seem most relevant to your proposal
- check for notices in the media about State-based research funding programs, which are usually published in the major newspapers in each State/Territory (eg in Queensland check in *The Courier Mail* and in New South Wales in *The Sydney Morning Herald*).

State/Territory funding is usually available for research that is of State significance and relates to functions or issues that are pertinent and/or exclusive to that State/Territory. For example, if a State health department is considering changing the way that they fund public hospitals there might be some money available for research that looks at how the different funding options affect people who use hospitals.

Local governments

Local governments rarely have formal grants programs for research. However, they may provide a small amount of financial support or access to council facilities. Their willingness to help usually depends on whether proposed research is of benefit to the local community and the local government. It is worth talking to the people working in the relevant council offices and it can also be beneficial to talk to your local politicians.

Philanthropic trusts and foundations

Trusts and foundations are an important source of research funds that are often over-looked. Most of them are generated by money bequeathed from the estates of individuals or donated by individuals or companies. Specific-purpose foundations, societies and associations sponsor research in a declared area of interest. The associated organisation usually undertakes fund-raising to generate the funds held by the foundation or trust.

The Australian Association of Philanthropy (Philanthropy Australia Inc) represents charitable trusts and foundations. It publishes the premier reference for grant-seekers *The Australian Directory of*

Philanthropy, which lists over 400 grant-makers.² Listings for the specific-purpose foundations, societies or associations, should be in current telephone books.

Each trust or foundation has different guidelines. Some have regular funding rounds with application forms, while others require only a letter outlining your research proposal and funding request. Some trusts and foundations will be more inclined to fund research that culminates in a ‘product’ (ie a booklet or other resource). In this way they can promote the work of their trust or foundation and encourage others to bequeath or donate monies.

Service clubs

Service clubs, such as Rotary, Lions, and the Returned Services League, may provide a small amount of funding for projects. These are most accessible at a local level, but State-wide and national funding for larger projects is also possible. To find your local clubs look under Clubs in the telephone directory. A telephone call to the club president or secretary is the best way to find out if they are interested in supporting your research.

Like the philanthropic trusts and foundations, service clubs often prefer to donate funds to research that has, as an outcome, tangible resources that they can have their name on and which can be used to promote the good work of the club.

Commercial or industrial sponsorship

Corporations and other large organisations sometimes provide funds for research, particularly in areas that relate to their business. For example, Telstra funds research into communication. While such funding programs may be advertised in the national or State/Territory media, if you are seeking funding from an organisation that has not advertised funding, it is worth contacting them directly (find contact details in the telephone book).

One of the difficulties for researchers accepting commercial or industrial funding is to challenge or contradict the work of their funder. Ethical issues arise, for example, if a pharmaceutical company sponsors research whose findings challenge or contradict the company’s position. Another ethical consideration is that the outcome of such research will be profit orientated with returns to the sponsor. A further cause for concern could be the industry’s use of their sponsorship as ‘advertising’ or public relations; they could be using their funding of consumers’ research to improve their image. As such, the consumer group becomes a ‘tool’ for the industry’s advertising.

It is essential that clear agreements are signed between the funder and the researchers to ensure that the terms, conditions, rights and responsibilities of all parties are clearly understood.

4.2 Following the application guidelines

Most people applying for funds are academics and professional researchers, and you will stand out because you are not. This can work to your advantage if you meet the academic standards by which most funding sources judge applications. It can also work against you and you may be judged more strictly because the funders are uncertain about your ability to undertake the research.

Understanding the decision-making process and the criteria funding bodies use to assess applications is essential to your success.

Inexperienced researchers can greatly improve the reception of their funding proposal by closely adhering to the funding body’s guidelines for research. It is essential that you read the application form and any accompanying instructions carefully. In particular, take note of any special

² Enquiries about the book can be made to Philanthropy Australia Inc on (03) 9620 0200 (Vic) or (02) 9362 3264 (NSW) or by email to pa@philanthropy.org.au. The Association’s website is at www.philanthropy.org.au.

requirements, especially with regard to the budget. Be sure that you understand what the funding body will and will not fund, and do not hesitate to contact the funding source if you have any questions. If you do not meet the funding body's criteria in any regard, your proposal is likely to be left unassessed and unsuccessful.

The information you provide in your research proposal must be well written and organised. This aspect will be easier if you have thoroughly planned your research before applying for funds since most of the information required in the funding application is essentially a summary of the research proposal developed in the planning process.

All funding bodies require applications to be considered by a panel of assessors. More often than not these assessors, although specialists in your general area, may not be specialists in your proposal area, especially if your proposal is innovative. It is essential, therefore, to assume that the person assessing your proposal has no background knowledge or expertise in the specific area of your proposal. At the same time, you need to show a clear understanding in the field so that an expert can see that you know the area well. Keep your language as simple as possible and avoid jargon (especially jargon specific to your proposal area) and acronyms. If you need to use specific terms, explain these so that an educated but not specialist person can understand their meaning. Others reading your proposal may be able to point out jargon or acronyms that you take for granted but that are not known to others.

The physical presentation of applications is important to ensure that the assessor will spend time reading it. Make sure you fill out the funding application correctly. For example, if the funding body states that something should be no longer than one page, keep to that limit as it is common for pages in excess of the stipulated amount to be ignored. Remember that the people making the decisions will often be reading boxes full of applications. Your application must be concise, clear, legible, and on time.

A good research application will:

- avoid excessive jargon and be easy to read quickly;
- be typed;
- be presented to the funder with the correct number of copies;
- be presented to the funder on or before the due date; and
- answer all questions/provide responses in all required sections of the application form.

Completing the funding application form can take a long time. Make sure you give yourself plenty of time to get it done. This includes time to get other people to read and comment on it. If you do not have an experienced researcher working with you, it is worth seeking out at least one experienced researcher to assess and provide comments on your application. It will help if this person is experienced in the idiosyncrasies of the particular funder you are approaching. Sometimes funding sources will provide assistance in completing applications.

Modifying the project

If your project does not quite fit the guidelines of the desired funding body, or is too expensive for the program, you will either need to modify your project so that it fits the funding body's requirements, or look for an alternative funding body.

In order to modify your project to fit the funding body's guidelines you will probably need to 'think laterally'. For example, you might like to carefully review the guidelines to see if the funder's real or unstated meaning is wider than the literal meaning. You may be able to extend the meaning of the guidelines so that your project fits within them, or you may be able to show how your proposal

deals particularly well with one aspect of the guidelines, maybe at the expense of another. You may propose a State-wide piece of research to pilot your ideas before developing a national research method, or a local government area before developing a State-wide method.

Alternatively, you may be able to modify your aims slightly so that they allow you to achieve what you want while allowing you to achieve the funding body's goals. If you have not already done so, you need to think about how the funder could become one of the project's audiences. This might involve thinking about how the project could produce something, such as a report, that can be used by the funder. Funding bodies are often keen to know what results and knowledge will exist at the end of the project, and how these results and this knowledge will influence the practices and policies of the funder or funding program. Funders will want to know how they can achieve benefits from your research.

If your project is too costly for the program you may consider scaling it down so that the overall costs fall within the desired limits. This can sometimes be done simply by reducing the size of the project. For example, instead of interviewing 100 people, you may choose to interview 30 (as long as this does not remove your ability to generalise your research findings if this is a part of your aim). Alternatively, you may decide only to pursue a part of the proposed project. This may entail focusing on only one of the original aims rather than all of them. If you decide to take this option it is worth selecting that part of the project that is most likely to produce interesting results or outcomes which can then be used to persuade or convince the funding body of the need for the full project.

If the funding body will not fund all of the items required for the successful completion of your project, you may like to consider applying to a benevolent fund for a part of the project (ie for equipment items) while applying to the original funding body for the components covered in their guidelines. Note that if you receive funding from more than one funding source, you are usually required to list all sources of funding (and for what) on the application form to ensure that you do not receive funding from more than one source for the same item.

In developing the budget for their project, General Practice Care After Miscarriage, the researchers worked out what was actually needed to conduct the project. They took a realistic look at how many people could be included in their samples by noting the upper limit for a seeding grant from this funding body of \$10,000 and designed their project accordingly. However, given the resources available both from SANDS and the UQ Centre for Primary Health Care, the researchers were assured of a safety-net should the need arise.

4.3 The funding application

Most funding applications will cover a similar range of topics. These are described below to help clarify what funding committees will probably be looking for in your application.

Title and brief description of the research

Develop a title for your proposal that clearly states what it is the proposal is considering. The title and it needs to be carefully considered as it will represent your proposal during the assessment process. The title can be expanded upon in your brief description of the project. The brief description of the research should clearly summarise your research aims and objectives, methodology and expected outcomes. Sometimes you are asked for your research hypothesis. Except for in medical or scientific research where a research hypothesis is specifically requested, it is often sufficient to re-write your aims or objectives as research questions in the hypothesis section.

Background and justification

The background and justification section is your main opportunity to convince the funding source that your proposed research is important and worthy of funding. This section should show how the idea for the project came about and what research has already been done on the topic. This should include a summary of a literature review and a brief history that shows what has been done and where the gaps are. It is not necessary to quote all works that have helped you formulate your ideas, but it is important to include those that form the background reasoning for your assumptions and methodology.

Research design and methods

The section on research design and methods should include a clear and moderately detailed description of what you propose to do. This is where you include your strategies for meeting each aim/objective and how they will be implemented.

This section must include sufficient detail for people to assess whether or not your proposed methods are appropriate and feasible; the assessor should be left with a clear understanding of what it is you wish to do. You should discuss in this section your sampling method, your research methods and how the information is to be analysed.

Timeline

Many application forms request a timetable of the different stages of the research project. This aspect of the application is important as it shows whether or not the research plan is well developed and can be undertaken in the proposed timeframe. Ideally, the timeline should be adhered to once funding is approved so that your research is kept on track. It is easy to become sidetracked when doing research as many issues arise that were not previously considered. This is especially important for two- and three-year grants where re-funding is dependent on progress.

Your timeline needs to be realistic. If it is too long or too short it can be used as evidence that you do not know what you are doing. It should take into account the steps noted in your methodology but does not need to be rigid. Funding committees will not want to see an extremely detailed timeline but will want to see that every major step in the research plan is accounted for. At the very minimum the funding body will want to know a likely start date, the total number of months that the research project will run, and the proposed completion date. An example of a timeline to include in your funding application is as follows.

Jan–Mar:	Establish reference group Advertise, select, and appoint research assistant Develop database of research participants Develop questionnaire in collaboration with reference group Pilot questionnaire
Apr–May:	Distribute questionnaires
June–July:	Collect questionnaires and commence analysis
Aug–Sept:	Analyse questionnaires Meet with reference group to discuss findings Develop draft report
Oct–Nov:	Draft report to reference group and research participants Writing of final report
Dec:	Disseminate findings Evaluation

Budget

Noting when each stage of your research project will take place and how long it will take, as outlined in your timeline, will aid you in assessing when you will need particular budget items. The budget and budget justification sections are areas of the research application where many applications fall down. As previously stated, it is necessary to ensure that your financial needs are supported by the funding body. If, for example, the guidelines state that equipment costing in excess of \$2,000 will not be funded, do not ask for it unless you have discussed it with the funder and they have stated that they might consider an exception to this rule. Ensure that you have the latest quotes on items to be purchased, the salaries for personnel, (including an estimation of all on-costs or administration costs), and an estimation of maintenance items.

Insufficient budgets can be the sole reason for rejecting a research proposal, as can budgets that request more than is necessary. Your proposal should be cost-effective; the outcomes to be gained by conducting the research should justify the amount of support you are requesting.

It is essential that all aspects of the research be accounted for in some way in the budget. If you have access to such things as labour, materials, or equipment it is important to say so and point out that you are providing these at no cost. Conversely, if you require funds for such things as the principle researcher's salary, rent and other overhead expenses such as electricity, secretarial support and administration that are not normally catered for in a research application, you need to discuss these needs with the funding body and then, if they have agreed, attach a letter to your funding application explaining that you are an unfunded or poorly funded consumer group that does not have funds to pay staff or purchase office supplies for research purposes.

Typically, research funding programs will expect to see budgets that contain items such as:

- labour costs for the people who will do the research and for any professional researchers, consultants, or other assistance that you may hire, as well as any administrative support associated with the project;
- on-costs associated with employing people, such as workers' compensation, leave loading and superannuation;
- overheads such as office rent, electricity, telephone and facsimile, photocopying, and computer facilities; and
- other costs which arise in undertaking the research including venue hire, catering for activities such as focus groups, travel expenses, postage and stationery costs, and costs associated with publication and distribution of the research report (where permitted).

You need to estimate your research budget costs as closely as possible. This often requires some very detailed work. Funding bodies will not want to see excessive detail, such as separate costs for different stationery items, but you will need this level of detail for yourself as part of working out the costs of doing the research. Also, as it is quite common for funding bodies to request explanations or changes to budgets on the projects they decide to fund, your detailed costings will be useful to explain, argue for, or modify any costs that seem too high or too low to the assessors.

If you do receive funding you will probably be required to account for how the funds have been spent. This requires the keeping of careful and accurate records. Some funding bodies require a professional audit of how the research funds were spent. If this is the case, you can include the costs of record keeping and audits in the budget.

Any major re-allocation of funds from one part of your budget to another (such as from salaries to travel) requires notification to, and approval from, the funding body.

Personnel

Most funding bodies state that they will not pay for the salaries of the principal researchers as they assume that the applicants will be academics or paid researchers who are expected to do research as part of their job. In certain circumstances, however, supplementary funding will be provided on a case-by-case basis for the principal researcher or chief investigator where it is clear that his/her conditions of appointment do not include research. In this instance, a letter should be attached to the research application outlining the principal researcher's conditions of usual appointment, duties and salary details.

The NHMRC has recommended salaries for researchers ranging from the research assistant level to the research fellow level. Unless otherwise stated, it is advisable to use these rates as applicants applying for a rate higher than the relevant NHMRC rate will often need to provide detailed reasons which will be considered on a case-by-case basis.

SANDS and the UQ requested a research assistant in the budget for the project, General Practice Care After Miscarriage. Wages for this component of the project was the largest single budget item.

The research assistant conducted the focus group meetings and face-to-face interviews, which included obtaining the sample, liaising with all relevant players including the women to be interviewed, the Divisions of General Practice, the UQ, and the members of SANDS. The research assistant also entered the quantitative data into a computerised database and worked with the academic researcher in analysing the data.

The research assistant is a member of SANDS. Undertaking this role has been of considerable benefit to both the project and to herself. As a member of SANDS, the research assistant had empathy towards the women who were interviewed or who took part in the focus groups. This enabled her to draw out the issues. In addition, the research assistant could also offer support to the women following the interviews or focus groups, and could refer them to SANDS.

Budget justification

The budget justification need not be extensive but should reflect all anticipated expenditure for the duration of the project. The budget justification is a statement of why you need the personnel, travel and maintenance expenses that you are requesting. The statement should:

- outline the principal duties and skill requirements of each person for whom salary is requested;
- identify all items of equipment, justifying why the item cannot be provided by your organisation;
- provide an overall breakdown of costs for incidental items such as data processing (including software), postage, printing and stationery;
- provide a breakdown of travel costs for individual trips, who will undertake them, and the purpose of the trips; and
- provide a breakdown of 'method' costs — for example, the cost of venue hire and catering to conduct focus group meetings.

Ethics

The previous chapter looked at the issue of ethics in detail. It is important to note here that you will need to seek ethical approval for your research proposal before you submit the application for funding (see Section 3.2).

Curriculum Vitae

Applications for research funds usually include brief Curriculum Vitae from each of the people who will play a major role in the research (eg a principal or chief researcher and associate or co-researchers. The Curriculum Vitae, or resume, should outline all relevant experience, qualifications, training, previous research, and publications.

The Curriculum Vitae is one of the ways that funding committees judge the researcher's or the research team's ability to undertake the research. If there are some obvious gaps in your experience, you must demonstrate how this gap will be filled. For example, you may employ a consultant with the necessary qualifications (for example, in research design), but make sure that you include the cost of this in your budget. If possible, name the consultant and outline their qualifications.

Funding committees look for evidence of previous research and previous success at obtaining research funds. One of the ways of establishing this 'track record' is to first seek funding from research programs aimed specifically at inexperienced researchers. An alternative is to think laterally about what might count as experience. Some of the less obvious possibilities are:

- talks given at conferences, especially where the paper or even the abstract is published;
- newspaper coverage of some aspect of your group's work;
- newspaper or magazine articles;
- in-house publications, including newsletters;
- professional bulletins;
- articles in non-refereed journals;
- articles in refereed journals;
- joint articles, as well as single-authored ones; and
- chapters in books, or commentaries.

In order to improve your 'track record' it may be worth:

- undertaking unfunded research;
- linking up with an experienced researcher;
- applying for small grants designed for new researchers;
- producing outcomes from previous grants and previous research;
- writing up all your conference papers as articles, and getting publicity and professional exposure for the work you have done so far; and
- targeting areas where there are no experts yet.

In developing their research application for a seeding grant, the researchers in the General Practice Care After Miscarriage project decided to list the academic as the Chief Investigator since she could list both qualifications and publications.

Referees

If you are asked to nominate referees for your project, you need to ensure that those you nominate will comment positively and authoritatively but independently on your application. If you know early in the application process who you will nominate as referees, you should discuss the research

with them during the preparation of the proposal, and provide them with draft copies. In this way, they will know what it is that you want to do and may assist you in developing ideas to fit the application process and enhance your proposal.

If you do not know who you will nominate, it is important to try to find referees as soon as possible so that you can be sure that they:

- will assess your proposal positively;
- have good research skills and experience;
- are familiar with the methodology you will employ; and
- understand consumer issues and genuinely believe that consumers can do worthwhile research.

Some funding bodies will provide you with copies of your referees' reports for your comment and response. Most funding bodies do not. You need to assume, therefore, that the submission of your proposal is the final opportunity for expressing your ideas.

Auspicing organisation

Most funding bodies will insist that a group be in some way legally incorporated before they will hand over research funds. This can make it difficult for small consumer groups that are not legally incorporated. If your group is not incorporated under one of the Incorporation Acts you will usually need to find a 'parent' organisation that is prepared to act as an auspicing body. An auspicing body is simply an incorporated organisation that agrees to accept and pass on to you the research funds. The auspicing body may want to manage the money as though it is theirs or they may pass the entire amount on to you.

The other situation for which you may need to consider finding an auspicing body is if you seek funding from one of the benevolent or charitable institutions. These organisations insist that the recipient organisation has tax deductible status under the relevant taxation law. If you do not have such status, you may need to find an auspicing organisation that does.

4.4 The application process

Most research applications tend to follow a fairly standard assessment process. The steps that are commonly used are:

- the funding program, including the final date for submission and the contact details for information and application forms, is advertised;
- applications for funding are received and sent out to be assessed by referees;
- sometimes the referee assessments are sent back to the researchers for their responses;
- the applications, referees' assessments and researcher's responses are collated, examined and discussed by the committee responsible for making decisions about funding;
- sometimes changes in the proposal will be requested before funding is provided to the successful applicants; and
- successful and unsuccessful applicants are notified.

Not surprisingly, this process may take between three and nine months.

4.5 Assessment of applications

Referees are given a list of criteria by which to judge proposals. The referees often furnish a numerical score and written comments for each criterion. The criteria for reviewing applications usually include such things as:

- originality and relevance of the research topic;
- appropriateness of the proposed research methods;
- evidence of familiarity with the research topic and of work done in developing ideas;
- ability to undertake the research and complete it in the proposed timeframe; and
- the proposal's value for money.

It is hoped that this Manual will assist you in developing a quality research proposal that is viewed positively by assessors.

4.6 What next?

If you are successful in obtaining your research funds you will need to start dealing with the practicalities of the project fairly quickly. If you have not already done so, you will need to organise ethics approval (see Chapter 3). You then need to organise a reference group, or steering group, as well as an account for the grant and signatories to the account. It is also essential to find someone who will be responsible for administering the money and for basic bookkeeping if that has not been organised. You may also need to find a consultant or research assistant if that was how you decided to conduct your project. If possible, set up a small committee of key people to oversee this process and spend some time discussing precisely what you are looking for and what you require.

Before you start the project itself it may be worthwhile reviewing your application as a group to make sure that it is still appropriate and up to date — especially if it has been a long time since you submitted the original application. You need to make sure that changes in your group and the context in which you are operating have not made part of the project inappropriate or redundant. If the project needs modifying because of the changes, notify the funding body of the need for the changes and let them know how your proposed modifications will strengthen the project.

If your funding proposal is not accepted

If your funding proposal is not accepted, do not get too despondent. The research process is very competitive and you will not be the only ones who have been knocked back. Most of the grant programs have far more applicants than they can hope to fund.

It is usually worthwhile to contact the funding body soon after you have been notified of the decision to learn why you were not successful. You may be able to alter your application and re-submit it in the next funding round. If you plan to re-submit, it may be worth obtaining a list of the projects that were successful to get ideas about the stated and unstated priorities and criteria that were used in selecting the projects to be funded.

Alternatively, you might submit your proposal to a different funding source. In this case, you will need to adjust your proposal to meet the guidelines and criteria of the new funding body. You might also like to consider doing a part of the project without funding, or doing all or part of the proposed project using voluntary labour and resources of the group. You may also decide to have all or part of the project completed by an undergraduate or postgraduate student at a nearby tertiary institution who would work under your overall direction with supervision from the group and the person's academic supervisor (see Chapter 1).

5 Research methods

During the planning of your research project, you will have considered the methodology and methods that you will use. The methodology is the system of ideas that underpins your research project. Research methods are the techniques used for gathering the information to be analysed in your research. The choice of methodology and methods will vary according to your beliefs, the issue being researched and the purpose of the research.

Summary — Research methods

Methodologies

- A **quantitative approach** to research aims to collect and analyse numerical and statistical data to produce findings that test or confirm existing theories (deductive reasoning).
- A **qualitative approach** to research aims to gather interpretive information and to develop theories based on themes within the gathered 'soft' data (inductive reasoning).
- Both quantitative and qualitative methodologies have flaws but are potentially useful in certain circumstances. It is important to be clear as to: why you have chosen your methodology; how assumptions behind the methodology are revealed in research actions; and how unstated beliefs may influence your research.
- Other research methodologies, such as **action research** and **feminist research**, seek to address the power imbalance between researcher and research subject. These methodologies may be of interest to some consumer groups.

Research methods commonly used in consumers' research

- Most research involves a **literature review** (see page 49), which will show whether others have already done the proposed research and how your research will fit in with existing research.
- **Surveys** (see page 50) are a means of gathering information from research participants. Questionnaires are a useful method of surveying people across large geographic areas in a short period of time. Interviews are useful for collecting qualitative information from a relatively small number of people.
- **Focus groups** (see page 55) are used to examine the views of particular groups within the community (see page).
- **Experiments** (see page 58) involve taking action and observing the consequences. Experiments are commonly used in health research but are not usually undertaken by consumer groups.
- **Participant observation** (see page 58) is used when the research requires observing people's lives, parts of their lives, or particular situations.
- **Case studies** (see page 60) use a range of information sources and other research methods to examine a single person, event, situation or organisation.
- **Unobtrusive research methods** (see page 60) seek information from written material, recordings, physical traces and observation rather than directly from people.
- **Evaluation research** (see page 61) assesses the value or worth of an activity.

Selecting a research method for your project

- The choice of an appropriate research method or methods will be determined by many factors including the purpose of the research, and its aims and objectives; whether you need quantitative or qualitative information, or both; available time and resources; and your research participants.

- The intention in choosing a research method or methods is to find the best solution to a complex problem. Methods can be combined in a way that will foster the strengths and minimise the weaknesses of the individual methods.

5.1 Methodologies

There are many forms of research and many approaches to carrying out research. Research can be exploratory (aiming to explore a situation), explanatory (aiming to explain a situation) or descriptive (aiming to describe a situation). The system of ideas that underpins a research project is known as the methodology, while the techniques used to gather information for analysis are the methods.

The two most commonly employed methodologies are:

- the quantitative approach to research, which aims to collect and analyse numerical and statistical data to produce findings that test or confirm existing theories (deductive reasoning); and
- the qualitative approach to research, which aims to gather interpretive information and to develop theories based on themes within the gathered ‘soft’ data (inductive reasoning).

Both quantitative and qualitative methodologies have flaws but are potentially useful in certain circumstances. It is important to be clear as to: why you have chosen your methodology; how assumptions behind the methodology are revealed in research actions; and how unstated beliefs may influence your research.

Although there is usually considerable merging of these methodologies, in practice, they have produced two different types of research actions, as outlined in the table below.

QUANTITATIVE	QUALITATIVE
Aims to measure and count things	Aims to collect people's interpretations of things, people's reasons for their actions, people's stories
Data are analysed using numbers and statistics	Data are analysed by finding themes
Results are reported through numbers and statistics	Results are reported in the language and words of the research participants
Often characterised as reliable with 'hard' data	Often characterised as valid with 'soft' and subjectively 'rich' data

Both qualitative and quantitative methodologies are valuable research tools. Proponents of quantitative research is the only path to certainty and that qualitative research is unstructured, unreliable, subjective, biased (too easily influenced by the researcher), and ultimately too inconclusive and uncertain to be of much value. This is true in some situations and for some questions, but not all. Qualitative research may also be misunderstood by both ethics committees and funding bodies because of the perception that qualitative researchers ‘invade people’s social lives to collect data’.¹

¹ Daly, J. ‘Social Science Health Research’ in J. Daly (ed) 1996, *Ethical Intersections: Health Research, Methods and Researcher Responsibility*, Allen & Unwin: St. Leonards, p.92.

Qualitative research can be seen as the collection of ‘slices of life’ which are then dissected and analysed using categories and themes which emerge from the data and from social science theory.²

Qualitative researchers sometimes see quantitative research as shallow, invalid, unable to explore and explain the complexities of human activities, and insupportable because it is based on assumptions that are unsustainable (particularly those relating to an objective and stable social reality that can be understood by measurement and counting). Again, this is true in some situations, but not all.

Although, increasingly, many researchers are adopting a more moderate path which acknowledges that each methodology is potentially useful, and that each methodology has flaws, some of the criticisms outlined above will probably be made about the research you do, or are planning to do (especially when seeking funding). There is an element of truth in all of these criticisms, and to some extent they are unavoidable. They are mentioned here because you need to know what to expect from some of your critics, and to emphasise that it is important to be able to explain why the approach you have chosen is appropriate in the circumstances. It may also be important to acknowledge that strongly held beliefs may lead their exponents to use negative labels about ‘the others’.

Other methodologies

Other than quantitative and qualitative methodologies, there are other types of methodology that may be of interest to your consumer group. These include Action Research and Feminist Research. It should be noted, however, that the traditional models of research are changing, with greater consumer or participant involvement in research increasingly being sought.

While the two methodologies outlined below seek to decrease the power imbalance between the researcher and the researched, it is unlikely that the power imbalance will ever be removed. The challenge in undertaking consumers’ research is to be aware of this power imbalance and to minimise it as far as possible.

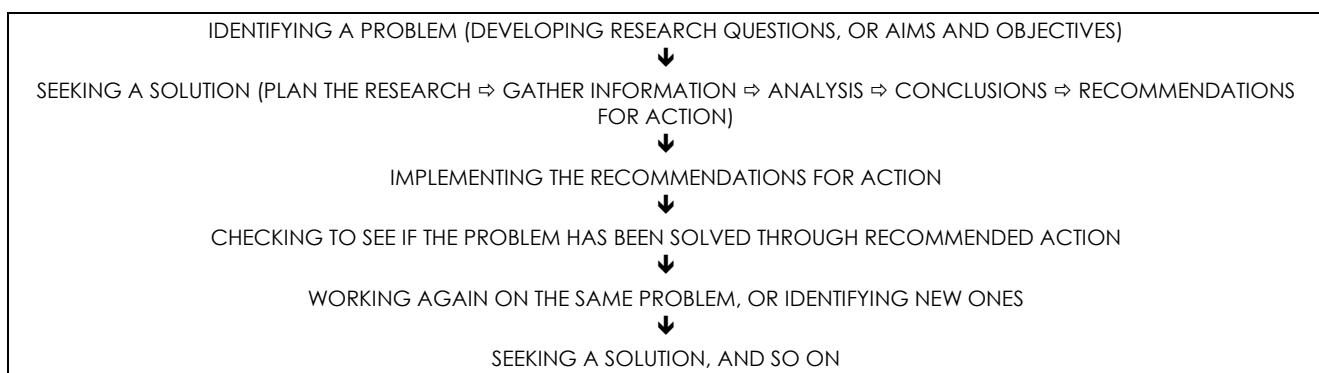
Action research

Action research can also be referred to as participatory research. This type of research arises from a different set of assumptions than other methodologies. Action research aims to find solutions to practical problems. It emphasises the involvement of the stakeholders (those who have an interest in the problem) in actually doing the research and implementing the solutions. These stakeholders are seen as the experts in the situation. The research is conducted from ‘inside’ the situation by these experts rather than from ‘outside’ by a researcher, although it may be assisted by an experienced researcher.

In traditional research, the researcher has exercised authority over the research participants, with the researcher as ‘active’ and the participant as ‘passive’. In action research, the researchers ‘doing to’ the research participants are meant to be the same people as the research participants being ‘done to’. Consequently, the assumptions and ideas that form the basis of an action research project are the assumptions and ideas held by the people doing the research. In this way, action research attempts to erase the imbalance of power that usually exists between the researcher and the researched.

Usually action research is not a one-off research project but a continuing cycle as shown below.

² Daly, J. ‘Social Science Health Research’ in J. Daly (ed) 1996, *Ethical Intersections: Health Research, Methods and Researcher Responsibility*, Allen & Unwin: St. Leonards, p.92.



Feminist research

Like action research, feminist research attempts to remove the power imbalance between the researcher and the researched. Instead of encouraging a distance between the researcher and the research participant, feminist methodologies require that the researcher close this distance as far as possible, involving the research participants as active players and equal partners in the research. However, unlike action research, there is no single definition of what constitutes feminist research, and there is ongoing debate as to whether a feminist methodology actually exists.

Although initially feminists worked within the positivistic or more quantitative methodologies, a gradual shift took place and feminist research moved through qualitative methodologies to new and different methodologies. These methodologies are still being developed, but the assumptions and emphasis that mark them as new and different point in directions that some consumer groups may want to explore.

Central themes in feminist research are power, patriarchy and women as an oppressed group within society. Feminist research is one tool among many aimed at correcting a long-standing imbalance between the status and power of men and women. It is argued that, too often, women have been invisible in research, with the whole research process being nearly always constructed from a male viewpoint which assumed that the male view was the universal view. Feminist research aims to take account of women's issues and concerns, and women's contribution to life and history. It emphasises that women's experiences are different from those of men.

5.2 Research methods commonly used in consumers' research

There are many research methods in existence. This section focuses on those methods most likely to be used by consumers in undertaking research, including literature reviews, surveys, focus groups, participant observation, experiments, case studies, unobtrusive research and evaluation research.

Literature reviews

Most research involves an extensive review of published literature. The literature review is vital for checking whether others have already done the research you propose to do, or to assess how your research project fits in with the research that has already been done. A search of the literature may highlight gaps in the area which your research could fill, or may alert you to research methods that could work for your proposed project.

At times, the literature review may be the whole research project. In these cases, the findings and analysis of the literature must be detailed in a report. When the literature review is used as background material or only as part of the research, summarising the main findings is all that is required.

The process of finding and assessing the literature is important for both literature reviews that are the whole project and for those that inform the project. Literature reviews are discussed in detail in Chapter 6.

Surveys

Surveys are a means of gathering information from research participants. Depending on the type of information required by the research, surveys take the form of questionnaires or interviews.

Questionnaires

Questionnaires are commonly used to collect specific information from a relatively large number of people. Questionnaires can be self-administered (such as those sent through the post), or administered by an interviewer face-to-face or over the telephone. Questionnaires are frequently used to collect quantitative data, such as demographic information (ie age, gender, ethnicity, income). Questionnaires are also an excellent way of finding out about people's views and attitudes.

The strengths of questionnaires are that:

- they use a fixed set of questions, always presented in the same way and in the same order, which generates a high degree of reliability;
- they provide a relatively quick way of collecting information;
- they can be used to survey people across large geographical using the post or telephone; and
- they provide respondents with more anonymity than a face-to-face interview.

The major weakness of questionnaires is that, because they are predetermined and inflexible, they provide no opportunities for the researcher to probe particular responses, or to clarify or re-word a question to make it more meaningful to a particular respondent. This inflexibility can reduce the validity of the questionnaire. Postal questionnaires also have problems with low response rates and uncertainty about whether the person you wanted to survey was actually the person who responded.

Using questionnaires successfully requires good preparation and attention to how they are administered. In preparing a questionnaire you need to consider: the content and style of the questionnaire; the construction of the questions and the layout of the questionnaire; and whether the questionnaire will gather the information you need.

Questionnaire content and style

The most important issues relating to your questionnaire's content and style are determined by your research plan. Key issues from your research plan that will shape your questionnaire include:

- aims and objectives;
- who will be surveyed, and how many;
- how the research will be undertaken; and
- how the results will be analysed.

A good questionnaire is sharp, short and clear, and this can only be achieved if you know what information you need to collect. Be guided by your aims and objectives, identifying which ones relate to the information you want to collect through your questionnaire. Start writing specific questions that will provide you with the information you need to fulfil each of these objectives.

At this stage you could consult an experienced researcher to find out if there is an appropriate 'instrument' already in existence that you can use or adapt for your purposes. It is not always necessary to reinvent the wheel as there are some standard validated and respected questionnaires that will help you to compare your results to other research.

Your initial questions will undergo numerous changes and revisions. When you think you have your final set of questions, go back and link each question to the appropriate objective or objectives. If any questions do not relate to any objective, they should probably be taken out.

Conversely, if you find that some objectives are no longer covered you will need to insert the necessary questions. This exercise can also point out objectives that should be modified, taken out or added. Make the necessary changes, but be wary of radically modifying your research at this stage.

When there are several people involved in the research there must be agreement from all of them on what information is being sought with the questionnaire. Although this seems simple and obvious, it is surprisingly common for people working together on a questionnaire to have very different ideas about why they are doing it, and what they want to get out of it.

It is important to know who is likely to be answering the questions. This will determine how you ‘pitch’ the questions. A questionnaire aimed at adolescent males may use very different language and assumptions than one aimed at women aged over 70. If your survey is going to include people from non-English speaking backgrounds, you need to be certain that the questions will translate and have the appropriate meaning in another language/culture.

The number of people in the survey will influence the balance between closed-ended questions (ie tick the box questions) and open-ended questions (where there is usually space provided for the respondent to write or say whatever they think is appropriate). Not surprisingly, it is much quicker to analyse closed-ended questions since the data are more ‘finite’.

The two elements of the questionnaire most affected by how it will be administered are:

- the introductory information provided to the research participant; and
- the directions on how to complete the questionnaire.

When a questionnaire is self-administered (such as with a postal questionnaire) the introductory information and the directions must be very clear, complete and unambiguous. They must also be very user-friendly and attractive to the research participants, otherwise the participants’ interest in completing it and sending it back will be minimal. In contrast, when a questionnaire is administered over the telephone there is more opportunity for the interviewer to establish rapport with the respondent.

Considering how the questionnaire will be analysed is one of the most commonly ignored or forgotten steps in questionnaire design. It is essential to know in some detail what is going to be done with the answers before they are collected. This is a key issue in deciding both the content and the question format (closed-ended or open-ended). If somebody else, such as an experienced researcher or statistician, is going to be involved in helping you to analyse the results, they must be involved in the design of the questionnaire to ensure that the questions asked give you the desired scope of answers. Testing, or piloting, the questionnaire can also be useful here to help you see more clearly what information the questionnaire will collect and whether it will support the analysis you plan to do.

Preparing a questionnaire

It is useful to keep the following points in mind when preparing your questionnaire.

- Keep the language clear and simple, avoiding jargon and language that is ambiguous. Short questions are better than long ones.
- Avoid questions that ask two questions at once. For example: ‘Do you ever suffer from dizziness and blurred vision? Yes/No.’ The person may reply to either of the two aspects, or assume that the question relates to suffering dizziness and blurred vision at the same time. It would be better to use separate questions for each.

- Keep the wording of questions as neutral as possible and avoid leading questions. For example, ‘People should not go to the doctor too often. How many times have you seen a doctor in the last 12 months?’ is a leading question which is likely to deter the respondent from saying they had gone to the doctor frequently in the last 12 months, even if they had.
- Make sure questions do not assume knowledge that the person answering may not have. For example, asking the question, ‘Do you think the vocational registration of general practitioners has changed anything?’ assumes that the respondents know something about vocational registration of general practitioners.
- Avoid personal or embarrassing questions if they are not absolutely necessary. These can be related to money, sex, age or other significant aspects of a person’s life.
- Avoid questions that involve memory. It is doubtful whether people could answer accurately the question, ‘How many times did you visit your GP in the last 24 months?’.
- For closed-ended questions make sure that the possible answers listed are as extensive as possible. It is useful to include an item labelled ‘no opinion’, ‘do not know’, or ‘not sure’. Sometimes it is appropriate to include ‘other (please specify)’, making sure that participants have enough room to write their answer. Testing the questionnaire can be a useful way of identifying the range of possible answers.

The organisation and layout of a questionnaire are important and can play a role in encouraging or discouraging people from completing the questionnaire. It is necessary to gain and maintain people’s interest. The following hints will assist you in the layout of your questionnaire:

An introduction and general information should be included as a separate cover letter for the respondent to keep. The cover letter should also advise participants how and when to return the questionnaire. As well, the cover letter should include the following items, which are applicable to most research projects:

- the purpose of the research;
- who the researchers are and where they can be contacted;
- an explanation of how and why they are being asked to participate, and why their help is important;
- what will be done with the results;
- how anonymity will be protected when you report on the research;
- whether the research has been approved by an ethics committee;
- if appropriate, an informed consent form which outlines specifically what information you are seeking, the extent of the participant’s involvement, and how the confidentiality of their information is to be protected. This information should clearly state that their participation is voluntary and that they can withdraw their consent and their participation at any time.

You should leave a space, often in the top right or left hand corner of the first page, for you to number the questionnaire. This number can be useful when collating and analysing the results.

Instructions about how questions should be answered must be clear. For example, you might instruct participants to ‘Tick one box only’ or ‘Tick as many boxes as apply’ or ‘If there is not enough space for your answer please finish your comments on the back of this page’.

The order of the questions should encourage the respondent to continue and should be logical. It is often a good idea to begin with easy questions and move on to more difficult ones. Grouping

questions into sections can help, and using a variety of question formats can keep the questionnaire interesting.

Use space freely: do not clutter or cramp the page, and do not use very small print. It can be overwhelming to see too many questions crammed into a single page. Make sure there is plenty of room for responses to open-ended questions. It is often recommended that only one side of the paper be used.

Interviews

While questionnaires are often used to gain data from a large number of participants using specific questions, interviews are usually used to collect qualitative information from a relatively small number of people. Interviews are useful when:

- you are gathering responses to smaller numbers of questions;
- you need a high response rate in a defined period of time;
- the aims and objectives of a research project are concerned with understanding things from the perspectives of the research participants — interviews allow the research participants to tell you in their own words and in their own ways their views and experiences in relation to your research topic; and
- complex issues and situations are being researched.

There are various forms of interview:

- structured interviews involve a rigid set of questions, always administered in the same way and in the same order. Structured interviews are the same as questionnaires being done face-to-face;
- semi-structured interviews are made up of fairly specific questions, but with flexibility in the way questions are actually worded and the order in which they are covered. This gives the interviewer the room to tailor questions and explanations as necessary, and to explore and probe answers;
- unstructured interviews rely on the interaction between the interviewer and the research participants to gather information. This type of interview can appear to be an ordinary conversation, but the interviewer controls the conversation and steers it towards the research interests; and
- in-depth interviews, which may be unstructured or semi-structured, have been defined as ‘repeated face-to-face encounters between the researcher and informants directed toward understanding informants’ perspectives on their lives, experiences or situations as expressed in their own words’.³

How much ‘structure’ is used in an interview is an important issue. The more specific and rigid the questions are, the more the interviewer is in control. The amount of structure will depend on the type of information you want to gather through your interviews:

- structured interviews are quicker, but unstructured or semi-structured ones collect more detailed information;
- a more structured interview is easier to analyse, but less structured interviews provide more insight into complex issues;

³ Taylor S.J., Bogdan R. cited in Minichiello, V., Aroni, R., Timewell, E., Alexander, L. 1995, *In-Depth Interviewing* (2nd Edition), Longman: Melbourne, p.68.

- structured interviews require less skilled interviewers, but are less flexible and less responsive to research participants than unstructured interviews;
- if there is more than one interviewer, more structured interviews help to generate some uniformity between interviewers;
- in structured interviews the researcher's ideas and preconceptions determine what information is collected, whereas in unstructured interviews the research participant's views, ideas and experiences will largely determine the information offered; and
- while a more structured interview is more reliable, a more flexible interview is more likely to be highly valid. This is because the latter is more likely to be an accurate reflection of the research participants' understanding of the world.

Preparing an interview

Preparing an interview plan is similar to developing a questionnaire (see page 51). Preparation involves developing your questions or topics for the interview and then testing or piloting them. Because in-depth interviews rely extensively on the skills of the interviewer, testing the interview plan also involves testing and improving your interview technique.

Piloting the interview plan will give you a good indication of how long the interviews will take. Potential research participants will need to know how long they will be required for the interview. Interviews should not exceed two hours as it is difficult to maintain concentration. If the interviews must be very long, you should consider doing several interviews over a few weeks rather than one very long one.

If, based on the results of your pilot interviews, you make substantial changes in the interview plan, it will need to be piloted again. Also, if you see that parts of the plan clearly do not work after one or two interviews, make some changes before continuing the pilot. This could save you having to do another round of pilot interviews.

Unlike questionnaires, interviewing also involves analysing information while you are collecting the information. Interviews require you to make judgements and decisions about which of the research participants' answers you want to probe. The degree of structure in your interview plan will determine the extent to which the interviewer can probe particular answers and how far from the original questions or topics he/she will encourage the research participant to go. It is this potential diversity of responses that can make unstructured interviews difficult to analyse. For researchers without much experience, semi-structured interviews are more manageable for the final analysis.

Conducting interviews

After the piloting has been completed you should begin contacting the people you want to interview. When you contact them you will need to: explain the research; get their agreement to be interviewed; and organise a suitable time and place for the interview.

As with all research, potential research participants should be provided information about the research. Before beginning the interview, you should provide each person with information about who you are, what you are doing, and what will be done with the information they provide. Depending on how the interviews are organised and who the participants are, the information can be sent through the post before the interview, or provided when the interviewer meets the research participant. At this stage, participants should also be informed of their right to leave the study and who to advise should they wish to do so.

In addition to the information routinely given as outlined in the section on questionnaires (see page 52), you should let people know how long the interview will take. Permission should be sought

from participants for the interviewer to take notes and/or audio or videotape the interview. It is also worth considering what, if any, assistance you can provide to help interviewees participate in the research, such as transportation, child care, or other access issues.

You will need to tell participants how the interview notes or tape will be stored for the duration of the research and what will happen to them after the research is completed. You will also need to reassure the participants about how their information will be kept anonymous in the write-up of the research. This is especially important if you use direct quotes. You should also outline how you will get back to the research participants for them to check on, or report on, the research results.

Since part of the value of in-depth interviews is that they get below the surface to find out the participants' perspectives, you will need to find ways to establish rapport and trust between yourself as interviewer and the research participant. From the start, you should try to keep the interview as much like a conversation as possible. Unlike a social conversation, however, you must maintain a neutral position in response to the things said by the research participant. You also need to encourage the person to continue participating and make them feel comfortable about talking to you. This can usually be achieved by listening very attentively, not interrupting, making notes, and making encouraging but neutral comments. Remember, you are there to find out what they have to say, not the other way around. You need to make sure that you influence their responses as little as possible.

Use your interview plan to keep the interview on track. The interview plan is essentially a prompt for the interviewer, reminding them of what information needs to be collected. You need to regularly refer to it to see what has and has not been discussed, and gently steer the conversation appropriately. Do not be overly concerned about the order in which things are discussed. Some flexibility is essential to keep the conversation flowing and to let the research participant talk about things in the way that is most meaningful to them. You will need to be very familiar with the plan so that you can move between questions or topics, making notes without interrupting the flow of the interview.

If the research participant gets well off the subject of the interview, you should gently bring them back to it. Try not to abruptly cut them off. Patience and tact are essential to maintain the flow of the conversation. Similarly, do not end an interview too abruptly. You can signal the end of the interview by asking a wrap-up question such as, 'Is there anything important about [the subject] that we haven't discussed?' Make sure you thank the research participant for their involvement when the interview is complete.

Your work is not finished when you leave the interview. As soon as you can, go over the interview notes and add any relevant points or ideas that came out of the interview while they are still fresh in your mind. However, make sure that you identify which notes are summaries of what has been said (and which are your interpretations) and which are direct quotations.

Focus groups

A focus group is a small number of people brought together to discuss a particular topic. Focus groups are often used to examine the views of particular groups within the community. The information generated through focus group discussions is qualitative.

Focus groups can be used as the sole information collection method in your research, or they can be used with other methods. For example, the whole research project could involve four or five focus groups each composed of a different age group to compare views on a certain subject. Alternatively, a single focus group could be used to identify the key issues that should be covered in the questionnaire or interview plan.

The advantages of using focus groups for your research include the following:

- the dynamic discussion that takes place between the participants generates ideas;
- participants discuss, argue, explain, defend and elaborate their ideas in a way that reveals information that is not possible for researchers to obtain in any other way. Information and ideas often surface that could not be anticipated by the researcher; and
- the examination of this interaction between research participants is often central to the aims and objectives of the research.

Focus groups can also be a relatively inexpensive and quick way of gathering information. This is particularly the case when the focus groups are made up of people that already exist as a group, such as a self-help group, church group or classroom of students. The researcher can contact the group and, if they are willing, arrange to do a focus group discussion at the time and place they usually meet. For research on a limited budget, focus groups can be a cost-effective way of involving people from non-English speaking backgrounds by having different focus groups for different languages and the appropriate interpreters present.

However, focus groups do have a number of disadvantages:

- focus groups cannot provide the detail of in-depth interviews;
- they are not particularly good for collecting the sort of statistical data that can be gathered through questionnaires (although questionnaires can be distributed and collected from the focus group members);
- the groups can be dominated by a few individuals; and
- participants may say what they think the group wants to hear, rather than what they really think.

Preparing focus groups

The main tasks in preparing for focus groups are identifying the topic and issues for discussion, recruiting participants, and planning and organising the ‘event’.

Planning the discussion involves planning the topic and planning the role of the researcher. The topic that you want the focus group(s) to discuss should be based on your research aims and objectives. Working out the specific topic for a group discussion should take into account the following points:

- it must be of interest to participants;
- the participants must know something about it;
- it must be capable of generating discussion, that is, there need to be a range of views about the topic; and
- it must be expressed clearly and simply.

Depending on the chosen topic, you may also include issues specifically related to that topic. The topic and any related issues that you want covered in the discussions will help determine how much freedom you give the groups to move into a discussion of other aspects and/or related issues. You need to balance a narrow focus which permits participants to understand what you want from them with a broader focus which encourages participants to actively and energetically engage with each other in discussions based on their ideas, experiences and views.

The role of the researcher must also be considered before convening the focus group. The level of your involvement in guiding the discussion will vary with the requirements of your research and the group. Your primary concern is that the topic is adequately and actively discussed. Minimally, this involves keeping the discussion on track and keeping the discussion going.

How you contact participants will depend on whether you are working with an already existing group, or bringing together a number of individuals using methods of sampling. In addition to the general preliminary research information outlined earlier, focus group participants naturally need to know the time, place and duration of the focus group.

The number of participants for a focus group can vary widely, especially taking into account that some people are likely to not show up. A group of around 6 to 12 people is usually ideal as a wide range of experiences and views is represented but the group is small enough to generate a discussion in which everyone has the opportunity to hear and be heard.

Focus groups can be made up of people who already know each other, or strangers. Depending on the aims of the research and the topic of the discussions, you need to consider whether or not it is an advantage or disadvantage for focus group members to know each other beyond the context of the focus group.

The issues you should consider in organising the ‘event’ include timing, venue, catering and support for people to attend. The time set for the focus group is important. No matter what time you have it, this will automatically exclude some people from participating. Think carefully about what might be appropriate and ask people what times would suit them. People in paid employment are unlikely to be available during working hours. Some times are better than others for people with young children. Some people may not want to go out at night or in cold or rainy weather.

If you need to organise a venue, make sure that it is accessible to everyone who is coming. Some of the things you should consider are: parking; access to public transport; wheel-chair access; toilets for people with disabilities; and comfortable seats. Other considerations include the need for quiet, heating and cooling and, perhaps, access to a kitchen or other catering arrangements.

It is usually appropriate to provide some light refreshments to the participants, and sometimes a meal. Most focus groups are run for 1–4 hours, in this time people will usually appreciate something to drink and eat.

Many potential participants will find it easier to be involved if there is some assistance available for other ‘incidentals’. Some of the things you should consider and make allowances for in your research budget include:

- child care;
- availability of interpreters;
- transportation;
- attendant care if the participant needs it, or if the participant cares for someone at home; and
- any dietary requirements of members the focus group.

Piloting of focus groups is not frequently done. However, piloting can be an effective way of finding out if your topic is of interest to your participants, developing your facilitation skills and checking the effectiveness of the method you are using to record the discussions.

Conducting focus groups

The most important aspect of any focus group is the discussion. As a facilitator you need to encourage people to discuss the topic with each other. Frequently, participants will be inclined to address everything to the facilitator and not to each other. Make it clear from the start that your role is only in getting the discussion going and helping to keep it on track. Sitting in a circle or around a table can help with this.

It is also important to ensure that everyone has opportunities to be heard. This may involve ‘sitting on’ one or two dominant voices and encouraging a few of the more quiet ones to speak. But you need to be careful about how you do this. Sometimes people are quiet because they have nothing to say about a particular point, and it can do more harm than good to put them on the spot by addressing a particular question to them.

As with in-depth interviews, you will find yourself having to bring people back to the topic. Do this gently, and do not do it prematurely because something that appears to you to be off track may actually be a central issue for one or more of the participants. You must carefully keep discussion on track without stifling people’s interest and enthusiasm. Difficulty keeping the discussion on track may be an indication that your expectations about important issues are wrong, or that you have not explained the purpose of the research clearly enough.

There are several things you can do to bring the discussion back to the topic, or to get it moving again after it has stalled. Often, in addition to having a topic for the discussion there may be some specific aspects of it that you would like discussed. These can be used to move things on. Also, you can use techniques similar to those of in-depth interviews where you probe people’s responses. In focus groups you could also explore a particular area of agreement or disagreement between the participants.

One of the most difficult things in a focus group can be for the facilitator to remain neutral. Participants may look for your intervention when there are disagreements. In this instance it may be beneficial to re-state that, as a researcher, your role is to remain neutral; you are there to find out what the participants think is a useful strategy. This is also part of emphasising that the focus group is a discussion between the participants, and not a discussion between the participants and the researcher.

When the time is up you will need to signal that the focus group has concluded. In concluding it is often useful to provide a summary of what you think the key points were, and see if the participants want to add or change anything. This helps to increase the validity of the results.

Recording focus group discussions can be difficult. It is most easily done by using a good quality audiotape recorder. It can also be done by having an assistant at the focus group whose job is to take notes on the discussion.

Participant observation

Participant observation requires the researcher to participate in the everyday lives of the people or the situations being observed. This method of research is most useful when the research questions require observing people’s lives or parts of their lives (such as work or school), or particular situations (such as what goes on in a hospital ward or in a doctor’s waiting room). Participant observation can be used to examine the dynamics of a particular situation, for example how consumers are treated in a hospital setting.

The main advantage of participant observation over other research methods, such as surveys using questionnaires or interviews, is that it goes directly to people’s activities and can avoid the problem of the difference between what people say they do (or would do) and what they actually do. Questionnaires and interviews are valid ways of finding out about what people say they do, but are less valid if you are using them to find out what people actually do. Participant observation (and observation without participation) can be a valid way of determining what people actually do, although even this observation can change people’s behaviour.

One of the advantages of participant observation over observation without participation is that you can talk to the people you are observing, and this can be used to find out more about what is going on, what people think, and why they are doing what they are.

Participant observation as a research method is very similar to what we already do in our everyday lives, except that it is more systematic, more careful, more thorough, conscious, and done for a specific purpose. There are a number of basic requirements that are necessary if you wish to turn the everyday process of participant observation into research:

- carefully and regularly write down your observations in a diary or field journal as you make your observations or as soon as possible (this should be at least daily);
- observe and keep notes on as much as possible. You will have to be selective to some extent, and it is important to write down why you have selected particular things and not others to observe;
- your notes need to include both your observations (what you know happened) and your thoughts and ideas (what you think is going on and why). It is vital to label which is which in your notes;
- collect other relevant information including photographs, video and audio recordings, and written material; and
- ask questions when appropriate. This may be the only way to find out why people are acting in a particular way.

One of the main problems with participant observation is how to become part of the situations that the researcher wants to observe. For members of self-help groups this is probably less of a problem as you are likely to be interested in researching situations in which you or group members are already involved.

The extent of participation by the researcher can vary considerably from being a central and active participant, to being on the boundary of a situation. If the role of the researcher is so insignificant that the researcher is effectively invisible, then the research method is considered to be observation rather than participant observation.

One of the most perplexing issues for researchers engaged in participant observation is whether or not they tell the people they are observing that the research is being carried out. Sometimes it is necessary and useful to tell the people being observed, in other situations it could make the research meaningless as people change their behaviour when under observation. There is also the question of whether it is ethical to research people who do not know they are being researched. Hence, ethical approval (as discussed in Chapter 3) should be sought for this type of research.

You will need more information about participant observation if you are seriously considering using it in gathering information for your research project. Many social research texts have extensive discussions of participant observation, and there are whole books devoted to the subject. See the Bibliography for relevant references.

Experiments

It is not common for a self-help group to be interested in undertaking an experiment. However, experimental designs are commonly used in health research and have shaped much of the thinking in social research, particularly regarding the collection and analysis of quantitative data.

Understanding the basics will assist you in understanding and analysing the articles presenting these experiments in the health literature.

Experiments involve taking action (or applying an ‘intervention’) and observing the consequences of that action or intervention. Classic experimental design involves:

- random assignment of research subjects to two different groups — an ‘experimental group’ and a ‘control group’;

- manipulation of one or more variables (called independent variables) in the experimental group by the researcher;
- measurement of the effects on the experimental group of this manipulation on one or more other variables (called dependent variables);
- measurement of the same variables in the control group (to which nothing has been done); and
- comparison of the results for the experimental group and the control group.

In health research, a particular treatment is often the independent variable, and its effects are the dependent variables. The strength of experimental designs is in their power to explain why something occurs (causal relationships). A good experimental design is very reliable and has high internal validity, terms which are explained in Chapter 7. Because of their often artificial nature, though, experiments can have low external validity. That is, the results may be repeatable in laboratory conditions, or under the specific conditions created to do the experiment, but are not repeatable outside of these conditions.

Experiments used in an evaluation often compare people who have access to a particular service with those who do not. These and similar situations are called ‘natural experiments’ because they require no manipulation of the independent variable by the researcher; the manipulation has occurred ‘naturally’. For example, a natural experiment could compare the health of two communities that are comparable in all ways except that one has a community health centre and one does not. In this case, the independent variable is the existence or non-existence of a community health centre. The dependent variable is people’s health (which must be defined and measured quite specifically), and the control group is those people without a community health centre.

Case studies

Case studies use a range of information sources and other research methods to examine a person, event, situation or organisation. It is also common to use a small number of individual case studies within a single research project. For example, you could look very closely at four or five doctor-patient relationships. Gathering the information could involve in-depth interviews with both the doctors and the patients, a content analysis of the relevant medical records held by the doctor and any relevant records held by patients, and video-taping of consultations between the doctors and the patients. Analysis of the information could then include discussions or interviews with some experts on communication and/or doctor-patient relationships.

With case studies the number of ‘cases’ examined is usually quite small, often only one. The emphasis is on the depth of information gathered. The strength of case studies lies in the use of multiple methods for gathering information, and multiple sources of information about the one case. This allows a comparison between different views and the opportunity to build a more complete picture of the case than is otherwise possible. If done well, case studies are seen to have very high validity as a consequence of the range and depth of information gathered.

It is often difficult to claim that a single case study, or a small number of case studies, is representative. Therefore, the ability to generalise is often limited. However, case studies are often used when generalisation is not a necessary part of the research. Nevertheless, if generalisation is necessary this can sometimes be achieved by choosing the case or cases very carefully. It is important to realise that even if you make no generalisations from a case study, the person who reads your research report will often generalise from it because they see many aspects of it as being typical of other cases.

Unobtrusive research methods

Unobtrusive or indirect research methods are essentially those methods that do not seek information directly from people. Indirect methods rely on other sources of information. These include, but are not limited to:

- written material (ie previous research, medical records, diaries, newspapers, books, letters, government documents);
- audio and visual recordings (ie television, radio, photographs, films);
- physical traces (ie graffiti, worn steps, cemeteries, garbage); and
- observation.

Of these, written materials, particularly relating to research results, public policies and existing statistics, are most likely to be of importance and interest to self-help groups.

Physical traces can provide very useful and powerful information. For example, if you were interested in assessing how well general practitioners informed their patients about their fees you could look for fee schedules displayed in surgeries as an indicator. The availability of information in a variety of languages could be used as evidence of attempts by community health centres to be sensitive to, and interested in, people from non-English backgrounds.

With materials such as written documents, photographs, television, films and radio, a ‘content analysis’ can be undertaken. For instance, you could collect all the annual reports for one year from all the hospitals in your State or Territory and inspect them for indications of how each hospital has or has not involved consumers, community groups and self-help groups.

Observation as a research method is identical to participant observation except that the researcher only observes and does not participate in the situation or activities being observed. In practice, the activities of an observer are the same as those of a participant observer which were summarised above, except that the problem is usually how to remain invisible rather than how to gain entry.

Evaluation research

Evaluation research differs from other forms of research in its purpose, which is to assess the value or worth of something. Any of the research methods discussed above can be used in an evaluation. Evaluation can often be a highly political activity, and the politics of what you are doing need to be carefully considered, monitored and (if appropriate) engaged in as part of the evaluation process.

One of the first steps in undertaking an evaluation is to identify the criteria by which you will judge the success or failure of the activity being evaluated. It is important to be clear about the values informing your criteria. The sort of criteria that can be used include key principles, and the anticipated effects of the specified goals of the service or program being evaluated.

Evaluation research is often discussed in terms of two different categories of evaluation. These are process evaluation (also known as formative evaluation) and outcome evaluation (also known as summative evaluation). Process evaluation is concerned with how well an activity is being done and is frequently used as part of the development of a program. Outcome evaluation is concerned with assessing effects and effectiveness. Evaluations can include elements of both.

As noted in *Everyday Evaluation on the Run*,⁴ we all engage in evaluation all the time. Everyday examples include things like deciding which apples to buy, or deciding which route to take to get to the shops. However, evaluation within a research project requires an explicit and systematic

⁴ Wadsworth, Y. 1991, *Everyday Evaluation on the Run*, ARIA: Melbourne.

approach to strengthen the reliability and validity — and ultimately the credibility — of something we already know how to do.

Useful references regarding evaluation research are listed the Bibliography.

5.3 Selecting a research method for your project

When considering which research method to use for your research, make sure that you do not get too ambitious. It may be appropriate to use several research methods within the one project. The previous section has shown how each method has its strengths and weaknesses. Using more than one method can foster strengths and minimise weaknesses.

The intention in choosing a research method or methods is not perfection but, rather, the best solution to a complex problem. Choosing the appropriate method, or combination of methods, for your research can be difficult. You may wish to seek the advice of one or several experienced researchers before making your decision. However, if you have a clear outline of the purpose of the research and its aims and objectives, it should be easier to determine the appropriate method(s) to use for your research.

The following questions will help you decide which methods to use:

- What information is required in order to meet your aims and objectives?
- Is this information qualitative or quantitative, or a combination of both?
- How much time do you have to complete the project?
- How much time do the researchers have to contribute to the research?
- What resources are available for your research?
- What type of participants does your research require and how easy will it be to enlist appropriate participants?

Quantitative methods can answer questions such as, what? where? when? who? and how many?, whereas qualitative methods can answer questions such as, why? and can investigate people's experiences. Your choice of qualitative or quantitative research methods may also be influenced by your intended audience and what you are trying to achieve. If your intended audience is doctors you should consider a quantitative method but do not exclude qualitative research. Similarly, although an audience made up of the media or politicians may be more receptive to a qualitative approach you should not exclude quantitative 'facts and figures'.

The Older Women's Network used a qualitative research method — focus groups — to obtain the information that would meet the aims and objectives of their project. Six focus groups were held across Sydney and outer Sydney — two with groups of carers, two with women from a non-English speaking background (Vietnamese and Spanish), one with frailer older women (half of whom also happened to be carers) and one with a group of women who saw themselves as fit and well. Over 72 women participated in these groups.

While the overall direction for the Project was provided by the Health Committee of the Network, the method was worked out at a meeting of the members of the Network. This meeting produced draft questions to be used in focus groups. The complement of focus groups was decided by the Health Committee based on the needs that had been voiced over the years, and on the Network's philosophy of non-discrimination.

The amount of time available to complete the research will effect your choice of method(s). The need for results within a limited time frame may be driven from outside the group (ie by the need for your group to have a response to an approaching government enquiry). Some research methods, such as focus groups, can take a lot of direct, face-to-face time to administer and analyse. Even though the preparation time to run a focus group may not be as great as other methods, time is taken up in conducting the focus group meetings, transcribing tapes and/or coding data,⁵ and in analysing the data. Distribution of a mailed questionnaire, on the other hand, may take time in preparation and analysis but, once the questionnaires are mailed, the researchers will have some time available to focus on other activities as they await the questionnaires' return. If the questions are structured with a majority of closed-ended questions, the questionnaire will take less time to analyse than if the questions are unstructured, with a majority of open-ended questions.

The restriction of other resources may limit your group's ability to undertake certain types of research. Resources required could include particular research skills, as well as tangible items, such as various pieces of equipment. If you are developing a research project using the group's existing resources, you will need to weigh up the pros and cons of doing so. For example, if you need to use the group's computer for analysis of the data, other group members could well become disgruntled at their lack of access to the computer for the equally vital work of developing the group's newsletter. You might also give some thought to the impact that losing some of the group's more active members to the research project might have on the running of the group itself, and how you might deal with that. It is imperative for your organisation's long-term survival and success that you keep within your limitations and do not take on too large a project.

If you are developing a research proposal for funding, you might consider 'buying in' particular resources, such as equipment or computer software or skills training. However, you will need to match your request with the parameters for funding set by the different funding bodies. As discussed in Chapter 4, budget funds for resources vary with the funding body. If resources cannot be bought in, your choice of method will be limited. You may find that small, structured questionnaires are easier both to develop and to collate and analyse.

It is important to consider the best type of participant for your project, how many of them will provide a sample appropriate to your project and where you will find them. For example, if you wanted to research the psychosocial impact of thyroid disease on Australians who have thyroid disease, your potential participants could be found through support groups, endocrinologists (specialists) and general practitioners. Naturally, you would not be able to meet every person who has thyroid disease, but a written questionnaire that used a combination of closed-ended and open-ended questions could set you on the path to finding some of the information you require. You could also plan to run some focus groups to 'flesh out' some of the points raised in the responses to the questionnaires. Issues of sampling are discussed in Chapter 7.

⁵ 'Coding data' is discussed more fully in Chapter 7.

6 Literature reviews

As discussed in Chapter 5, most research involves an extensive review of published literature. The literature review is vital for checking whether others have already done the research you propose to do, or to assess how your research project fits in with the research that has already been carried out. A search of the literature may highlight gaps in the area which your research could fill, or may alert you to research methods and questions that could work for your proposed project.

At times, the whole research project is the literature review. In this case, the findings and analysis of the literature must be detailed in a report, rather than presenting the main findings in a summarised format, as is often required when the literature review forms a part of the research.

Literature reviews involve finding and analysing existing written materials such as research reports, journal articles, census statistics, and books that are relevant to your research. Because all literature reviews involve looking at what other people have done, this is often described as examining ‘secondary’ sources and doing ‘secondary’ analysis. This is in contrast to ‘primary’ sources and ‘primary’ analysis which is when researchers gather their own information.

There are three main steps to undertaking a literature review. The first step is the preparation — deciding what you need to find and where to begin looking. The second step is actually finding and getting copies of the literature you want — the literature search. The final step is examining the literature and considering what it means in the context of your research — this is the actual ‘literature review’.

Summary — Literature reviews

Preparing for a literature review

- The planning you have done for the research project is good preparation for a literature review. In preparing for your literature review, you should consider how much time is available, how complete or exhaustive you need to be, and any requirements of your funding body.

Finding the literature

- Your search for relevant literature should start in a library, preferably with the assistance of a librarian.
- There are a number of major guides and resources available in most large and many small libraries that may be of use to you. These include computerised catalogues, other catalogues, computerised databases on CD-ROM or computer networks, and specialised reference books.

What to look for in the literature

- You will need to judge the quality, including the reliability and validity, of the material you have collected. You will also need to identify issues of relevance to your research.
- It is useful to keep a clear record of all references and to make notes as you read through the literature.

6.1 Preparing for a literature review

When literature reviews are used as one part of a research project they are often done at the very beginning. Indeed, a substantial part of the literature review should already have been done in preparing your research plan or proposal. However, an alternative way of doing a literature review is to do it after the other information is collected and much of the analysis has been done. This is sometimes done with qualitative research. In this case the emphasis is on keeping an open mind when collecting the other information, and drawing out themes, ideas and interpretations from the

information collected rather than relying on other researcher's perceptions of what is or is not important. This is known as 'grounded' research.

The Older Women's Network's Project Officer undertook the literature search for the Older Women's Health Project. Members of the Network also suggested relevant pieces of literature for the Project Officer to review. The Project Officer had sufficient skills and resources and did not encounter problems during this stage of the Project.

The planning you have done for the research project is good preparation for a literature review. The aims and objectives of your project should be re-visited to assess what information you need to gather in your literature review. For example, if you want to investigate how doctors deal with women's psychological needs after miscarriage, you might want to know what (or how) other researchers have found out about the communication between patients and doctors. You would probably look up literature on miscarriage to see what had been written about the needs of women experiencing miscarriage, and you would probably investigate further the psychological impact of this particular experience on a person and her family.

This initial assessment should start to give you some clues regarding the definitions and key words for which you need to search the literature. In developing this list, it is important to remember that different literature sources may use different words to mean the same thing. For example, 'disability' and 'handicap' may be interchanged, and 'intellectual disability' is often referred to as 'mental retardation' in the United States literature. The list of definitions and key words should be continually updated as the literature review progresses since you will get new ideas from the articles you find.

It is also useful to list where you think you might find your literature and other sources of information. There will be several levels to this list. At one level will be the major sources or locations of information such as libraries; people who might have key documents or access to them; and perhaps someone with access to the Internet or other computer network. Another level might be more specific: books; professional journals; newspapers; census reports; or government publications. If you know the names of some people who have written about the topic, add their names to your list. Again, this list of sources should be regularly updated as new information is needed and as new sources are discovered.

When thinking about libraries as a source of information, do not restrict yourself to public or university libraries. While these will give you access to generalised literature, other libraries are more specialised. Most large corporations, nearly all branches of government (Commonwealth, State/Territory and local), hospitals, specialist health organisations, and many other organisations have libraries which you can access for specialised literature. In addition, many individuals who have worked extensively in a particular area have developed their own collections of literature and are often quite happy to share their libraries. These libraries can be particularly valuable because they often include conference papers and less widely known published and unpublished materials.

Preparation also involves being as clear as you can about how much time is available to carry out the literature review, and how complete or exhaustive it needs to be. For example, are you able to spend four Saturday afternoons on it, or can you spend two days a week for six months? Do you just need a general idea of what other people think about the topic, or do you need to thoroughly examine what other research has been done in the last 20 years? You will need to define the breadth, depth and period of your search.

If your literature review is for a grant application, you will need to consider the funding body's requirements. For example, you may need to demonstrate that you have searched the major databases with which the funder would be familiar.

The extent of your literature review depends on what you are using it for and what has been published. With some topics there might be very little published material and it is quite easy to do a comprehensive review of all relevant materials. With other topics there may be literally thousands of books and articles. In this case, a useful strategy is to check the common references from eight or ten books and articles on the topic; this is a good indication of what other researchers think is the essential literature on the subject. In addition, it is important to include a small number of very recent references and any references that are specific to the population of your study (ie Australian studies or studies concerning people in your State/Territory).

6.2 Finding the literature

Libraries are a good place to start your literature search. The first thing to look for in any library is a guide to the library and the librarian. Large libraries often have librarians specialising in specific areas. Enquiries are always welcomed, especially if your request makes it clear that you are not looking for someone to do your work for you. You will get the most help if you make your enquiries when the library is not very busy, and sometimes it is worthwhile to make an appointment, especially with private libraries. Some libraries also provide short courses, workshops and other opportunities to learn about the library and how to search for literature.

The literature review for the General Practice Care Following Miscarriage project was jointly undertaken by the coordinator of SANDS and the academic from the UQ. The academic had access to the Internet and found many recent articles. Although SANDS already had some resources and literature, the coordinator spent a day at the University library searching for articles. The two researchers reviewed the literature, summarising and discussing their findings with each other. Both had experience of searching for literature and acknowledged that without this experience the literature review stage would have been much more difficult.

There are a number of guides and resources that are available in most large and many small libraries, including:

- computerised catalogues that allow you to 'search' for books and other publications in many ways — such as by author, title, subject and combinations of key words;
- other catalogues, bibliographies, indexes and directories of books, official publications, articles in newspapers, magazines and journals, and Masters and doctorate theses;
- computerised databases on CD-ROM or computer networks — these contain both statistical information (for example all of the Australian census data is widely available on CD-ROM) and indexes (such as Health Education and Promotion System [HEAPS], which is an index of health promotion resources and activities throughout Australia); and
- specialised encyclopedias and dictionaries, bibliographies, handbooks, yearbooks, statistics and abstracts (short summaries of journal articles).

Ask the librarian if you have any trouble finding what you need. Librarians have an understanding of their library — of how books and journals are indexed and stored. They can also help you with your search, find or recall missing books and articles, or order in books or journal articles not held in their library.

In searching for articles and obtaining a copy, it is probable that you will be charged for this service (even up to \$20 per journal article). Thus you will need some financial resources in undertaking this stage of the research, as well as time. If an article or publication needs to be brought in from overseas, you could face some delay in accessing this literature.

You will probably also need to consult the librarian if the database you wish to search uses a controlled vocabulary such as MeSH (Medical Subject Headings) as used in Medline. Medline, produced by the United States National Library of Medicine, is the largest medical database which can be accessed on-line on the Internet. The controlled vocabulary of Medline could prefer, for example, the word 'neoplasm' rather than 'cancer'.

The indices/abstracts and databases available include:

- Australian Public Affairs Information Service (APAIS) or AUSINET — a subject and name index which outlines current literature in selected journals and newspapers published in Australia or about Australia;
- Public Affairs and Public Policy Index (PAIS);
- Index Medicus or Medline (MEDLARS online) for medical journal articles;
- Science and Social Science Citation Indices (SOCIAL SCISEARCH) — allow you to track a paper forwards through time. For all the papers published in a calendar year, the Science and Social Science Citation Indices list the references that these papers have cited or mentioned;¹
- Sociological Abstracts — for abstracts of social research articles;
- Psychological Abstracts (PSYCHINFO) for abstracts of psychological research articles;
- Biological Abstracts — international and includes medical, physiological and pharmaceutical literature dating back to 1926. The Guide to the Use of Biological Abstracts is a useful outline of how to find the abstracts you need;
- Cumulative Index to Nursing and Allied Health Literature (CINAHL) — lists articles on nursing and allied health professions such as occupational therapy, physiotherapy, medical records and health education;
- Excerpta Medica or EMBASE — the European equivalent of Medline. It primarily covers journal articles, but also includes books, conference papers and dissertations. The Guide to Excerpta Medica Classification and Indexing System is essential if you are going to use this service; and
- The Cochrane Library on CD-ROM — the Cochrane Collaboration's database of systematic reviews.

It is a good idea to start your literature search with the most recent literature and work backwards. In this way you can follow up the studies that these authors have used which, of course, will be older than the ones you are perusing. It is also a good idea to read the material you collect as you go along, rather than piling it all up until the end so that you get a feel for the area and have a better idea when to stop your search.

There are more published papers that might be relevant to a research study than a researcher could possibly read. Instead, papers need to be read selectively and progressively. A quick skim through the abstract should indicate whether the paper is worth more detailed review. Ask yourself whether

¹ Crombie, I.K., Davies, H.T.O. 1996, *Research in Health Care: Design, Conduct and Interpretation of Health Services Research*, John Wiley & Sons: Chichester, p.70.

the article will provide you with information that you need. Only if the answer is a definite ‘yes’ should it be read further; if the answer is ‘well, it might be useful sometime’ then it should be filed.²

Given the wealth of information available, it is vital that your search be systematic in order to make the best use of your time and to be sure that you find the most important items and not just what is easiest to obtain. It is inevitable that you will spend a few fruitless hours of looking for something that is not there or is of no value to you when you finally find it. It is worth remembering, though, that often the most useful material requires some digging, and you cannot always know whether something is worth looking for until you find it.

6.3 What to look for in the literature

When you have found some literature you will need to start reading it and make decisions about what it means in relation to your research. To do this you will need to make judgements about the quality, including the reliability and validity, of the material you have collected. You will also need to identify issues of relevance to your research and keep track of this information.

The very first thing to do when you find material that warrants examination is to accurately record the reference information for the material. This is essential so that you can find it again if necessary, and so that you can include the reference when you write your research report. A good and widely used guide for referencing systems is included in the Style Manual, which is published by the Australian Government Publishing Service (AGPS).³ Referencing is also discussed in Chapter 8 (see page 98).

Write clear and understandable notes as you go. Make sure that you keep track of which notes go with which reference. Carefully copy and identify any quotes that you might later want to use in your report. A common method is to use large index cards for notes. These are easily handled and can be easily rearranged. Typing notes directly into a computer can also be useful.

When reading a wide range of literature it is easy to get lost in a world of jargon. However, as you read more and more, and spend more time on the topic you will find the literature increasingly easy to read. Being able to understand the jargon that is used in different professions can be important later to your credibility when you present your research to different audiences. However, it is important to guard against being coopted to accepting jargon that is offensive to consumers. Quite often jargon reflects a ‘world-view’. Therefore, if your group’s world-view is different, you should guard against the use of jargon that has connotations in the broader society.

Assessing the literature

To help you decide the depth to which a book, paper or report should be read it is helpful to preview it, to inspect it before reading it in more detail. The preview can involve looking briefly at the headings and subheadings, the abstract or parts of the discussion, or the tables and figures. Previewing provides an overview, a framework, within which further information from the paper can be organised. It will also determine whether the paper needs to be read in detail, because the results may be interesting or because other parts of the paper contain useful information. When approaching a paper, it is useful to ask what lessons can be learned and what the findings mean.⁴

² Crombie, I.K., Davies, H.T.O. 1996, *Research in Health Care: Design, Conduct and Interpretation of Health Services Research*, John Wiley & Sons: Chichester, p.71.

³ AGPS 1994, *Style Manual for Authors, Editors and Printers*, 5th Edition, AGPS: Canberra.

⁴ Crombie, I.K., Davies, H.T.O. 1996, *Research in Health Care: Design, Conduct and Interpretation of Health Services Research*, John Wiley & Sons: Chichester, p.73.

Outlined below are some suggestions for things to look for and take notes on when you are reviewing research articles or reports (see Chapter 7 for explanation and discussion of sampling, analysis and certainty):

- title, aims and objectives, research questions/hypotheses — Why was the research done? What research question(s) was it trying to answer?
- literature review — What literature was examined and is any of it of interest to you?
- methods — How was the research done? Were the methods used properly and were they appropriate to the stated research objectives?
- sampling — How was the sample chosen? How large was the sample? Are claims made about it being a probability sample and/or a representative sample justified? What are the possible sources of bias in this study?
- analysis — How was the analysis done? Were the statistical methods described and if so were they appropriate for the data? Are the assumptions underlying the statistical methods likely to be met? Was allowance made for confounding factors?⁵
- results and conclusions — Are these relevant to your research? Were the conclusions justified? Were the limitations of the study acknowledged and taken into account? Were alternative explanations considered? Is an overemphasis given to positive findings with negative findings being dismissed?⁶
- certainty — How certain can you be that the research has been done properly? How much can you trust the results and conclusions? If generalisations were made was the sample representative? Was the research done in ways that maximised reliability and validity? Are the limitations of the research discussed?
- what do you think? — Write down your own ideas about the quality of the research and what it means in the context of your own research.

Writing up the literature review

Having taken notes on the literature you have read, you need to write up your findings in a coherent manner, referencing the literature to which you refer. If the literature review forms a part of your application for funding, you will need to follow the instructions regarding the word count. Whether or not you are applying for funding, writing up the findings of your literature search and review is vital to both shape and justify your project. You clearly need to state what literature supports your research and how, and what literature highlights gaps that your project will seek to fill.

⁵ Crombie, I.K., Davies, H.T.O. 1996, *Research in Health Care: Design, Conduct and Interpretation of Health Services Research*, John Wiley & Sons: Chichester, p.75.

⁶ Crombie, I.K., Davies, H.T.O. 1996, *Research in Health Care: Design, Conduct and Interpretation of Health Services Research*, John Wiley & Sons: Chichester, p.75.

7 Collecting and analysing data

Having reviewed literature and determined which research method(s) are appropriate to your research, you will already have taken some decisions as to how data for your research will be collected. In collecting information it is important to consider the integrity of your data in terms of reliability, validity and generalisability. You will also need to decide how your sample population will be selected. Information needs to be collected in a form that is suitable to analysis.

Analysis of your data will allow you to draw conclusions from your research. The means of analysis, whether quantitative or qualitative, should be appropriate to the data that you have collected. Tests of significance and sources of bias are essential elements in your analysis as they help to generate ‘certainty’ in research.

The fundamental issue in any research project is how certain you can be that the information you collect is accurate; that your analysis is appropriate; and that your conclusions are correct. Within the context of the purpose of your research, its audience and your available resources, you will need to make sure that you have as much certainty in your research as possible.

Summary — Collecting and analysing data

Collecting data

- **Reliability** (see page 71) is usually judged on the basis of how consistently the same results can be achieved under similar circumstances. Reliability is about consistency and repeatability.
- **Validity** (see page 72) is the extent to which you can be sure that the information you have collected and your results are an accurate reflection of reality.
- **Generalisability** (see page 73) refers to the appropriateness of applying the results of your research to other people, situations, places and times. If you need to generalise your findings, these generalisations need to be valid.
- **Sampling** (see page 74) is used when you cannot involve every relevant person, group, situation or object in your research. In probability samples every member of the research population has an equal chance of being included in the sample. Non-probability sampling techniques are generally easier, faster and less resource intensive but are less reliable and representative.

Analysing data

- Analysis is the process of turning the information you have collected into something meaningful. The type and level of analysis will be determined by the nature of the information collected and how relevant it is to your research aims and objectives.
- **Quantitative analysis** (see page 79) is used for quantitative information, and statistics are used to summarise the information and explore what the data mean.
- **Qualitative analysis** (see page 87) is used for qualitative information (usually the words of the research participants) and a range of techniques is used to summarise information and explore its meanings.

7.1 Collecting data

Four concepts are of importance in the collection of data:

- reliability is concerned with consistency and repeatability;
- validity is concerned with how accurately your results reflect reality;
- generalisability refers to the appropriateness of applying the results of your research to other people, situations, places and times (generalisability can be improved by good sampling); and
- sampling is used to obtain research participants when you cannot involve every relevant person, group, situation or object in your research.

Reliability

Reliability is usually judged on the basis of how consistently the same results can be achieved under similar circumstances. For example, if you wanted to test the reliability of your bathroom scales in measuring your weight you could simply step on and off the scales four or five times in a row. If you get the same result each time, then your scales are reliable.

Some of the techniques for increasing reliability during your research include:

- administering a questionnaire to a small number of people on two different occasions, or to two similar groups and comparing the results (a common part of piloting or testing a questionnaire) — *test-retest reliability*;
- if more than one person is doing interviews, making sure that everyone is asking the same questions in the same way — *intertester reliability*; and
- when interpreting information for analysis, have several people do the same task independently and compare the results — *interobserver reliability*.

Reliability is particularly difficult to achieve in qualitative research methods, such as in-depth interviews and focus groups when the responses to the initial research question(s) develop into further discussion. ‘The concern is whether or not, and under what conditions, the interviewer would expect to obtain the same finding if he or she tried to do the research again in the same way.’¹

Since reliability for the whole research project or for parts of it depend on their being repeatable, it is necessary to carefully record exactly how you have done the research.

This should be done in such a manner that any reader or prospective reader can find details of how and why the researcher made certain decisions in the research process; their perceived impact on researcher and informant/s; how the data were collected (interviews only or personal documents in addition to in-depth interviews or multi-method use); and how they were analysed.²

If there is not an accurate record of how the research was done, it will not be possible for someone to consider repeating either the whole study or even one aspect of it. Even if the research is never repeated, by presenting this information you allow other people to scrutinise how your research was done and determine for themselves how reliable and valid it is.

¹ Minichiello, V., Aroni, R., Timewell, E., Alexander, L. 1995, *In-Depth Interviewing* (2nd Edition), Longman: Melbourne, p.178.

² Minichiello, V., Aroni, R., Timewell, E., Alexander, L. 1995, *In-Depth Interviewing* (2nd Edition), Longman: Melbourne, p.178.

Validity

Validity is the extent to which you can be sure that the information you have collected and your results are an accurate reflection of reality. “Validity is concerned with the accuracy of a test or measure; in other words, the amount of measurement error. The concept of validity implies that we can know the true value of a test, that is, we have a ‘gold standard’.”³

Just because you get the same results from repeated measures does not mean that all is well. Going back to the example of the bathroom scales, the results are a valid measure of your weight only if they are accurate. You could consistently weigh a certain amount (reliability) but your scales may be in error and, in fact, show your weight as five kilograms more than you actually weigh. This can be tested by checking your weight on other scales that are known to be accurate. Hence, it is possible to obtain reliable data without obtaining valid data. However, if the scales were not reliable, they could not be valid. That is, if you did not consistently get the same results when stepping on and off the scales, then the issue of their accuracy would be meaningless. Without a reasonable level of both reliability and validity throughout the research process you cannot claim a reasonable level of certainty about your conclusions.

There has never been a perfect research project, and there is no single right way to do research. You are looking for the best fit, not the perfect solution to often insoluble problems. Considering reliability and validity when planning and undertaking your research can improve your certainty about having achieved a ‘good fit’ between your research aims and objectives, your research design (sampling, methods and analysis) and the available resources.

There are three types of error which are said to make research invalid. A type one error is believing a principle to be true when it is not. A type two error is rejecting a principle when in fact it is true. A type three error is asking the wrong question.⁴

A type three error is the type of error most commonly found in qualitative research. This relates to content validity.

Content validity

Content validity means being sure that you have asked the right people the right questions about the right issues. Content validity can also be illustrated with the bathroom scales example. If you were using the scales to measure something other than weight (for example height or whether you are male or female) this would not be valid.

Piloting your research project is one way of evaluating whether your content is valid. If your preliminary results do not give the data required to meet the aims and objectives of the project, you will need to re-assess your method and modify the project accordingly. In some instances this will be as simple as altering the questionnaire or broadening the sample of participants (see discussion of sampling below). For example, a question in your questionnaire may have been interpreted in different ways by the participants of the pilot project. In this instance you will need to clarify the question to remove the ambiguity.

You can make certain that you are collecting the right information by:

- talking to other people and finding out what they have done;
- ensuring that other members of the research team agree that you have asked questions that allow the respondents to provide answers which truly reflect their lives and experiences;

³ Polgar, S., Thomas, S.A. 1995, *Introduction to Research in the Health Sciences*, (3rd edition), Churchill Livingstone: Melbourne, p.165.

⁴ Minichiello, V., Aroni, R., Timewell, E., Alexander, L. 1995, *In-Depth Interviewing* (2nd Edition), Longman: Melbourne, p.177.

- taking the results of your analysis back to the research participants and asking their views about whether your analysis and conclusions seem accurate and meaningful to them; and
- using your literature review to find out what people have done in your area of interest, and in other related areas.

In order to validate research undertaken using qualitative methods, the researcher should both concentrate on the consistent themes of the research and check their understanding of the responses with the research participant(s). In qualitative research, specifically in-depth interviews and focus groups, probing and exploring issues, and cross-checking information are forms of validity.

It is a common mistake to state conclusions more strongly than the research can actually support. It is difficult to prove something beyond all doubt. All research has limitations; gaps, problems and shortcomings are inevitable. You do not have to emphasise these when you write reports or present the results of your research (see Chapter 8), but limitations must be acknowledged and addressed when discussing the certainty of your conclusions. If you do this yourself, your research will be credible. If you leave it for your critics, your research will be seriously undermined.

External validity

Conclusions can be stated more strongly if the research has external validity. External validity is achieved when it is shown that the research conclusions are true beyond the study itself. This is most commonly demonstrated by showing that other research has reached similar conclusions. External validity can also be established by demonstrating that the people and/or situation you have researched are typical of other times and places and leads to the ability to generalise your research findings.

Generalisability

Generalisability refers to the appropriateness of applying the results of your research to other people, situations, places and times. Depending on the goals of your research and its aims and objectives, you may or may not need to generalise your findings. If you do need to generalise your findings, these generalisations need to be valid.

The ability to make valid generalisations from your research will depend on how representative the research is of the usual situation. When the research has used primarily qualitative data, representativeness is based on how typical the research participants and the research situation are in relation to the people and/or situations to which you are generalising. When the research data is quantitative, the concern is how well the sample (the people from whom you have gathered information) represents the population from which it was chosen. The accepted approach is to use particular methods of choosing the sample (see below) and particular types of statistical calculations called ‘inferential statistics’ to make generalisations (or inferences) from the sample to the population.

The degree of confidence in generalising your findings will depend on the strength of your results. For example, if you interviewed 200 people in a shopping mall and everyone of them said that they were satisfied to very satisfied with the range and quality of services provided by the local community health centre, then you could quite comfortably generalise that the local community was generally satisfied with the range and quality of services at the local community health centre. However, if the results were much more mixed, such as: 50 very dissatisfied; 20 dissatisfied; 45 did not know; 65 satisfied; and 20 very satisfied, it would be difficult to make any generalisation. The potential for mistakes and uncertainty about how representative these people are of the whole community would not allow you to generalise these results to the whole community.

It is rare to be able to generalise with absolute certainty. Few samples are absolutely representative, few people and situations are absolutely typical. If you generalise from the specific people, place and time of your research be aware of, and acknowledge, the limits of your ability to be certain.

Sampling

Sampling is used when you cannot involve every relevant person, group, situation or object in your research. In research, all the people or things that you want to seek information from are considered your population. If you want to survey all 40 members of your self-help group (all the members of your research population) you will not need a sample because you can easily involve all of them. However, if you want to survey the eligible voters in your State/Territory you will need to use a sample.

You need to be careful about choosing a sample if you want to be able to generalise from the sample to the research population. If you want to generalise from quantitative data collected from your sample, you will usually want to make sure that you have used a probability sampling technique (see below). In probability samples every member of the research population has an equal chance of being included in the sample (but, because it is a sample, of course not everyone is included). With quantitative data and a probability sample, inferences (and inferential statistics) can be used to make generalisations from the sample to the research population.

Generalisations based on qualitative information will be more convincing (and have more validity) if the sample from which the information is collected is representative of the research population. In representative samples the characteristics of the research population are present in the sample in the same proportions that are in the population. Another way of saying this is that the members of the sample are typical of the members of the population. Probability sampling techniques can be used for this but, more often, non-probability sampling techniques (see below), particularly purposeful and quota sampling, are used. Non-probability sampling techniques are generally easier, faster and less resource intensive than probability sampling techniques.

Probability techniques are often seen as more valuable than non-probability sampling techniques because they are more reliable and more representative. A large and well-done probability sample has a high likelihood of being representative of the population and, consequently, can usually be repeated with similar results. However, probability sampling can be difficult to do well and can also be time consuming and expensive. With non-probability sampling techniques, reliability and representativeness can vary widely depending on the specific technique and how it is used. However, it is possible with non-probability sampling to have samples that are very representative and reliable.

Not every piece of research requires a reliable sampling technique or representative sample. If you do not want to make generalisations and the issues you are examining are very specific to a particular group of people, time and place, issues of sampling reliability and representativeness are irrelevant.

Sampling is one of the most important issues in designing a research project. Particularly if your research needs to be reliable and representative, it would be wise to discuss how your sample will be chosen — and why — with at least one experienced researcher. If you have hired a research consultant or if you are working in partnership with a professional researcher, make sure that they are extensively involved in choosing the sampling technique that will be used.

Non-probability sampling techniques

Four of the most commonly used non-probability sampling methods are outlined below.

Purposive sampling occurs when you identify particular people that you want to include in your sample for particular reasons. You will also find these types of samples called judgemental or

theoretical samples. This sampling technique is often used to select people that are believed to be typical of those you wish to study. For example, if you are trying to find out what makes for a vigorous and active self-help group, you might identify a number of groups that fit this criteria and interview key people (such as the groups' leaders), look at minutes of meetings or copies of previous newsletters.

Purposive sampling is also used to identify and select the best, worst, unusual or extreme from a population. In some situations you might want to only look at a sample of situations in which the results have been very positive to try and understand why it worked out so well, or how to avoid disasters or serious mistakes. At times, examining the extremes or the unusual can tell you more than examining the typical.

Quota sampling is often used to produce representative samples without random selection. In quota sampling the researchers find out what proportion of the population have the particular characteristics (variables) that they want to include in the sample, and then chose a sample that matches those proportions. For example, if quotas involving age were used and it was known that 25 per cent of the population was between 20 and 35 years old and the sample size was 100, then the first 25 people the researcher found that were between 20 and 35 years old would be chosen for the sample. Quotas for other age groups would likewise be filled.

Unlike random samples (see below) these samples are not random because the researcher is free to choose any 25 people who fit the criteria and, consequently, it is very possible for some biases to become involved. For instance, in this example on age quotas, it may be that a researcher is more comfortable interviewing men than women so more men than women may be selected.

It is possible, and common, to construct more complex quotas using a range of relevant variables such as age, sex, ethnicity and income.

Convenience, or incidental, samples are also frequently called availability samples. These are very common and include such things as interviewing people in shopping malls or using phone-ins. It is impossible to know how representative the people are of the research population. However, the ease and quickness of using convenience sampling means that it is frequently used in spite of the potential difficulties of making generalisations.

The General Practice Care after Miscarriage project employed a research assistant who conducted the focus groups and the in-depth interviews. In total, about 20 women took part in the qualitative stage of the research. The sample for the focus groups was drawn from the local members of SANDS, while the sample for the interviews was developed by:

- *referrals from local (Brisbane) general practitioners;*
- *placing a notice about the study at the Royal Women's Hospital;*
- *word of mouth from staff of the Centre for General Practice at the UQ and doctors from the local Divisions of General Practice.*

In this way, purposive sampling was used. This was the most appropriate non-probability sampling method to use as the people required for interview at this stage were women who had experienced miscarriage.

The quantitative part of the survey was undertaken by mailing the questionnaire (which had been piloted with a group of about 30 general practitioners attending a local conference) to 240 general practitioners selected randomly from the two local Divisions of General Practice. The researchers made the decision to survey in detail south-east Queensland rather than the whole of Queensland as this would permit a more detailed study rather than an overview. In this way, the two samples

were drawn from the same areas in south-east Queensland. The sample of general practitioners could be called a convenience, or incidental, sample.

Snowball sampling, like convenience sampling, is not representative. Snowball sampling is used primarily for interviews. It involves identifying one or several key people and asking them during the interview to identify other key people that should be interviewed. These other people are then interviewed, and also asked about key people to interview. Depending on the research topic, it often only takes between four and six rounds of interviewing before no new names are suggested. It is not always necessary or possible to continue interviewing until this occurs.

Members of the Older Women's Network set up the focus groups for the Older Women's Health Project. There were three facilitators of the focus groups — two members of the Older Women's Network, and a project officer employed by the Older Women's Network.

The participants of the focus groups were women who were members of the Older Women's Network; women from the Network who enlisted other older women from their own personal networks; and older women who were approached via other organisations. Over 72 women participated in these groups.

The sample was derived by purposive sampling and part snowball sampling. In this way, a broad cross-section of older women from Sydney and outer Sydney participated in the research.

Representativeness of the results was discussed in feedback and analysis of the results with the members of the Older Women's Network.

Probability sampling techniques

Four of the most common probability sampling techniques are discussed below.

Random sampling is both effective and difficult to implement. Since a random sample is one in which all members of the population have an equal chance of selection, a random sample is more likely to be representative than an incidental sample.

Developing a random sample involves:

- construction of a list of all members of the population; and
- using a method such as dice, coins or random number tables to select randomly from the list the individuals required for the sample.⁵

A simple example of a random sample is provided by a common raffle, where names on equal size papers are put in a hat, shaken and selected 'blind'. Many lotteries use numbered balls that are drawn randomly from a barrel. Another way to draw a random sample is to construct a list of all the members of the population and assign a number to each element. Then a table of random numbers, generated by a computer, could be used to select a random sample.⁶

The advantages of random sampling methods over incidental or non-random methods are:

⁵ Polgar, S., Thomas, S.A. 1995, *Introduction to Research in the Health Sciences*, (3rd edition), Churchill Livingstone: Melbourne, p.45.

⁶ Polgar, S., Thomas, S.A. 1995, *Introduction to Research in the Health Sciences*, (3rd edition), Churchill Livingstone: Melbourne, p.45.

- as the exact sizes of the sample and population are known, it is possible to estimate exactly how representative the sample is, that is, the size of the sampling error. This cannot usually be done with non-random sampling methods; and
- as random samples are usually more representative than non-random samples, the sample size needed for good representation of the population is smaller.

The major disadvantages of random sampling methods are:

- the researcher needs to be able to list every member of the population. Often this is impossible because the full extent of the population is not known; and
- it is much easier and less costly to use conveniently available groups. Random sampling usually involves considerable planning and expense, especially with large populations.⁷

Stratified random sampling is the ‘same as quota sampling, except that each quota is filled by randomly sampling from each sub-group, rather than sampling incidentally’.⁸ Stratified random sampling is often used to increase the representativeness of the sample.

For example, if the issue being examined is likely to involve considerable differences between men and women it is important that their views be equally represented in the sample so that they can be compared easily. In this instance, one would need a list of all females and all males in the population and then sample randomly from these lists with the numbers in each group in the sample being decided based on the corresponding proportions of females to males in the population.

It is possible and common to stratify for several variables⁹ such as age, sex and education if these are perceived to be important within the research. However, there is always a danger of overlooking a key variable or choosing ones that are meaningless in your particular research context when choosing the variables for stratification.

The advantages of stratified random sampling are:¹⁰

- all the important groups are proportionally represented. This is particularly important when key sub-groups in the population occur in low proportions; and
- the exact representativeness of the sample is known. This has important statistical ramifications.

The disadvantages are:¹¹

- a list of all members of the population, their characteristics and the proportions of the important groups within the population is required;
- cost; and
- the gain in accuracy is usually very small in comparison to simple random sampling.

⁷ This section taken and modified from S. Polgar, and S.A. Thomas 1995 *Introduction to Research in the Health Sciences*, (3rd Edition), Churchill Livingstone: Melbourne, p.45, emphasis added.

⁸ Polgar, S., Thomas, S.A. 1995, *Introduction to Research in the Health Sciences*, (3rd edition), Churchill Livingstone: Melbourne, pp.45–46.

⁹ A variable is a characteristic that has more than one category or value such as age, sex or level of satisfaction with a hospital.

¹⁰ Polgar, S., Thomas, S.A. 1995, *Introduction to Research in the Health Sciences*, (3rd edition), Churchill Livingstone: Melbourne, p.46.

¹¹ Polgar, S., Thomas, S.A. 1995, *Introduction to Research in the Health Sciences*, (3rd edition), Churchill Livingstone: Melbourne, p.46.

Systematic sampling is more convenient and more frequently used than simple random sampling. Like simple random sampling it requires a complete list of the research population. Systematic sampling involves selecting your sample from the population systematically. For example, you might select every tenth person from the population list if your sample size is 100 and your population is 1,000.

When using this method, it is important to be certain that the population list you are working from does not group the people systematically in a way that will reduce the representativeness of your sample. For example if you are choosing every fourth person from a list that alternately lists males and females, you will get a sample of only males or females.

Multistage cluster or area sampling is frequently used when it is too difficult to find or create a complete list of your research population. One of the most common methods of multistage cluster sampling is to use geographic areas. For example, there might be no single list of all the households in a city. But it is possible to select (using random, stratified random and/or systematic sampling methods) a number of blocks within the city, and then streets, and then houses or flats.

The trade-off for the relative ease and convenience of multistage cluster sampling is that if it is not very carefully done, the equal probability that each member of the population can be chosen is easily lost. Along with this, there is a potential of selecting an unrepresentative sample. For instance, in the above example, if the sample includes a relatively small number of blocks it is easy to under or over-represent different parts of the population, such as people from non-English speaking backgrounds, or older people, or wealthy people. In this example, this particular problem can be minimised by choosing a large number of initial clusters and ultimately a small number of people from each of these.

The flexibility that makes this technique so useful also gives rise to numerous pitfalls. Various pitfalls of probability sampling are discussed below.

Common problems in probability sampling

The reliability and validity of a probability sample are reduced when chances of each member of the population to be chosen for the sample are no longer equal. If differences in equality grow beyond insignificant levels, the result is a non-probability sample. The two most common threats to this equality are: not obtaining a complete list of the research population and non-responses.

Probability sampling requires a complete list of the whole research population from which the sample will be chosen. If this list is not complete, then everyone in the research population does not have an equal chance of being chosen. Existing lists such as electoral rolls are often used. Be careful when using existing lists; you must know how they are compiled so that you can judge how complete they are. You must also judge the validity of the list. Is the list you have a list of the population you want to research? For example, a list of all registered voters in Australia is not a list of all adults in Australia.

The other common problem is ‘non-responses’. If you send a questionnaire out to a sample of 150 people and only 100 of them respond, you no longer have a probability sample. Your sample has become the 100 people that did respond, and it is likely that there are significant differences between the people who responded and those who did not. Generally face-to-face interviews have much higher response rates than posted questionnaires, with telephone interviews somewhere in between. Apart from the research method, the problem of non-responses can be minimised by further research which identifies some of the differences between those who responded and those who did not, and analysis which takes these differences into account.

7.2 Analysis

Analysis is the process of turning the information you have collected into something meaningful. If the project has been carefully planned, the data analysis stage does not need to be difficult. The type and level of analysis that you should do is determined by:

- your research aims and objectives; and
- the information you have collected — it is important to know how the data will be analysed before embarking on the data collection so that you collect the right data in the first place.

This section aims to assist you in matching the appropriate analytical techniques to the information you have collected as well as to assist you in understanding others' research. There is a range of statistical methods available that are not discussed here. The Bibliography contains some suggested references for further reading in this area.

Elements of successful data analysis include:

- choosing the appropriate ways of analysing the information you have collected;
- being able to explain what was done with the data and why;
- striving for accuracy; and
- remaining aware of the fact that the information you have collected represents real people and their lives.

The processes you use for analysis will depend on the types of information that you have collected. Quantitative analysis is used for quantitative information, and statistics are used to summarise the information and explore what the data mean. Qualitative analysis is used for qualitative information (usually the words of the research participants), and a range of techniques is used to summarise information and explore its meanings. A single research project may include both quantitative and qualitative analysis.

If an experienced researcher is doing the analysis for your research, it is important that you still have a reasonable level of involvement so that you understand what is being done and why, and agree with it. By remaining involved, you can ensure that the results of the analysis will fulfil your aims, that you have confidence in the results, and that you will be able to explain and defend the analysis to other people.

Quantitative analysis

Quantitative analysis uses statistics as a basic tool. It has been said that, 'statistics resembles Tabasco sauce in its ability to produce a strong reaction in many people'.¹² Statistics can cause a certain amount of apprehension. However, since many statistical ideas and techniques have a vital role to play in research, the fundamental concepts of chance, probability, confidence intervals and hypothesis testing are discussed and de-mystified in this section.

Chance

The importance of chance is that it can create interesting results where none exists, but it can also act to conceal important effects which do exist.¹³ The main feature of inferential statistics is that they determine the likelihood that the results from the sample are real and not a product of chance.

¹² Crombie, I.K., Davies, H.T.O. 1996, *Research in Health Care: Design, Conduct and Interpretation of Health Services Research*, John Wiley & Sons: Chichester, p.243.

¹³ Crombie, I.K., Davies, H.T.O. 1996, *Research in Health Care: Design, Conduct and Interpretation of Health Services Research*, John Wiley & Sons: Chichester, p.244.

All of us are affected by chance in our everyday lives. Unusual, ‘out of the blue’ events do happen. Not many of us in a lifetime will win Gold Lotto — but people do win!

With probability sampling there is always a chance that you have chosen a very unusual group of people that are not representative of the research population. Tests of significance (see below) are statistical calculations used to determine how certain you can be that the results from your sample can be applied to others.

Carrying out a survey, in which a sample of patients is selected, can be compared to drawing a hand of cards at bridge. In the game you would expect to get a mixture of cards including one or two kings and aces. You would also expect that in the next game the hand you are dealt will broadly reflect the composition of the deck it came from, but its exact composition will be influenced by chance.¹⁴

When it is said that a particular result is ‘statistically significant’ (or more often, simply ‘significant’), it means that it is unlikely that the result was just caused by chance. If a result is statistically significant it can be generalised from the sample to the population. That is, it is quite likely to be true for other similar situations and people. However, do not be misled by the term ‘statistical significance’. It does not mean that the result is important; it is quite common to have significant results that are unimportant as will be discussed later in this chapter.

Probability

Probability describes the chance of something happening. For example, the chance of tossing a coin and turning up a heads is 1/2 or 0.5. The chance of drawing the queen of hearts from a deck of cards is 1/52 or 0.019, since there is only one queen of hearts in the deck of 52 cards. Probabilities tend to be written as decimals rather than fractions (ie 0.5 rather than 1/2), or as percentages (ie 50 per cent rather than 0.5).

Probabilities can vary between zero — which means that the event would never happen — and one — which means that the event would always happen. For example, if a questionnaire sampled only 50 men, every respondent would be a man; the chance of the respondent being a man is 50/50, with a probability of 1 or 100 per cent. In statistics, probabilities in the range of 0.01 (1/100) to 0.05 (5/100) are considered to be small; probabilities between 0.2 (20/100 or 1/5) and 0.5 (50/100 or 1/2) are considered to be quite large.¹⁵

Probabilities in research are referred to as the p-value. These are calculated with simple statistical programs. If the p-value is less than 0.05 ($p<0.05$), it is considered that the finding is not due to chance. This is what is called ‘statistically significant’. The smaller the p-value, the less likely it is that the finding was just a coincidence. When $p<0.05$ it means that the same result would happen 95 times out of 100. A very small p-value (ie 0.0001) means that there is only a remote chance that the event was a ‘fluke’.

Confidence intervals

At first glance, the influence of chance can make it difficult to interpret the findings of the research. For example, it could appear that a certain medical condition caused a dramatic increase in the rate that people with the condition died. That is, people with the condition died younger than would otherwise be expected. Without sampling the whole population of people with the condition it could be difficult to firmly state the findings. Sampling this whole population may be very difficult because, for example, there will be people who will not participate in the study, there will be people

¹⁴ Crombie, I.K., Davies, H.T.O. 1996, *Research in Health Care: Design, Conduct and Interpretation of Health Services Research*, John Wiley & Sons: Chichester, p.244.

¹⁵ Crombie, I.K., Davies, H.T.O. 1996, *Research in Health Care: Design, Conduct and Interpretation of Health Services Research*, John Wiley & Sons: Chichester, p.245.

who do not know they have the condition, or there may be no ‘list’ of all the people who have the condition.

Confidence intervals (CIs) provide a means of estimating the range within which the overall or actual value or rate might lie. The most commonly used range is the 95 per cent confidence interval: the 95 per cent confidence interval is the level at which $p=0.05$.

If a friend asks how long it takes to drive into town and you reply ‘half an hour, give or take 10 minutes’, you have given an estimate (30 minutes), with a confidence interval of 20–40 minutes. A confidence interval has a lower and upper limit — in this example, the lower limit is 20 minutes, and the upper limit is 40 minutes. This means that however many times someone repeated the journey, 95 per cent of the time the result would fall between the upper and lower limits of the confidence interval. That is, the journey might take 24 minutes, or it might take 38 minutes — but it would be between 20 and 40 minutes for 95 trips out of 100. In this example, the journey would be reported as being 30 minutes (95 per cent CI: 20–40).¹⁶

Tests of significance

As has been seen, statistical significance gives some reassurance — but no guarantee — that a research finding was not due to chance. The limitations of tests of significance relate to:

- spurious significance;
- importance not significance;
- insufficient size; or
- borderline significance.¹⁷

Having generally accepted that a p-value of 0.05 ($p=0.05$) minimises possibility of the result being achieved by chance, there is always the possibility that, at this level (that is, at a rate of 1 in 20) the result happened by chance. Smaller p-values, such as $p<0.01$ (that is, 1 in 100), or $p<0.001$ (that is, 1 in 1,000), provide reassurance that the results are not due to chance. But events do happen by chance at the rate of one in 1,000. Such unlikely but chance happenings are spuriously significant.

It has been noted that just because a finding is significant, it does not have to be important. If very large samples are used, small changes can become statistically significant. However, it is important to remember that it is the size of an effect which determines its importance, not the level of significance.¹⁸ On the other hand, sometimes a study fails to find a significant effect when one had been expected. The absence of statistical significance does not necessarily mean that there was no effect, but rather that the study failed to detect one.¹⁹

Hence, both large samples and small samples can result in findings of significance that do not reflect the importance of the findings. It is important to remember this in designing the research; an experienced researcher or statistician can assist consumer groups in deciding how big the sample should be to yield appropriately significant results.

¹⁶ Adapted from The Australian Cochrane Collaboration 1996, *Making Sense Out of Health Care Research: Workshop Pack*, The Cochrane Collaboration: Adelaide.

¹⁷ Crombie, I.K., Davies, H.T.O. 1996, *Research in Health Care: Design, Conduct and Interpretation of Health Services Research*, John Wiley & Sons: Chichester, p.256.

¹⁸ Crombie, I.K., Davies, H.T.O. 1996, *Research in Health Care: Design, Conduct and Interpretation of Health Services Research*, John Wiley & Sons: Chichester, p.257.

¹⁹ Crombie, I.K., Davies, H.T.O. 1996, *Research in Health Care: Design, Conduct and Interpretation of Health Services Research*, John Wiley & Sons: Chichester, p.257.

Sources of bias

In research, bias is a systematic error — something that is consistently ‘tipping the scales’ the wrong way. Apart from chance, various biases can also come into play that distort the findings and reduce certainty. Some of these are:

- selection bias;
- measurement bias;
- regression to the mean;
- association not causation;
- trends over time; and
- confounding.

Selection bias may arise in a research project when participants volunteer and/or select themselves as participants in the research. Participants who volunteer for a research project are often different to those who do not.

Measurement bias relates to errors in the actual data measured. This can arise, for example, in questionnaires being incorrectly filled in, or by interviewees responding to questions based on the way the interviewer asks the question. Although equipment to measure data ('objective data') may be faulty, measurement bias is more common in research where responses depend on memory or opinion ('subjective data'). Bias results when all, or most, of the errors are in the same direction.²⁰

Regression to the mean relates to the tendency of some variables to change over time. For example, in measuring blood pressure, the measurements will change depending on a person's level of stress or anxiety. Readings on two separate occasions can differ quite markedly, whereas 10 readings would average out more realistically. Regression to the mean should be investigated in any research that makes measurements before and after an intervention where the measurement is something that could change over time.

Because two events are related does not mean that one causes the other — that is, there can be association not causation. For many years lung cancer has been associated with smoking tobacco, but the tobacco companies claim that there is no evidence that tobacco smoking causes lung cancer. Medically, claims about causality can become quite complicated. In health research it is often difficult to claim that something causes something else; more often discussion and debate centres around association. Only in a formal experiment to test an hypothesis about cause can you be confident that the right cause has been identified — that is, by a randomised controlled trial. In order to claim causation and not just an association or a coincidence, and in the absence of a randomised controlled trial, a researcher needs a lot of data and studies to narrow down the research findings.

When more than one factor changes over time, the resultant trends may make data difficult to interpret. At any particular time it may become ‘fashionable’ for a certain treatment or test to reveal an apparently higher incidence of a particular disease or illness. For example, systematic screening for skin cancer will result in an apparently higher number of people with skin cancer, since many people with skin cancer would not have known it except for the screening.

Confounding may occur when two variables can be related to a third variable and this third variable is what brings about the association. Confounding can create effects where none exist or can

²⁰ Crombie, I.K., Davies, H.T.O. 1996, *Research in Health Care: Design, Conduct and Interpretation of Health Services Research*, John Wiley & Sons: Chichester, p.259.

conceal relationships. Sometimes confounding is easy to spot. [One researcher] gives the example of the finding that people who carry matches are at an increased risk of lung cancer. It is more likely that the effect was due to smoking tobacco rather than to lighting matches.²¹

Confounding can also be about missing some other factor that brings about an association. In completing your research analysis, some of the questions you need to ask are:

- How reliable and valid was each part of the research process, and how did this influence the results and affect the certainty of the analysis and conclusions?
- How did the sampling technique used influence the information collected, and affect the certainty of the analysis and conclusions? If appropriate, this should include considerations of the time, place and culture in which the research took place.
- Who was not included, and who/what was missed out that could have been important?
- Were the right questions asked the right way?
- What could have been done better? What would you do differently next time?
- Did the limits of time, energy, resources and experience adversely affect the research?

Hypothesis testing

Research often asks questions about similarities or differences between two or more groups. For example, research has investigated whether mothers who smoke cigarettes are more likely to give birth to low birthweight babies. This asks whether the babies born to mothers who smoke are lower in weight at birth than babies born to mothers who do not smoke. What is being measured is birthweight, with the difference between the groups being due to the mother smoking or not. While there is an inclination to prove that the two groups differ, statistical methods can only show that it is unlikely that the two groups are the same.

In this instance, the researcher's proposal or hypothesis is that babies born to mothers who smoke are lower in weight at birth than those of mothers who do not smoke. What the researcher would like to show is that it is the mother's smoking, and not chance, that makes babies' birthweights lower. In hypothesis testing, because statistical methods cannot prove the difference, the following process is undertaken.

First, the researcher proposes that the two groups do not differ other than by chance. In the example above this would suppose that mothers' smoking has no effect on the birthweight of babies — that any difference could only be caused by chance. This is called the null hypothesis (H_0). The researcher then calculates how likely it is that the results could have arisen simply because of chance — that the null hypothesis is true — with this likelihood being expressed as a probability. If the probability obtained is small, it can be said that the two groups differ for a reason other than chance. At this point the null hypothesis is rejected; the null hypothesis is not true. If the null hypothesis is rejected, the alternative hypothesis (that there is, in fact, a difference between the groups) is accepted.

As noted above, if the probability or p-value is less than 0.05 ($p < 0.05$), chance is largely ruled out as a possible explanation for the two groups being different. The smaller the p-value, the less likely it is that the difference is due to chance.

²¹ Crombie, I.K., Davies, H.T.O. 1996, *Research in Health Care: Design, Conduct and Interpretation of Health Services Research*, John Wiley & Sons: Chichester, p.261.

Undertaking quantitative analysis

Analysis of quantitative data requires the researcher to run the data through a statistical technique as well as applying interpretation to the numerical findings. The statistics show what is going on in the data and the researcher's interpretation makes sense of the statistical findings.

Many books, as outlined in the Bibliography, describe the various statistical techniques. In many instances, researchers are advised to enlist expert help from other more experienced researchers and/or statisticians in performing the statistical analysis of their data. If the numbers are small, however, careful analysis using a calculator to work out percentages and averages may be all that is required. In all circumstances, it is imperative that the data analysis phase is considered in the planning of the research so that the appropriate data is collected in a form that can be analysed.

Linking aims and objectives to data analysis

Data analysis begins with a review of your aims and objectives. From your aims and objectives, decide what tables or graphs you will need to answer your research questions. This will help you to analyse the different data in different ways to address the different objectives.

For example, if you want to find out about the extent of consumers' health research by consumer groups in Australia as well as the difficulties consumer groups face in undertaking research, you would need to have asked at least two specific questions — one about the extent of research and one about the difficulties consumers face in undertaking research. The extent of research could be found using a closed-ended question — ie have you done research? The difficulties of research could be found by a closed-ended question — ie have you faced difficulties? (Yes or No) — and/or an open-ended question — ie what difficulties have you faced?

In analysis, you would quantify (1) how many groups had done research (2) how many groups said they had faced difficulties and (3) the range of difficulties faced by consumers in doing research and (4) how many groups had faced each particular difficulty.

The response rate

All analyses should start by describing the number of respondents or participants in your research. For example, you can calculate the 'response rate' when you know how many questionnaires you have collected. The response rate in this instance is a calculation of how many questionnaires have been collected compared with how many were distributed. That is, if 9 out of 10 people returned a questionnaire, you have a 90 per cent response rate.

The response rate will help you to judge how certain you can be about whether you have collected questionnaires from people who are representative of the population you are researching. When probability or representative sampling techniques are used and the response rate is less than 70 per cent, most researchers would no longer feel confident that they have a random or representative sample.

Coding the data

The most time-consuming stage of data analysis is getting the data into a format that can be fed into the statistical package. There are now several easy to use statistical packages for IBM compatible and Macintosh computers that can be purchased or used, for example, at universities, colleges or schools. If you are keen to pursue analysing your own data it would be worth tapping into any local university, college or school resources in your area. The statistical package will often give guidance regarding the coding of the data which are subsequently entered into the statistical package.

Coding for quantitative analysis is the process of turning the information you have collected into material that can be counted so that it can be described and examined with statistics. For example, if you are analysing the results of a postal questionnaire, coding will involve two steps that must be undertaken for each question on your questionnaire. The first step is to decide how to categorise the

answers or responses to each question. The second step is to go through every questionnaire you have collected and put each response into the appropriate category, that is, to actually categorise the responses.

In the Consumers' Research Project Member Survey,²² the difficulties faced by consumers in doing research were coded under the categories:

- *lack of funds/money;*
- *lack of equipment/resources/personnel;*
- *lack of time;*
- *lack of research expertise; and*
- *difficulty complying with funding requirements/obligations and controversial outcomes.*

In developing your coding categories, it must be remembered that:

- every answer must fit into a category;
- each category must be separate with no overlap between categories; and
- categories must be an accurate representation of the answers.

The number of categories you have will depend on the type of information collected. It is usually advisable to begin with as many categories as seems necessary to maintain the detail of the information collected. If the number of categories becomes unwieldy or too numerous for analysis, they can often be combined later. It is much easier to combine several small categories later than it is to divide large ones that do not have enough detail.

For closed-ended questions, decisions about coding categories are made when the questionnaire is being developed. The coding categories are the range of possible answers you provide on the questionnaire.

The following examples of closed-ended questions which are already coded are extracted from the questionnaire for the *General Practice Care Following Miscarriage* project undertaken by SANDS and the UQ.

²² Consumers' Health Forum of Australia Inc. 1997 *Consumers' Research Project Member Survey*, Unpublished.

1. Please read the following statements and for each indicate whether you agree or disagree

	Strongly agree	Agree	Unsure	Disagree	Strongly disagree
The earlier a miscarriage, the less likely it is to lead to emotional problems	5	4	3	2	1
Most women benefit from talking about their feelings after a miscarriage	5	4	3	2	1
Many women experience a strong sense of loss following miscarriage	5	4	3	2	1

2. Are you aware of any resources that exist to support women following miscarriage?

	Aware of resources?		Have you used?		Would you use if available?	
Written information (eg leaflet)	Yes	No	Yes	No	Yes	No
Counsellor or social worker	Yes	No	Yes	No	Yes	No
Hospital staff	Yes	No	Yes	No	Yes	No
Other health care provider	Yes	No	Yes	No	Yes	No
Self-help group	Yes	No	Yes	No	Yes	No

4. Of the female patients you have seen in the last year, about how many

Have had a miscarriage at some time (to your knowledge)? None 1-2 3-4 5-6 More than 6

Presented to you following miscarriage? None 1-2 3-4 5-6 More than 6

Developing categories for coding answers to open-ended questions is often done after the questionnaires are collected, or with anticipation, while you are awaiting the return of the questionnaires. Coding open-ended questions is done by using the purpose of the question together with the similarities and differences between responses to identify the appropriate categories.

The following example of open-ended questions is extracted from the questionnaire for the *General Practice Care Following Miscarriage* project undertaken by SANDS and the UQ.

3. Is there a need for more information/resources to assist general practitioners to support women following miscarriage?

- Yes → If yes, please describe what you think would be most useful _____
 No _____

For open-ended questions you will often have to go through all the questionnaires several times constantly revising and changing categories to get it right. This is time consuming and can be frustrating, but do not hesitate to do this if it provides a more accurate and useful portrayal of the responses. This coding will be the foundation of your analysis, and without this accuracy your results will not be reliable or valid.

After the categories for each question have been developed you usually need to go through every questionnaire and write down the appropriate code for each answer. Usually the code will be a number, a letter or a word. These codes should be written on the questionnaires as close to the original answers as possible.

It is vital to check each other's work if more than one person is involved in coding the questionnaires. You need to make sure that everyone is coding the same answers the same way. One way of doing this is to have everyone code the same 10 or 20 questionnaires independently and then compare results. Ideally you want a very high level of agreement, and any problematic areas need to be sorted out.

Statistical techniques

In analysing the data, it is important to begin with the most simple of statistical techniques. Only if a technique cannot adequately analyse your data should you move to the more complex techniques. There is a greater risk of error and confusion in using complicated techniques.

Presentation of data

Although you might need to provide the numbers so that readers can do different statistical calculations themselves, in presenting your research findings it can be more useful to display your data graphically than in columns of numbers. Graphs help the researcher to see what is going on, as well as helping the observer to get a feel for the research. Many computer packages have the facility to generate graphs, and texts listed in the Bibliography can also give some direction here.

At times, the research findings are straightforward — but this is not always so. It is just as important to correctly interpret the research findings as it is to collect and statistically analyse them. Data analysis usually throws up lots of findings, some interesting, others less so. The key findings should derive directly from the research questions defined at the start of the project. Other findings need to be considered in terms of why they happened, why they happened in that way and what the true importance of the result is. These fortuitous findings should have less weight attached to them than the results of analyses planned at the start of the study.²³

Qualitative analysis

Like quantitative research, the goal of qualitative analysis is to accurately summarise and interpret the information you have collected with a view to answering your research questions. The focus of qualitative analysis is usually on words. Consumer groups have also used photographs to illustrate their point, and the success of their research. Qualitative information can be collected through most research techniques including literature reviews, questionnaires, interviews and focus groups. For simplicity, this section will consider qualitative analysis in the context of information collected through interviews and focus groups, but the techniques can also be applied to qualitative information collected from other sources.

Qualitative analysis requires that you first work to understand what the research participants mean by their words and how they interpret the world. You must find out about their perceptions, ideas, views and reasons. One of the difficulties is in setting aside your own interpretations so that you can see theirs. You must make a conscious effort throughout qualitative analysis to listen to what the research participants are saying. Your own views and ideas will shape how you interpret what they say, and you must be careful and self-critical so that this is kept to a minimum, otherwise your research will be biased and of little value. Audio or video tape-recording followed by transcription of interviews or focus groups can help you to interpret what was said more accurately.

Sometimes qualitative analysis stops at this first level, and the research results are essentially a descriptive summary of what people have said. Often, however, your research aims and objectives will require you to take your analysis further. This is done by using one or several techniques to move beyond what each individual has said to interpretation of what it means as a whole.

²³ Crombie, I.K., Davies, H.T.O. 1996, *Research in Health Care: Design, Conduct and Interpretation of Health Services Research*, John Wiley & Sons: Chichester, p.255.

The Older Women's Health Project's focus group meetings were taped and transcribed. The resultant document of the Project, Well-Being: For and By Older Women²⁴ contains generalised information and analysis from these focus group meetings, as well as quotes from participants at the focus groups. This document was developed by the Project Officer in consultation with the Health Committee of the Older Women's Network. The membership of the Network also provided input to the document before completion. These consultations enabled the focus group discussions to be reported on, discussion of the issues raised, and exploration of the potential and priorities of the Network membership.

Because of the emphasis on interpretation in qualitative analysis, the researcher's judgements are at the core of the process. There are two common problems that you need to be aware of in order to make a conscious effort to avoid or minimise them and to ensure that your judgements are fair and appropriate. First is the tendency to be too easily convinced or committed to your first impressions based on the early information you collect. This results in giving information collected early more importance and credibility than the later information you collect. This can lead to ignoring information or ideas that do not agree with your first impressions.

The second common problem involves information overload. There are limits to how much information with which you can actually work. You need to write things down and find meaningful ways of organising and summarising the information you have collected. Be wary of the tendency to spend most of your time and energy analysing the areas on which you have collected the most information. You may have a lot of information about something because it is easy to collect, rather than because it is important. Particularly in qualitative analysis, the number of times something is said may not be as important as the idea itself. In the interpretation of qualitative data, it is important to remember that what is not said is often as important as what is said.

There are specific computer programs that have been developed to assist people to analyse qualitative data. These are probably of most value to the more experienced researchers undertaking medium to large-scale qualitative research projects. Standard computer word processing will often suit the needs of the novice qualitative researcher. All qualitative analysis, however, requires sorting the information into themes - whether to enter data into a computer software package, or just to draw out the more important themes.

In qualitative research analysis usually takes place as the information is collected. For example, if your research involves 15 in-depth interviews you should probably do some preliminary analysis after every four or five interviews. Alternatively, if you are conducting three focus groups you may want to do some analysis after each one.

There are four reasons for this:

- your memory of what was said and how it was said are fresher, and this facilitates better analysis;
- later interviews can be used to test some of the preliminary ideas that arise from the analysis of early interviews;
- later interviews can benefit from improvements in your interview technique and any minor modifications to the interview schedule; and
- doing analysis throughout the research process can help prevent you from becoming overwhelmed with too much information at the end.

²⁴ Older Women's Network 1993, *Well-Being: For and By Older Women*, Older Women's Network Inc: Sydney.

In qualitative analysis you will need to constantly revisit and change your interpretation of the information as new ideas and information come to light. This can be a frustrating process, discarding or radically modifying work that may have taken days or weeks to do. But with every change you make to your interpretation of the information, you are getting closer to a useful outcome. Like all analysis it is a repetitive process, full of careful tedium and the occasional moments of excitement.

Undertaking qualitative analysis

To analyse your qualitative data you need to gather all the information you want to analyse. The information you have collected needs to be put into a format that will facilitate analysis. If you have audio or video recordings of the interviews or focus groups you will need to go through these and transcribe and/or make notes. If you are working with a lot of information it will be much easier if it is typed directly into a computer word processing program. However, this is time-consuming and is not always necessary, especially for small research projects. Make sure that your notes are as accurate as possible. Notes of qualitative information usually include a large number of precise or verbatim or word-for-word quotes, and detailed summaries of key points arising from discussions and observations.

Read through your research aims and objectives several times and keep a copy in front of you. This will help to keep you focused on what you are looking for in the information you have collected. Go carefully through all the information you have collected referring back to your aims and objectives.

The SANDS and UQ project, General Practice Care Following Miscarriage, analysed the qualitative data gathered in the first stage of the project by categorising the themes that came through from the focus groups and the interviews. De-identified anecdotes added to the presentation of the findings from this stage of the research. The themes, along with themes found in the literature, were used to develop the questions in the quantitative questionnaire that was sent to the general practitioners.

Part of the qualitative analysis process is to immerse yourself in the information you have collected. The intention is to become very familiar with it. This ‘immersion’ is vital if you are to see the world from the eyes of the research participants. It is also an essential part of helping you to see the broader themes and patterns in the information in relation to the research aims and objectives.

You will already have developed some ideas about what the information you have collected means during the interviews or focus groups. Now is the time to test, revise and add to these ideas. At all times you need to carefully and critically examine your interpretation in relation to the information you have collected.

One of the most difficult things about working with qualitative information is that there is so much of it and it contains so much detail. Summarising and sorting the information are essential to refine this information into something that is both meaningful and manageable. Summarising and sorting the information are two parts of the same process. In order to summarise the information you must have some idea about how you want it sorted, and in order to sort the information it must have been summarised. It is likely that you will need to summarise and sort the same information in different ways to capture all of the meanings. This process of summarising and sorting qualitative information is sometimes called coding because it is similar in some ways to the coding process used for quantitative analysis.

Always work from copies of the original notes from the interviews or focus groups. If you are working by hand you will need to make photocopies. If you are using a computer, you will need to

make copies of the original files which contain the complete notes, and work from these copies. Cut and paste key points and quotes together under relevant headings. Make sure that each item is labelled to that you can trace it back to its original interview or focus group.

Often a key point or quote will relate to more than one heading. You will need to include this point or quote under each relevant heading. Often, the initial headings are based on the questions or topics used in the interviews or focus groups, and the ideas that have surfaced after reading through your notes several times.

Headings can include:

- specific events, situations and locations;
- perspectives;
- relationships between people, between organisations, between activities or a combination of these; and
- processes such as people's lives over time, the changes in an organisation, or the development of a policy.

As your analysis is based on your interpretation of the information, it is likely that there are several equally valid ways of interpreting it. Consequently, it is important to experiment and try several different ways of sorting the information you have collected. You may find that three or four (or more) different sets of headings or topics are useful for sorting the information. Each of them may be useful and may serve a different purpose. Some information, however, may be relevant to more than one heading. This information should be included under each relevant heading.

It is vital not to ignore things that stand out as different or that do not fit easily under your headings. One way of dealing with pieces of information that seem important but do not easily fit somewhere is simply to create a 'miscellaneous' heading. These items are often the solution to creating a better framework of headings. They might also indicate important points that should be followed up in future research.

After you have organised the information collected under the appropriate headings you should summarise it further. Write short summaries of the information under each heading or group of headings. These can be basic descriptions and/or your interpretation of what it means. At this stage you may be able to fulfil some, or all, of your research aims and objectives. It is likely, however, that for at least some key issues you will want to take the analysis one step further.

For this further analysis it is important to be clear about which research aims and objectives you will fulfil. Often each of these requires a different way of looking at the information you have collected and a different analysis technique. The Bibliography lists some resources which explain techniques for further qualitative analysis.

Direct quotes from the research participants can add authority and authenticity to the points made in the analysis of qualitative data. Direct quotes and the strategic use of photographs can make a report or article come alive. One of the strengths of qualitative research is its ability to communicate to other people what the world looks like from the perspective of the research participants. Using direct quotes helps to capitalise on this strength.

Drawing conclusions

Analysis of the data you have collected, both qualitative and quantitative, will lead you towards your conclusions. Drawing conclusions involves pulling together the analysis to answer your research questions or to fulfil your aims and objectives.

Most research projects involve collecting information from a range of sources and using several different techniques for analysing it. For example, you may have collected most of your information through a literature review, a couple of focus groups and questionnaires. Each of these is usually analysed separately using either qualitative or quantitative techniques. To draw conclusions you need to bring all of this information together.

Bringing each element of your research together involves summarising your previous analyses and organising them so that the most important issues are clear and prominent. It can be particularly helpful and worthwhile to use your research aims and objectives as an outline for the discussion. A common practice is to go through each objective (or research question) and discuss what you have found out and what conclusions you can make.

At times, not all of your objectives or research questions can be answered. Sometimes, rather than clear conclusions, you are left, instead, with a better idea of the questions you should have asked, or a better understanding of just how complex and unclear the subject of your research is. In these cases, simply shedding some more light on the issue is an important step forward. The world is not a simple place: conflicting and uncertain findings are often the result of this complexity. If this is what you have found, your conclusions need to reflect this. It is not unusual for research to raise more questions than it answers.

An important part of stating your conclusions is being clear about how certain they are. To overstate your conclusions is to invite disaster, and to underestimate them reduces the value of the research. Both overstating and underestimating your conclusions is ultimately misleading.

Acknowledging the limitations of your research increases its credibility. If the limitations are not acknowledged, your research is very vulnerable to attack and criticism. As was discussed earlier, tests of significance and an identification of sources of bias in research can help the researcher in stating conclusions with confidence.

There are two keys to drawing conclusions properly:

- make certain that you have included all of the information you have collected in your analysis before you draw your conclusions. There is a temptation throughout the analysis process to avoid including things that do not easily fit into the conclusions most of the information seems to point to. These contradictory points must be presented in your research report, and depending on their seriousness they should influence and temper your conclusions. You cannot make conclusions that are not supported by the information you collected and your analysis. Particularly when writing up the research report it is essential that you show as clearly as possible how you reached your conclusions.
- understand the limitations of your research. Every research project has limitations. The strength of your research will relate to its reliability, validity, generalisability, significance and absence or minimisation of bias.
- Each step in the process of research is inter-related and this is especially clear when drawing conclusions from your analysis. The development of your research plan involved consideration of aims and objectives and of methods of data collection and analysis. These elements now come together in your conclusions, providing the basis for your research report (see Chapter 8).

8 Writing the research report and communicating the findings

Writing the research report and communicating the findings are important parts of undertaking research. As people write up their research they inevitably gain new insights and increase their understanding of the research data and the whole research process. In this way, writing the report takes the data analysis one step further. Report writing is where it all comes together in one place.

A report or article about the research also provides a record of what was done, why it was done, and what was found out. This is a record for yourself and anyone else interested in the research, without which there is often little to show for all the hard work that went into it and the new knowledge that came out of it. In addition, for ethical reasons a report should be written of the research. Given the resources that were used in doing the research — the use of participants' time, energy, feeling, memories, experiences or emotions, any money spent in undertaking the research, the arguments or justification given for undertaking the research in the first place, and the new knowledge gained from the research — it is an ethical imperative for anyone undertaking research to report and communicate their findings to the research participants, to members of the group, and to other identified audiences.

Summary — Writing the research report and communicating the findings

The research report

- Your research report should explain why you did the research, what you did or how you did it, what you found out and the meaning of your findings.
- The **title** (see page 94) of your report should give the reader a clear indication of what the research is about.
- An **abstract** (see page 94) is a short summary of the research, usually about 100–150 words in length. The abstract should summarise the findings and emphasise implications of the findings that you think are most important about the study.
- The body funding your research project may request that your report include an **executive summary** (see page 94) which outlines the aims, methods, results, discussion and conclusions of the research.
- The **introduction** to your report (see page 94) should explain what was researched and why.
- The **methods** section (see page 95) of the research report explains how the research was done. Discussion should cover the nature of the research, ethical issues, selection and characteristics of participants, development of research instruments, data collection and analysis.
- The **results** section (see page 96) presents summaries of the most important data collected. Data should be concisely presented and should support your conclusions.
- The **discussion** (see page 96) is based on analysis of your results which brings together all of the information you have collected and specifically addresses each of the research aims and objectives, or research questions.
- The **conclusions** (see page 97) summarise the research and emphasise the important points that it has raised.
- **Recommendations** (see page 97) may be included in non-academic reports. Recommendations should be supported by the research results and analysis and may provide a starting point for change or recommend further research.
- A **reference list** (see page 98) that includes all published materials cited in your report should be included. It is important to record references throughout the research process.

- Additional information that will be of interest to some readers but would reduce clarity if included in the body of the report can be included in an **appendix** (see page 100).
- **Presentation** of your report (see page 100) will have an effect on how readers respond to your report.

Communicating the findings

- It is extremely important to make sure that as many people as possible know about the results of your research. Communicating the research findings involves actively targeting your audience, participants and target groups with your findings.
- The structure and content of a **written report** (see page 101) to your own consumer or self-help group will not vary substantially from the research report described in Section 8.1. The report should present the issues raised by the research in a style suitable to its audience.
- Talking at **meetings** (see page 102) is an excellent way of communicating your findings and generating interest in your research.
- Separate **journal articles** (see page 103) can be developed from your research report to reach a specific readership.
- Communicating your findings through the **media** (see page 104), usually through a media release, is a means of reaching a very broad audience.

8.1 The research report

The content of any research report should be accurate and concise. The structure of the report should provide your audience with a logical framework. It is likely that your different audiences require differing styles of report writing, and the funding body is likely to have given some clear criteria and deadlines for the report to them, including an acquittal of the grant. A report for use by your self-help group is likely to be different from a report written for possible publication in an academic journal, and different to the report sent to the funding body. These reports will be different again to an oral report to your members or to professional groups such as doctors.

All research reports should answer four questions:

- Why did you do the research?
- What did you do or how did you do it?
- What did you find out?
- What do your findings mean?

In this way, the report structure follows the sequence of activities that you have undertaken to complete the research. This structure allows the audience to follow the research project from its background to see how the research questions are answered, and what conclusions are drawn.

Written articles for a journal or magazine have guidelines and a set format to follow, including size of font, headings to be used, and word count. However, the standard report structure, which can often be adapted to suit the particular requirements of a publication, is as follows:

- title — communicates the content of the report;
- abstract — short summary of the research and results (usually just a few paragraphs);
- executive summary — summary of the research (not standard in academic reports);
- introduction — what you researched and why, including background information;

- methods — how the research was done;
- results — what you found;
- discussion — what the results mean in relation to the research questions;
- conclusions — implications of the research;
- recommendations — actions that should be taken (not common in academic reports);
- references — list of materials cited in the report; and
- appendices — additional information that will be of interest to some readers, such as copies of questionnaires.

Title

The title of your report needs to give the reader a clear indication of what the research is about. More people will be interested in reading a report that has an engaging and catchy title. Using a quote from a research participant or a famous quote helps to ensure, at the outset, that the project is memorable. It is also common to use a title and a sub-title to help convey more information without the title becoming too long, for example, *Female General Practitioners: Are Their Practices Different?* Abbreviations should be avoided in titles.

Abstract

Abstracts are short summaries of the research, usually about 100–150 words in length. The abstract is an important part of the research report as, apart from the title, it is the only part read by most readers. If the article gets published in a journal, the abstract will be the only part of the article that is entered on the relevant databases.

The abstract should include a summary of the aims, methods, results, discussion and conclusions. The purpose is to give prospective readers enough information so that they can decide whether or not they should read the full report.

The abstract should summarise the findings and emphasise the implications of the findings that you think are most important. Given that abstracts are a summary of the report, they are usually written after the report is completed.

Executive summary

Executive summaries are not standard in academic reports and it is unlikely that an article or report will include both an executive summary and an abstract. However, the funding body or your organisation may request that an executive summary be included in your research report. Executive summaries are usually between one and five pages in length and, like abstracts, outline the aims, methods, results, discussion and conclusions of the research. Executive summaries, however, tend to focus on any recommendations arising from the research in order to promote change.

Introduction

The introduction to your report should clearly and concisely explain what was researched and why. It is important to introduce the important features of your project without including too much detail. An introduction should present discussion of:

- the aims and objectives of the research (*what* was researched). Although these were developed when the research was planned, they may have been slightly modified as the research progressed. You should state the final aims and objectives and note any significant additions or subtractions (with an explanation of why it was necessary to change them);

- the reasons for doing research (*why* the research was undertaken). In consumers' research, the importance of the research often comes from the personal experiences of group members. In this case, your introduction should explain briefly the origins of the project and why it is important to the group or yourself. However, it is still essential to explain as clearly and accurately as possible why the research was done, outlining explicitly any key values or assumptions held by the group. A large part of this should already have been addressed in your research proposal and planning (in the background or justification);
- your literature review to develop the background and context of the research. This is particularly important where your research has been done to address gaps in the previous research. Some research reports also use the literature review to explain or justify the use of a particular framework, set of values, or philosophical approach to the research. These can be stated explicitly rather than leaving it for the reader to speculate. For example, you may have based the research report on a belief that everyone should have access to an adequate range of good quality health-care services. If something is a critical feature of your approach, it is worth stating; and
- any important or unusual methodological issues arising from your approach or the research. Methodology is always important, but how much detail is needed in your research report is something on which you might seek some advice from an experienced researcher.

Methods

The methods section of the research report explains how the research was done. This has two purposes:

- it allows the research to be duplicated; and
- it provides the reader with sufficient information to decide whether they can trust the results and conclusions.

The second reason is the most important and should be used to help you to decide what to include in this section. Readers do not want to wade through all the details of how you did the research. Rather, they want a concise description that provides them with some essential information. This description should include:

- the nature of the research (ie whether it was exploratory, descriptive or explanatory);
- the way in which ethical issues have been dealt with (including informed consent, anonymity, confidentiality, whether there were any conflicts of interest, and ethics committee approval);
- how the research participants were chosen, your sampling method, how many people participated, the response rate;
- characteristics of your sample with whatever details are relevant to your study, such as age, gender and ethnicity;
- how the questionnaire, interview schedule, or other 'research instruments' were developed (including piloting);
- how the data were collected;
- when and where the data were collected; and
- how the data were analysed.

In addition to describing how the research was done, there should also be some explanation about why it was done this way. For example, you might explain why, as an exploratory project, it was

not necessary to use a random sample and interviewing key people was considered to be the best option.

Research does not always work out as expected, and any serious problems need to be discussed. For example, in a postal questionnaire the researchers may have been expecting, or depending on, a 50 per cent response rate. If they were only able to get 15 per cent, this must be acknowledged as a problem with some discussion of how this affected the research. For example, such a response rate may have led to a modification of the methods with the researchers going on to do a series of structured telephone interviews instead. An alternative option would be for the researchers to make do with the response rate but limit their conclusions appropriately, and making recommendations about how the research might have been conducted differently.

Results

The results section presents summaries of the most important data collected. Only the data that are most relevant to the conclusions should be presented. However, do not use this as an excuse for leaving out important results that do not fit easily into your arguments. The aim is to provide enough data so that the reader can have confidence in your discussion of the results and your conclusions. You need to leave a ‘trail’ so that the reader can see how you arrived at your conclusions. The reader should be led through the results to arrive at the point where they see that the conclusions are carefully considered statements based on the evidence, rather than bold assertions of personal opinion.

Good results sections do not overwhelm the reader with the minute intricacies of the data. Data should be presented as concisely as possible, but not so concisely that they become meaningless. A useful approach is to present the critical data in the results section, and to provide more detailed and supplemental data in an appendix.

Presentation of the results will depend on the data. Data often have most impact when they are presented visually. Charts, graphs, figures and tables can be very effective ways of summarising and presenting quantitative data, although the detail of the data is lost. Diagrams and flow-charts are often used to present qualitative data although, clearly, have little use if the research consists entirely of a review of the literature. Information presented graphically or visually should be self-explanatory, allowing the reader to draw their own conclusions from the data. Such information should be supported by discussion in the text of the purpose, explanation and interpretation of each visual tool.

In presenting qualitative results, many researchers use de-identified but verbatim quotes from the people interviewed. Since their words are your data, it is important that you use these to support your summaries of what was said. Care should be taken when summarising qualitative data as it is all too easy to misrepresent the overall direction of people’s comments by quoting only those who have said what you wanted to hear. A quote can be significant because it represents or sums up what the overwhelming majority of the people said, or because it shows a differing viewpoint from the majority, or because it is one of a wide range of views expressed. Quotes can be used to illustrate points of consensus, disagreement and ambiguity between the participants. Using a number of quotes, or extended quotes, can illustrate and substantiate key points in your discussion. Alternatively, if done confidentially, you could outline the comments of one person in depth as a ‘case study’ example within the findings.

Discussion

The discussion is used to explain what the results mean. It is not always a separate section, and is often included as part of a combined results and discussion section. The results represent your initial summarising and analysis of the data. The discussion is based on your further analysis which

brings together all of the information you have collected and specifically addresses each of the research aims and objectives, or research questions.

The discussion is your opportunity to clearly explain to the reader how you got from the results to the conclusions, including all the steps you used in coming to your conclusions. The reader must be able to reconstruct your analysis in order to see if they agree with it. Your audience needs to agree with your analysis in order to believe the conclusions. It may be that conclusions cannot be drawn from the results, or perhaps there are several conflicting conclusions that could be made. If this is the case, the discussion provides you with the opportunity to consider the alternatives.

In developing your discussion, it is vital to regularly remind yourself of the limitations of the study. If you have not already discussed the limitations of the research elsewhere in the report, it must be done here. If the limitations have been discussed, the discussion is a good place to remind the reader of what they are and how they have influenced your analysis. It is important not to overstate the strength of the results since critics can use this over-statement as evidence to discredit the research and report. It is also important to show which statements are supported by your research data and which are your opinions.

All the results that have been presented in the results section should be summarised and discussed. If they are not relevant to the discussion they should not be in the report at all. The discussion should provide an interpretation and explanation of what the results mean. In exploratory research the meaning of the results focuses on how it helps you to know more about the issues at the centre of the research, or perhaps simply to know what the issues are. In descriptive research, the relevance of the results is how they come together to provide a better picture of the subject being researched. In explanatory research the task of the discussion is to bring together the research results and theory in a way that provides a credible account of why the subject at the centre of the research is the way it is.

Conclusions

The conclusion provides the opportunity for you to summarise and emphasise what you believe are the important points raised by the research. Conclusions are usually most effective if they are short (a few paragraphs), and focus on no more than two or three issues.

Write your conclusions with the view that this is what you want people to remember most about the research. Hence, they should be short and thought provoking. Good conclusions indicate the implications that arise from the research. For example, what does this research mean for members of the self-help group? Does the research imply that some changes should be made to the health-care system?

Although the conclusions are often one of the last sections written in a research report and may require lengthy consideration and discussion, they can sometimes be written straight after the analysis has been completed. This allows time for revision and writing the rest of the report can be very focused; the conclusions can help you remember where you are heading.

Recommendations

Recommendations, like executive summaries, are more often found in non-academic reports. When the purpose of the research is to examine a situation with the intention of trying to change it, recommendations are an indispensable part of the report. Recommendations should only be made on issues that are developed and discussed in the research. The need for any changes that are recommended must be supported by the research results and analysis. A useful and ethical way to check the validity of, and support for, the recommendations, is to gain input from your consumer group and the research participants.

The main purpose of making recommendations is to provide a starting point for change. However, you can also make recommendations about future research, and not just practice or system change. Recommendations are often made on two different levels. The first level is concerned with underlying principles, guidelines and broad changes within which the more specific second level recommendations are framed. These second level recommendations are usually quite detailed and specific, and the most effective of these include the following features:

- they are achievable in the long or short term;
- they specify who should be responsible for implementing the recommendation;
- they specify a deadline or schedule for implementation;
- they are clear, direct and short;
- they include a process of monitoring their implementation;
- they are worded (if possible) to be attractive to those who must implement them;
- they are discussed (if possible) with all those who have a major stake in the issue before the report is published; and
- they are unambiguously supported by the research.

Like the rest of your research report, be selective with your recommendations. A few well-developed and targeted recommendations are often more effective than dozens of undeveloped ones. You do not want five or six really critical recommendations to get buried among 20 or 30 peripheral ones.

The Older Women's Network sought, and obtained, a grant of \$2,000 from the NSW Office on Ageing to print and distribute their research report, Well-Being: For and By Older Women. Although the funders of the Project itself did not approve the publication of the recommendations arising from the Project, the Older Women's Network incorporated their recommendations into a further proposal to the Women's Health Unit, NSW Department of Health, to establish Wellness Centres. This proposal was successful and a Wellness Centre has been operating for the past two years in Bankstown, Sydney.

References

Every time you have used somebody else's ideas or words in the report you must acknowledge the source. Referencing is how this is done. The purpose of referencing is to enable the reader to go and find the material that you have used, and to make it clear what work is your own, and what has been borrowed from someone else. If sources other than those cited in the text are included, the list is called a bibliography.

It is important to record references throughout the research process and, indeed, whenever you read something that is useful or whenever you take some notes from a book or other source, write down the complete reference and compile a list of references. It goes without saying that all the notes need to be clearly labelled so that you know which reference belongs to which notes. In addition, you will need to know which notes are direct quotes and which ones are summaries or paraphrases. If this is not done carefully, you will find yourself spending several days trying to track down a 'lost' reference.

There are numerous accepted systems for referencing. Whichever referencing system you use, be consistent in using the same system throughout the report. Two of the most commonly used referencing systems are the author-date (or Harvard) system and the note (or Vancouver) system.

- The author-date system acknowledges the author and date of publication in the text, with full details of the work in the alphabetical list of references at the end of the text. If it is a quotation the page number is also provided.
- The note system involves using a number after the ideas or quotes you have used. These can be small numbers placed slightly above the text, or numbers in parentheses. These numbers refer to the complete reference which is placed at the bottom of the page (footnote), or the end of the chapter or the end of the report (endnote) in the order in which they appear in the text.

In addition, a full list of references or bibliography are likely to appear at the end of the report. Both reference lists and bibliographies are set out alphabetically and then in chronological order.

Whichever referencing system you use, the basic information that should be provided in a complete reference list includes:

For books —

- author's surname and initials or given name;
- year of publication;
- title of the publication (in italics or underlined);
- titles of series, volume number, or edition, if applicable;
- editor, reviser, compiler or translator, if other than the author;
- publisher;
- place of publication; and
- page numbers(s), if applicable.

For journals and magazine/newspaper articles —

- author's surname and initials or given name;
- year of publication;
- title of article (in single quotes);
- title of the journal, magazine or newspaper (in italics or underlined);
- title of series, if applicable;
- volume number, if applicable;
- issue number or other identifier, if applicable;
- page number(s).

To reference properly you are advised to consult one of the many referencing guides available. One of the most commonly used guides in Australia is the AGPS *Style Manual*,¹ which is available in most libraries and can be purchased through most bookshops. However, as mentioned previously, if you are sending an article to a journal for their consideration, you will need to format your article

¹ AGPS 1994, *Style Manual for Authors, Editors and Printers*, 5th Edition, AGPS: Canberra, 148–80.

according to their set style. Whatever style you use for your references, it is important that you use it consistently.

Appendices

Appendices include important, but not critical, information, such as copies of questionnaires, details about how interviewers were trained, and lists of key people who were interviewed. The information included in the appendices may be of interest to some readers or support your arguments but is not included in the body of the report as it would detract from its clarity and conciseness. Some reports, particularly articles submitted for publication in academic journals, have no appendices. Other reports have so much in the appendices that these are published as separate volumes.

Presentation

In preparing your research report, it is important to note that the credibility of an otherwise excellent report may be undermined by poor presentation. Good use of vocabulary, punctuation, style, graphics and layout, and reports that look ‘professional’ have more credibility than those that do not. If it looks ‘sloppy’ it is hard to be confident that the rest of the work was done carefully.

The AGPS *Style Manual*² provides guidelines on standard style and usage in Australia.

8.2 Communicating the findings

It is extremely important to make sure that as many people as possible know about the results of your research. Communicating the research findings, however, is a demanding and time-consuming task, which involves actively targeting your audience, participants and target groups.

Communicating the findings is also referred to as disseminating the findings.

The most important issue in any dissemination strategy is re-visiting the audiences (see page 18) you want to inform or persuade. Communicating your findings entails putting your research results and conclusions into a format that is most appropriate for your audience and for others who should know about your research. You should consider how your research can be made accessible to people with specific needs (eg people who are print-handicapped) or those from culturally diverse backgrounds. More visual forms of presentation, such as a video or photographs, can increase accessibility. Too often research is inaccessible to people who might find it of great interest and relevance.

² AGPS 1994, *Style Manual for Authors, Editors and Printers*, 5th Edition, AGPS: Canberra, Part One.

The General Practice Care After Miscarriage project will be disseminated to:

- *general practitioners — general practitioners who participated in the research by filling out the questionnaire were invited to indicate if they wanted to see the research findings. A summary of the research findings will be disseminated to those general practitioners who requested this, as well as to Divisions of General Practice for possible publication in their newsletters. A full report of the research findings will also be disseminated to the two Divisions of General Practice that provided the sample of general practitioners. A copy of the full report will also be sent to the Royal Australian College of General Practitioners;*
- *SANDS — All members of SANDS will be made aware of the research findings through the SANDS newsletter and the annual general meeting. Information about the research will also be available on the Internet using electronic information systems established and maintained by the Centre for Primary Health Care at the Department of Social and Preventive Medicine; and*
- *relevant journals.*

Written reports

A written report for your own self-help group or other consumers may need to be different from the standard academic report outlined above. However, the overall structure and issues that need to be covered will not vary substantially. The differences are mainly in the emphasis given to particular issues in the report's contents, and presentation. In this report your audience is likely to share a common set of experiences and perspectives with you. This can contrast sharply with the need for you to write for unfamiliar academic or professional audiences. Although your language and presentation can be less technical and theoretical, you need to ensure accuracy of reporting in the hope (and expectation) that publications within the group will be accessed, used, and quoted by others. The overall aim in communicating the findings of the research to your group is to make the sometimes complex issues clear and understandable.

If the research report is of interest and value beyond the immediate membership of the group, you should try to distribute it as widely as possible. With increasing access to computers for word processing, laser printers for high quality presentation, and photocopiers for mass production, many self-help groups find that they can publish their own reports. This can be a quick and effective way of letting other people know what you have done.

The report should include the names of the authors, the date and some information about the self-help group (including a contact address and telephone number). It is also important to include acknowledgments of any help that was provided in doing the research and writing the report, including any funding source.

Costs depend on the size and number of copies, as well as such things as the binding and the covers. There are also costs associated with distribution such as envelopes, postage and time. Depending on your source of funding, you may need to seek specific funding for the printing and dissemination of your research findings. Sometimes there will be at least a small potential market for your report. In these instances you should price your report and advertise it, as long as you have checked the conditions of 'ownership' of the report. In some cases, any monies gained as a result of selling the report or publications arising from the research will be payable to the funding body or the conditions of your research grant may preclude your selling the report.

The Older Women's Network widely disseminated their research report, Well-Being: For and By Older Women.

Although not necessarily a result of the Older Women's Health Project's findings, the Older Women's Network feels that there has been some change in health policy and programs for older women. Members of the Older Women's Network often feel that their words are being used at the level of policy formulation, but they are more sceptical about how the concerns of older women have translated into policy implementation.

The Older Women's Network has seen a change in their role in the research arena. Members of the Older Women's Network are often asked to input into other researchers' research. However, older women's proven ability to identify issues for research has not been acknowledged to the same extent; often researchers ask members of the Older Women's Network to be involved in their research as participants, or to access participants, rather than identifying and developing issues for research, which would be the Network's preferred role.

Members of the Older Women's Network have been asked to participate as experts in the area of older women's health at various conferences and other forums.

Members of the Older Women's Network became empowered through the process of conducting, and disseminating the findings of, their Older Women's Health Project.

You should send copies of the report to the National Library of Australia,³ and to your State/Territory library. You are required to do this by law with anything you have published and to which the public has access. To do this you will need to contact your local State/Territory library. If you publish your report, you should get an International Standard Book Number (ISBN). This is also very easy and can be done by contacting the National Library of Australia.

Copyright is automatic in Australia. You do not have to apply for it. If you have deposited a copy of your report in your State/Territory library or in the National Library of Australia, this deposit can act as proof of the date of your copyright. If you want people to be able to copy and circulate your work widely (and you are not concerned about how many copies you sell), you can include a 'disclaimer of copyright' near the front of your publication. Disclaimers often say something like 'Copies can be made of all or part of this report. If you do so, please acknowledge the source'.

Talking at meetings

Talking to groups of people about the research is an excellent way of letting people know what you have found out, and of generating some interest in it. This can be a particularly effective method of reaching very specific audiences.

Conferences, meetings and seminars are constantly being held by different professional groups, such as general practitioners and nurses. Occasionally you may be invited to speak. More often, it is necessary to find out about the event while it is still being organised and approach the organisers with a proposal to present the findings of your research. For conferences, there is usually a 'call for papers' three months or even a year before the event. This requires the submission of an abstract or summary of what you will present. There are also opportunities for guest speakers and lecturers in universities and high schools. Convening your own seminars, meetings and workshops can also be very effective.

Approach your talk in a way that emphasises your strengths, for example, your strength as a member of a self-help group that has done their own research project. You have a personal stake in

³ Legal Deposit Unit, National Library of Australia, Canberra, ACT 2600; Tel: (02) 6262 1312.

the research and the research itself is an important personal experience. You can bring a personal perspective to your work that few professional researchers can. This, when combined with a well-done research project, can give you enormous credibility when talking to people.

An oral presentation must be immediately comprehensible. A lecture must also entertain and be of relevance to the audience. Speaking about your research requires an even tighter focus than writing about it. No matter how much time you have, it is often best to focus on a few key points, and to structure everything else that you say around these. The key is to tell the audience what you are going to talk about, talk about it, and then summarise what you have just said.

More general hints in presenting your research findings orally are:

- prepare well — know who your audience is, and angle your talk appropriately;
- provide an overview;
- introduce the subject;
- avoid using a lot of numbers — numbers work better on paper than in oral presentations;
- anecdotes or stories that highlight the significance of what you have done bring your work into the realms of reality;
- use visual aids such as overheads and slides, but make sure they are simple and easily read from the back of the room;
- maintain eye contact with your audience;
- change pace — use visual aids, cartoons, jokes, and pauses;
- have a take home message;
- be enthusiastic; and
- know, and keep to, your time limit.

Nearly everyone gets nervous before talking to a group of people. However, there are three things that can improve your confidence and keep this nervousness manageable:

- prepare carefully and thoroughly;
- rehearse your presentation with colleagues, family and friends, or other members of the group; and
- take opportunities to gain experience in public speaking.

Many people find that they are more relaxed if they write down exactly what they are going to say. However, your presentation may be boring if you are just reading to the audience. It is worth practising and learning your presentation so that you only need refer to your written copy for prompts.

You might want to consider handing something out either before or after your talk. Often people are interested in having copies of your written report, or copies of any overheads you have used. Unless you want people to be looking at your handout while you are talking, it is usually better to give them out after your talk. Use written materials to support and extend your talk, and to provide details which are appropriate on paper but which clutter up oral presentations.

Journal articles

Although the research report may be submitted in full to a journal, there are times when individual papers for separate journals can be developed from the one research report.

The first step when considering the development of papers for journals is to read those journals that might be appropriate, to find out about the general layout, content and style of the articles. Journals differ in their requirements for the structure of the paper. Most journals give guidelines as to the preferred style for articles.

There are many more papers submitted to journals for publication than could possibly be accepted so it is wise to expect rejections. Articles are selected by journals on the basis of whether they are topical, relevant to the journal's subscribers and readership, and presented according to the specified criteria. A rejection from a journal therefore does not mean that your article is not interesting.

At times you will receive comments on your submitted article from a reviewer. These may indicate that the presentation could be improved, or that aspects of the paper need better clarification. Although you have the option of appealing any decision to reject your paper for publication, an alternative option would be to consider re-writing or modifying the paper along the lines suggested by the reviewer, or looking for an alternative journal for the publication of your paper.

Once you have come this far and have done so much work, it is important (and ethically imperative) to persevere and find somewhere to publish it. Journal articles will get your research findings to a much wider audience than your report and will be the only way most people can find out about it in the future. To make this effort more worthwhile, make sure the journals to which you submit your findings have their articles indexed in one of the major databases, as discussed in Chapter 6, so that others doing literature reviews can find your article in the future.

The media

Journalists, editors and producers spend their lives making decisions about whether or not something is newsworthy. Your job in using the media to communicate your research findings is to make the decision about newsworthiness easy for them.

Newsworthiness is about:

- timeliness — has the research or its findings already been reported? Is there current interest in this issue or is it a tired issue?;
- relevance to the audience;
- perceived importance — does it involve someone or something that 'everyone' is interested in?; and
- credibility of the source of the story.

Your role in gaining media coverage for the findings of your research is to frame the information you want disseminated in a form that meets as many of these basic requirements as possible. You have to turn the most important research conclusions into a story that will interest people. If you can also structure your story so that it has some of the following characteristics your chances of success will be increased:

- human interest — reach people's emotions or get them to identify with the story;
- unusual, off the beaten track, or a new way of looking at an old issue;
- conflict — particularly in the style of 'David vs Goliath'.

There is a great deal of competition for getting information into the news. Whether or not you are successful will depend not only on how newsworthy your story is, but also on what other news stories are current at the time that you seek coverage. Each medium — newspaper, radio, television, and magazine — strives to find the best stories they can. It will be harder for you to get your story

into the media if there are more important stories on that day. Your chances are much better on a slow news day, such as Saturdays, Sundays and Mondays and the days around public holidays, such as Christmas. The disadvantage of getting your story in the media on slow days is that these days often have smaller audiences.

Media releases

Writing and distributing a media release is the most common way of letting the news media know that you think you have a story for them. The media release needs to demonstrate that your story is newsworthy.

Media releases should:

- be concise (preferably of one page, and no more than two, the media release should be typed, double-spaced with wide margins, and single-sided);
- be printed on your group's letterhead (if your group has no letterhead, provide the name of the group and address at the top of the page);
- be clearly identified as a media release (type MEDIA RELEASE below the letterhead);
- show the date of release (it is advisable to indicate whether the press release is for immediate use or embargoed until a specified date);
- be clearly presented with an interesting and accurate title or headline;
- be snappy and present the story in the first paragraph (say the most important things first, using short, sharp and clear sentences, and short paragraphs and aim to present a single clear message rather than trying to make too many points or explaining a complex issue);
- include quotes from the research report, research participants (remember not to use their names unless you check with them first) or members of the self-help group (quotes add interest to a story and can be used in a media release);
- provide enough information so that someone who knows nothing about you or the issue can understand what you want to say; and
- give the names and contact details of one or two people who could be interviewed further about your press release (somebody should be available any time of the day or night to respond to queries arising from the media release).

At times the contents of the media release will be all the coverage you get. At other times, especially if it is seen as an important story, the media release will result in a series of interviews for newspapers, magazines, television and radio. If the research is not exactly within your domain of experience as a consumer, you need to be prepared for people to ask for someone whose experience is encapsulated or affected by the research. If you can arrange for someone to be available, make sure your media release says this. That is, give more than the name as this will often be the single biggest key to getting coverage. For example, 'Mr 'X' who has diabetes... will be available for interview...'.

The media prefer people who can provide short, sharp and interesting points. The quotable quote or 'grab' is what they are after. Their primary concern is getting and keeping their audience, not your research. Do not give a journalist a copy of your report and expect them to make something out of it. If they do read it and use it, they will summarise it and probably not in the way you would have liked. It is better if you summarise it for them, and that is what the media release and interviews are for. Most journalists are not specialists, and they usually work to very tight deadlines. So the easier you make it for them to cover your story, the better are your chances of success.

If you hear nothing back, make a few follow-up telephone calls to see if you can generate interest. Sometimes, a journalist will become interested in something in your conversation — more so than your media release.

Radio and television

Working with radio and television requires more skills than newspapers. In particular, you have to be able to handle live interviews where someone else is in control of the questions and direction of the interview. Approaches that may help include:

- making sure that you and the journalist agree on the topics to be covered before the interview. The producer or researcher may request background information and even questions for them to ask you during the interview;
- avoiding one-word answers. This is your chance to make your points so make them;
- gently bringing the conversation back to the topic you want to discuss if the questions start taking you away from the points you want to make;
- knowing what you want to achieve in the interview; and
- finding out how much time you will have, whether there will be other speakers on the topic and whether the interview is to be taped or live to air.

Newspapers

Reading the letters section of the newspaper is a good way of finding out the sort of letters get printed. This is also where you will find the guidelines for writing letters for different newspapers. One way of using your research as a basis for a letter to the editor is to link the research to an issue currently being covered in the print media. The same rules apply here as they do with other avenues to media coverage: keep it short and sharp; cover only one or two key points; and make it interesting.

The different media

Each of the news media relies on different technologies, has different capabilities and reaches different audiences. An understanding of these differences is useful when developing strategies and delivering stories. Outlined below are some of the differences between newspapers, magazines, radio and television.

Newspapers and magazines can cover stories in more detail and depth than radio and television. There can be great value in publishing your findings in local newspapers which often have a large readership. The audience can take their time reading and thinking about the story. Each newspaper and magazine has a different audience. Try to get into the ones that will reach your audiences. People working for a particular publication will tell you who they think their audience is. If they can take a photograph to go with the story, its chances of coverage increase.

Radio is often the easiest coverage to get. The opportunities include a quick mention on the news, longer interviews and talk-back shows. Radio news tends to work to very short deadlines. Radio news coverage is usually limited to headlines with few sentences on each story. Interviews give you more time to make and discuss your points, but still require you to be very focussed on a few key points. Radio interviews may be between three and eight minutes which is a short time in which to express your points. Ring up talk-back shows, or suggest yourself as a guest on one. Think about which radio stations and what times are best for reaching your audience.

To get television coverage, your story will be helped by good pictures and a spokesperson who comes across well on this medium. Make sure you look beyond the television news and consider approaching current affairs, lifestyle and even entertainment shows. On the news you are unlikely

to get more than 15 seconds, so make sure you are well prepared (but not so well that it looks rehearsed).

You might also like to consider other products which could be useful to consumers, such as a pamphlet so that the consumer can see what the experience means for other people in their situation.

Abbreviations

AGPS	Australian Government Publishing Service
CI	Confidence Interval
GPEP	General Practice Evaluation Program
MeSH	Medical Subject Headings
NHMRC	National Health and Medical Research Council
SANDS	Stillbirth and Neonatal Death Support (Qld) Inc
UQ	University of Queensland

Glossary

This glossary provides definitions for terms used in this Manual and for terms used in the health-research literature. Terms have been taken from:

The Australasian Cochrane Centre 1996, *A Research Glossary for Consumers*. The Australasian Cochrane Centre: Adelaide.

Minichiello, V., Aroni, R., Timewell, E., Alexander, L. 1995, *In-Depth Interviewing*, 2nd Edition, Longman: Melbourne.

Polgar, S., Thomas, S.A. 1995, *Introduction to Research in the Health Sciences*, 3rd Edition, Churchill Livingstone: Melbourne.

Abstract	A brief summary of the research and its results. An abstract should describe what the research tried to show (aims and objectives), how the researchers went about it (methods), and what they found (results).
Action research	Action research is research joined with action in order to plan, implement and monitor change. Researchers choose to become participants in planned initiatives and use their knowledge and research expertise to aid their researcher participants or co-researchers to self research.
Anonymity	Anonymity refers to the research participant being anonymous or not individually identifiable.
Association	A known link, or statistical dependence, between two or more conditions or variables. For example, research shows that there is an association between smoking and lung cancer. A ‘positive’ association is one where the incidence of one condition increases the other condition or variable (that is, more smoking is associated with more lung cancer). There is a ‘negative’ association when an increase in one condition is apparently associated with a decrease in another condition or variable.
Bias	Bias is something that introduces a difference or trend that distorts, or could distort, the results of a study. Bias introduces systematic error into a study because what is being observed may not be the effect of research, but rather the effect of bias.
Case study	A case study is report of a single example, for instance, an anecdote about one ‘interesting’, ‘unusual’, or ‘typical’ person or situation.
Case-control study	A case-control study compares people with a disease or condition (‘cases’) to another group of people from the same population who do not have that disease or condition (‘controls’). A case-control study can identify risks and trends, and suggest some possible causes for disease, or for particular outcomes.
Causal explanation	Causal explanations explain results in terms of what causes them.
CD-ROM	CD-ROM stands for ‘Compact Disc Read Only Material’ – a compact disk storing large amounts of data and databases that can be retrieved on a computer.

Closed-ended questions	Closed-ended questions are questions in which the research participant is asked to respond by choosing between several predetermined answers.
Confidence interval (CI)	There will always be a level of uncertainty around predicting the results or outcomes for anyone who was not a participant in the research. A confidence interval (CI) is a way of quantifying the range of uncertainty around a result. The CI stretches between the lowest possible result that others could face, and the highest. The mean (average) result lies somewhere in between the two limits.
Confidentiality	Confidentiality refers to protecting the names of research participants, keeping confidences and protecting information about the participants.
Confounder or confounding variable	A confounder or confounding variable is a factor or effect that confuses the research. A confounder distorts the ability to attribute the cause of research findings to the intervention because something else could be influencing the result. For example, if people are receiving a number of different medications, it would not be possible to measure the effects of introducing a new medication.
Continuous/ dichotomous	Continuous and dichotomous are different categories of measuring results. A dichotomous result is a clear ‘either/or’ — for example, yes or no. A continuous result is one where there is, essentially, an infinite range of results — for example, weight expressed in kilograms.
Controls	In a research experiment, or a ‘trial’, people who are the ‘controls’ represent the norm against which the effectiveness of a treatment or intervention is tested. These could receive no intervention, a placebo intervention, or the standard or conventional intervention.
Convenience sample	A population being studied because they are conveniently accessible in some way is called a convenience sample. A convenience sample might be all the people at a certain hospital or attending a particular support group. As such, they could differ in important ways from the people who have not been brought together in this way and so are not a representative sample.
Critical appraisal	Critical appraisal is the process of assessing and interpreting evidence by systematically considering the results, the validity of the findings, and the relevance of the research.
Cross-sectional study	Cross-sectional studies are also called prevalence studies. They are like taking a snapshot of a group of people at a certain point in time and assessing the prevalence of diseases or other items in that population at that time.
Data	Data are the information collected by a researcher.
Data analysis	Data analysis is the process of systematically arranging and presenting the data in order to search for ideas and to find meanings in the information collected.
Descriptive study	A descriptive study is a study that describes the situation researched.
Effectiveness	Effectiveness refers to the extent to which the intervention does people more good than harm. An effective intervention or treatment is effective in real life circumstances, not just in the ideal situation.
Efficacy	Efficacy refers to the extent to which an intervention improves the outcome for people under ideal circumstances.

E-mail	E-mail refers to electronic mail and is a way of sending messages from one computer to another.
EMBASE	EMBASE refers to the Excerpta Medica database, a major European database of medical and health research.
Empirical	Empirical measures are based on observation and not on reasoning or belief alone.
Epidemiology	Epidemiology is the study of the health of populations and communities, not just particular individuals.
Ethics	Ethics is the study of standards of conduct and moral judgements. Ethics also refers to the system or code of morals applied to the research process.
Evaluation research	Research that aims to assess the value or worth of something.
Experiment	An experiment is a research design involving the allocation of research participants to groups and the application of different interventions to these groups. The aim of the experiment is to be able to validly conclude that differences in outcomes are caused by different interventions. Research experiments in a laboratory, or ‘in the field’ also involve research ‘participants’, ‘controls’ and ‘interventions’, but in the context of consumers’ research and research involving humans, the participants are people, and the intervention may be applied in more regular settings.
Explanatory research	Research that aims to explain a situation.
Exploratory research	Research that aims to explore a situation.
External/internal validity	Internal validity is the extent to which a study properly measures what it is meant to. External validity is the extent to which the results of a study can apply to people other than the ones that were in the study, how generalisable they are, and how applicable they are to the real world.
False positive/negative	False positives and negatives relate to two types of mistakes that can occur in research. A false positive says that something is true or real when it is not. For example, a false positive can suggest that a treatment or intervention is effective when, in fact, the treatment is not effective. A false negative is when the results of the study suggest that a significant result does not exist when, in fact, it does.
Feminist research	Research that aims to take account of women’s issues and concerns, emphasising that women’s experiences differ from those of men.
Focused or semi-structured interviews	Focused or semi-structured interviews use an interview guide which lists topics to be discussed with no fixed ordering or wording of the questions. The content of the interview is focused on the research question.
Generalisability	Generalisability refers to whether or not the results of the research are applicable or relevant to another group of people or to another population.
Hypothesis	A hypothesis is a theory or suggestion that is being tested with a piece of research. Studies are often framed to test the ‘null hypothesis’ that states that the intervention in question has no effect in order to show that, in fact, the intervention does have an effect.

In-depth interviews	In-depth interviews are face-to-face encounters between the researcher and the research participants directed toward understanding participants' perspectives on their lives, experiences or situations as expressed in their own words.
Incidence	The incidence is the number of occurrences of something in a population over a period of time, for example, the number of cases of a disease in a country over a year.
Informed consent	Informed consent is consent being given by a research participant for research to be carried out with full knowledge of what it is that they are consenting to.
Interobserver reliability	Interobserver reliability is the extent to which observers rating a particular phenomenon make the same judgement, or rate things in the same way.
Intervention	An intervention is anything that is meant to change the course of events for someone. An intervention could include surgery, a drug, a test, a treatment, or giving someone information.
Key words	Key words are a string of words attached to an article to be used to index or code the article in a database. In order to locate articles on a particular subject, key words are used to search the database for entries indexed according to the words.
Likert scale	A Likert scale is a five-point response scale used in questionnaires, eg strongly agree, agree, undecided, disagree, strongly disagree.
Literature review	A literature review is a report in which the previous research that has been done in the area is reviewed and related to the present topic being studied.
Matching	In a case-control study, if the controls are chosen because of particular similarities to the people who are in the intervention group, the cases and controls are said to be 'matched'. Researchers match people according to particular variables that are thought to be important and might involve, for example, choosing people in the same age group and gender.
Mean	The mean is the average score.
Median	The median is the number exactly in the middle of the range of outcomes that resulted from the research.
Medline	Medline is published by the National Library of Medicine in the USA and is an electronic database listing thousands of pieces of biomedical research published in a selected list of journals. It includes abstracts of the studies. Medline is available through medical libraries and can be accessed by CD-ROM and through the INTERNET. EMBASE is the European equivalent of Medline.
Meta-analysis	A meta-analysis is a statistical technique which summarises the results of several studies into a single estimate of their combined result. It is a key element of many systematic reviews or overviews. Meta-analysis produces a graph depicting the confidence intervals of all the studies. Also referred to as 'pooling data'.
Mode	The mode is the most frequently occurring score in a group of scores.
Morbidity	Morbidity relates to illness or harm.

Mortality	Mortality relates to death.
Multivariate analysis	Multivariate analysis relates to measuring the impact of more than one variable. For example, a researcher could look at the impact of age, gender and occupation all at once on a particular outcome.
Null hypothesis	The null hypothesis involves assuming that there is no difference between groups or no relationship between variables, for example, “Giving people 50 mL of drug ‘x’ has no impact on their blood pressure”. The researcher normally poses the null hypothesis and then tests it statistically. If it is rejected, the alternative hypothesis (that there is a difference between two groups or a relationship between variables) is accepted. The null hypothesis is represented by the symbol H ₀ .
Objective measures	Objective measures are derived from a mechanical measuring process involving a minimum amount of human interpretation.
Observational study	An observational study is a survey or non-experimental study. In an observational study the researchers examine and report on what is happening through their eyes without deliberately intervening in the course of events.
Odds	Odds relate to the probability of something happening.
Odds ratio (OR)	An odds ratio is a common way of estimating the effect of an intervention or treatment. An OR of more than one (>1) means the treatment or intervention is estimated to increase the odds of something. An OR of less than one (<1) means the treatment or intervention is estimated to decrease the odds of something. If the OR is exactly one, the treatment or intervention appears to have no effect on the outcome.
Online	A database or other source of information may be available ‘online’. This refers to the availability of the information using a computer with a modem, or information that is available on the Internet or the World Wide Web.
Open-ended questions	Open-ended questions are questions to which there are no sets of predetermined answers; the research participant can give any answer he or she wishes.
P-value	The p-value (probability value) determines whether or not the results of the study have happened by chance. If the p-value is less than 0.05 (<0.05), the result is not likely to be due to chance. A result with a p value of less than 0.05 is statistically significant.
Participant observation	Participant observation is a method of research in which the researcher takes part in the activities of a group or community being studied while also acting as observer.
Peer review	Peer review refers to a refereeing process that is used to check the quality and importance of reports of research. An article submitted for publication in a peer-reviewed journal is reviewed by other experts in the area. It aims to provide a wider check on the quality and interpretation of the report.
Pilot study	A pilot study is a preliminary study where the procedures and protocols are tested or ‘piloted’.

Placebo	A placebo is a fake (sham, dummy or inert) treatment or intervention given to people in the control group so that the participants in the research do not know whether or not they are in the experimental or the control group. Placebos are meant to be both useless and harmless with no effect. However, there is also such a thing as a ‘placebo effect’ which is where, if someone believes that they are getting the real or active treatment or intervention, they can experience effects (positive or negative), even if there is nothing in the actual treatment or intervention that could be the cause.
Population	In research, the term population is applied to the group of people being studied which may or may not be the population of a particular geographical area.
Pre-test/post-test design	Pre-test/post-test design relates to an experimental study in which measurements of groups are taken both before and following an intervention. This allows the direct comparison of pre-intervention and post-intervention results for individual subjects and groups of subjects.
Prevalence	Prevalence relates to the proportion of a population having a particular condition or characteristic.
Probability	Probability is the chance or risk of something happening.
Prospective/retrospective	In a prospective study, the study is designed ahead of time, and people are then recruited and studied according to the study’s criteria. In a retrospective study, the outcomes of the research are examined in hindsight using existing records. Retrospective studies are generally more limited in the data available for analysis as the data have rarely been collected with the needs of that particular study in mind. This limitation means that a retrospective study is usually less reliable than a prospective study.
Qualitative methods	Qualitative methods are methods that emphasise the non-numerical and interpretive analysis of social phenomena.
Quantitative methods	Quantitative methods are methods that emphasise the collection of numerical data and the statistical analysis of hypotheses proposed by the researcher.
Quasi-experimental design	A quasi-experimental design is one in which the research design is experiment-like but does not involve its full characteristics, such as a control group and a random assignment of subjects to intervention or treatment groups.
Random sample	When a group of people is being selected for study, one of the ways to try and ensure that the group is representative is to try and recruit people who have been selected randomly from the population. To be a random sample, everyone in the population must have an equal chance of being approached to participate in the survey, and the process is meant to ensure that a sample is as representative of the population as possible.
Randomisation	Randomisation is the process of randomly assigning participants into one or other of the research groups.

Randomised controlled trial (RCT)	In a randomised controlled trial, participants are randomly assigned to receive either the experimental or control intervention or treatment. The idea behind the randomised controlled trial is that when it is done properly the effect of a treatment(s) can be studied in groups of people who are: (1) the same at the outset; and (2) treated in the same way, except for the intervention(s) being studied. Any differences then seen in the groups at the end of the study can be attributed to the differences in the treatment or intervention alone, and not to bias or chance.
Recall bias	Recall bias arises from mistakes in recollecting events, both because of failures of memory, and because looking at things with hindsight has possibly changed people's views. People's reports of what is happening to them currently, therefore, can be more accurate than their recall of what happened some time ago, and how they felt at that time.
Regression to the mean	Regression to the mean refers to the phenomenon where an individual measured on a test obtains an extreme (very high or very low) score and then, upon re-measurement, tends to move towards (regress) the average score (mean). Regression to the mean may be misinterpreted as representing a real change in score.
Reliability	Reliability refers to the extent to which a method of data collection gives a consistent and reproducible result when used in similar circumstances by different researchers at different times.
Sampling	Sampling is the process of taking a subset of the population for study.
Sampling error	Because a sample is smaller than the population from which it is drawn, there is often a discrepancy (sampling error) between the values obtained from the sample and those that apply to the population. For example, the average age of a sample might be 22 years, but the average age of the population might be 28 years.
Semi-structured or focused interviewing	Semi-structured or focused interviewing refers to interviews in which there are no fixed wordings of questions or ordering of questions. Rather, the content of the interview is focused on the issues that are central to the research question.
Snowball sampling	Snowball sampling is sampling in which a group of original research participants put the researcher in contact with other potential participants.
Standard deviation	A standard deviation is a set measure of how far things vary from the average, or mean, result. The mean shows where the value for most people was centred. The standard deviation is a way of describing how far away from this centre, or average, the values spread.
Statistic	A statistic is a number with known properties derived from sample data. There are two types of statistics: inferential statistics which are used to apply statistical tests (for example, determining whether or not a result was statistically significant); and descriptive statistics which are used to describe characteristics of the sample (for example, '56 per cent of the group were women').
Statistical significance	The findings of a study may be just chance. A statistical test can determine whether or not the results of the study are likely to be chance or not. A statistical test calculates the probability of the result being caused by chance and provides a p value.

Stratification	In research, ‘strata’ are sub-groups of the population that share a characteristic, for example, an age group, gender, or socio-economic status. It is possible to compare these different layers separately, to try and see if the groups respond differently to a treatment or intervention, or if the effects of a treatment or intervention differ between the groups. Stratification is the process by which groups are separated into these distinct layers.
Structured interview	A structured interview is one in which the question and answer categories have been predetermined.
Subjective measures	Subjective measures are derived from a measurement process involving a substantial degree of human interpretation, for example, subjective ratings of pain.
Subjects	Subjects are participants in a study and are also referred to as ‘informants’.
Systematic review	A systematic review is a review of studies in which evidence has been systematically searched for, studied, assessed and summarised according to predetermined criteria. Systematic reviews often use a meta-analysis to summarise results of comparable studies.
Test-retest reliability	The test-retest reliability refers to the situation when a test or assessment procedure is administered twice to the same group of people. The correlation between the first score and the second score is the test-retest reliability. This is a measure of the reproducibility of the assessment procedure.
Transcript	A transcript is a word for word, or verbatim, written version of an interview.
Type I error	When a researcher, on the basis of a statistical test applied to a sample of data, wrongly concludes that there is evidence of an association between variables or difference between groups and the population, they have committed a Type I error. The probability of a Type I error is represented by the symbol α .
Type II error	When a researcher, on the basis of a statistical test applied to a sample of data, wrongly concludes that there is no evidence of an association between the variables or difference between the groups in the population, they have committed a Type II error. The probability of a Type II error is represented by the symbol β .
Unstructured interviews	Unstructured interviews are interviews in which neither the questions nor the answer categories are predetermined, thus relying on social interaction between the researcher and research participant to elicit information.
Validity	Validity relates to the degree to which a result is likely to be true and free of bias.
Variable	A variable is a factor which differs among and between groups of people. Variables include things like age and gender, as well as things like smoking or employment. There can also be treatment or condition variables, for example, in a childbirth study, this could be the length of time someone was in labour. All these factors can potentially have an impact on outcomes.

Bibliography

The following books and resources may be useful to consumers undertaking research.

- Abramson, J.H. 1988, *Making Sense of Data*, Oxford University Press: Oxford.
- AGPS 1994, *Style Manual for Authors, Editors and Printers*, 5th Edition, AGPS: Canberra.
- Albury, R., Dodds, S., Thompson, C., Secomb, L. 1996, *Ethical Research: Issues for Institutional Ethics Committees*, University of Wollongong: Wollongong.
- Anderson, B. 1990, *Methodological Errors in Medical Research*, Blackwell: Oxford.
- Bastian, H. 1998, 'Speaking Up For Ourselves: the evolution of consumer advocacy in health care', *International Journal of Technology Assessment in Health Care*, 14:1.
- Bilton, T., Bonnett, K., Jones, P., Stanworth, M., Sheard, K., Webster, A. 1987, *Introductory Sociology*, (2nd edition), Macmillan: Hounds Mills.
- Bland, M. 1995, *An Introduction to Medical Statistics*, Oxford University Press: Oxford.
- Boyle, F., Chapman, R., Hancox, J. 1998, *General Practice Care After Miscarriage: Consumer and Provider Views*. Sudden and Neonatal Death Syndrome (SANDS) Qld Inc and Department of Social and Preventive Medicine, The University of Queensland.
- Brown, R.A., Swanson Beck, J. 1990, *Medical Statistics on Microcomputers*, BMJ: London.
- Consumers' Health Forum of Australia 1996, *Developing the Research Question*, Consumers' Health Forum: Canberra.
- Consumers' Health Forum of Australia 1996, *How to put Together a Research Application*, Consumers' Health Forum: Canberra.
- Consumers' Health Forum of Australia 1996, *Understanding and Using the Health Research Literature*, Consumers' Health Forum: Canberra.
- Consumers' Health Forum of Australia 1997, *Consumers' Research Project Member Survey*, Unpublished.
- Crombie, I.K., Davies, H.T.O. 1996, *Research in Health Care: Design, Conduct and Interpretation of Health Services Research*, John Wiley & Sons: Chichester
- Daly, J. (ed) 1996, *Ethical Intersections: Health Research, Methods and Researcher Responsibility*, Allen & Unwin: St Leonards.
- Daly, J., McDonald, I., Willis, E. (eds) 1992, *Researching Health Care: Designs, Dilemmas, Disciplines*, Tavistock/Routledge: London and New York.
- Daly, L.E., Bourke, G.J., McGilvary, J. 1991, *Interpretation and Uses of Medical Statistics*, Blackwell: Oxford.
- Gardner, H. (ed) 1992, *Health Policy: Development, Implementation and Evaluation in Australia*, Churchill Livingstone: Melbourne.
- Gardner, H. (ed) 1997, *Health Policy in Australia*, Oxford University Press: Melbourne.
- Hamilton, H., Gray, G. 1992, *Grant Application Know How*, Royal College of Nursing, Australia: Melbourne.
- Hill, A.B., Hill, I.D. 1991, *Principles of Medical Statistics*, Edward Arnold: London.
- Huff, D. 1954, *How to Lie with Statistics*, Gollancz: London.
- Kranzler, G., Moursund, J. 1995, *Statistics for the Terrified*, Prentice Hall: New Jersey.
- Marmot M.G., Kogevinas, M., Elston, M.A. 1987, 'Social/economic status and disease', *Annual Review of Public Health*, 8: 111–35.

- Matrice, D., Brown, V., 1990, *Widening the Research Focus: Consumer Roles in Public Health Research*, Consumers' Health Forum of Australia: Canberra.
- Minichiello, V., Aroni, R., Timewell, E., Alexander, L. 1995, *In-Depth Interviewing: Principles, Techniques, Analysis*, (2nd edition), Longman: Melbourne.
- NHMRC 1995, *Guidelines for Health Research and Aboriginal and Torres Strait Islander Communities*, NHMRC: Canberra. <http://www.health.gov.au/nhmrc/publicat/synopses/e11syn.htm>
- NHMRC 1999, *National Statement on Ethical Conduct in Research Involving Humans*, NHMRC: Canberra. <http://www.health.gov.au/nhmrc/publicat/synopses/e35syn.htm>
- Older Women's Network 1993, *Well-Being: For and By Older Women*, Older Women's Network Inc: Sydney.
- Patton, M.Q. 1987, *How to Use Qualitative Methods in Evaluation*, Sage Publications: Newbury Park.
- Polgar, S., Thomas, S.A. 1995, *Introduction to Research in the Health Sciences*, (3rd edition), Churchill Livingstone: Melbourne.
- Rowntree, D. 1991, *Statistics without Tears*, Penguin: London.
- Swinscow, T.D.V. 1983, *Statistics as Square One*, BMJ: London.
- Taylor, S.J., Bogdan, R. 1984, *Introduction to Qualitative Research Methods: The Search for Meanings*, John Wiley & Sons: New York.
- The Australasian Cochrane Centre 1996, *A Research Glossary for Consumers*, The Australasian Cochrane Centre: Adelaide
- The Australasian Cochrane Centre 1996, *Making Sense out of Health Care Research: Workshop Pack*, The Australasian Cochrane Centre: Flinders Park.
- van der Heide, G. 1995, *Ethics, Consumers and Research*, The 1995 General Practice Evaluation Conference Proceedings, National Information Service: Adelaide, pp.95–99.
- Wadsworth, Y. 1984, *Do it Yourself Research*, Victorian Council of Social Service: Collingwood, Victoria.
- Wadsworth, Y. 1991, *Everyday Evaluation on the Run*, ARIA: Melbourne.