Research Methods in Clinical Linguistics and Phonetics

A Practical Guide

Edited by Nicole Müller and Martin J. Ball

WILEY-BLACKWELL

Research Methods in Clinical Linguistics and Phonetics

Guides to Research Methods in Language and Linguistics

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The science of language encompasses a truly interdisciplinary field of research, with a wide range of focuses, approaches, and objectives. While linguistics has its own traditional approaches, a variety of other intellectual disciplines have contributed methodological perspectives that enrich the field as a whole. As a result, linguistics now draws on state-of-the-art work from such fields as psychology, computer science, biology, neuroscience and cognitive science, sociology, music, philosophy, and anthropology.

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1 Linguistics, Phonetics, and Speech-Language Pathology: Clinical Linguistics and Phonetics

Nicole Müller and Martin J. Ball

1.1 A Brief Historical Overview of Clinical Linguistics and Phonetics

The speech-language sciences and arts have, of course, informed speech-language pathology for a long time; for example, the knowledge of normal articulation was imported from phonetics, the use of terms for word classes (such as nouns and verbs) from traditional grammar. However, the more recent close interaction between linguistics and communication disorders started only in the 1970s. Kent (2011), in a review of the development of the journal *Clinical Linguistics and Phonetics*, points to Duchan's online survey of the development of speech-language pathology, where she refers to the period from 1965 to 1975 as the "linguistic era" (see Duchan, 2011).

In the 1970s and 1980s David Crystal and his colleagues developed linguistically based profiling techniques for the analysis of normal and disordered syntax and morphology (Crystal, 1979; Crystal, Fletcher, and Garman, 1976), and then phonology, prosody, and semantics (Crystal, 1982). At the same time an interest in the clinical application of modern phonological theory began to emerge, with publications by Grunwell (1982), Ingram (1976, 1981), Edwards and Shriberg (1983), and Elbert and Gierut (1986), among others. Interestingly, however, the appearance of the term "clinical linguistics" dates to the end of this period, with the publication of the book of that title by David Crystal (1981). Crystal defines clinical linguistics as "the application of linguistic science to the study of communication disability, as encountered in clinical situations" (Crystal, 1981: 1). He added to this definition: "clinical linguistics is the application of the theories, methods and findings of linguistics (including phonetics) to the study of those situations where language

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handicaps are diagnosed and treated" (Crystal, 1984: 31). Limiting the direction of application from linguistics to language disorder is intentional: "the orientation … should be noted. It may be contrasted with the approach of neurolinguists, for example, who study clinical language data in order to gain insights into linguistic or neurological theory" (Crystal, 1984: 30–31). Nevertheless, despite Crystal's wish for clinical linguistics to be a unidirectional hybrid discipline, many researchers working in the field have adopted a bidirectional approach. For example, Ball and Kent (1987: 2) wrote that they preferred a definition that allows "either applying linguistic/phonetic analytic techniques to clinical problems, or showing how clinical data contribute to theoretical issues in linguistics/phonetics." The work of Grodzinsky and colleagues (e.g. Grodzinsky, 1986, 1990) illustrates the use of data from language disorder to inform syntactic theory.

Clinical linguistics developed through the publication of a number of important books (some noted above), the drawing up of analysis procedures and the development of instrumental techniques (to which we return below). An important milestone for this new field of study was the launching of a new academic journal, *Clinical Linguistics and Phonetics*. This took place in 1987, with an initial volume of just two issues (soon increased to four). Now in its twenty-fifth year, the journal publishes 12 issues a year, testimony to the increase in interest and work in clinical linguistics.

1.2 The Role of Clinical Linguistics and Phonetics in Speech-Language Pathology

In this section we will look at some of the contributions made from clinical linguistics and phonetics to clinical practice and research in speech-language pathology, starting with the investigation of speech output impairments as informed by clinical phonetics. The description of disordered speech has benefitted in several ways from the input of clinical phonetics, not least in phonetic transcription, which forms the foundation on which much of both clinical decision-making and clinical speech research builds. Phonetic transcription using the IPA (International Phonetic Alphabet) has long been the norm in data analysis in disordered speech. However, it became clear fairly early on that the range of sounds encountered in the clinic appeared to be larger than the range encountered in natural language. At first ad hoc symbolizations were devised by speech-language pathologists (SLPs) to deal with sounds that could not be denoted through the use of IPA symbols or diacritics because they did not occur in natural language (Grunwell, 1982). In 1983 the King's Fund in the UK published a paper describing a proposed range of additional symbols for just these atypical sounds: the Phonetic Representation of Disordered Speech (PRDS; PRDS, 1983). While a step forward, these PRDS symbols had limited currency, being little known, for example, in North America. The 1989 meeting of the International Phonetic Association in Kiel instituted a committee to examine the symbolization of atypical sounds found in disordered speech. It considered the PRDS

symbols and other suggestions and eventually recommended a set of Extensions to the International Phonetic Alphabet (extIPA) for clinical use. This was described in Duckworth *et al.* (1990), and has been updated since (see, e.g. Ball, Müller, and Rutter (2010) for the most recent (2008) revision).

The provision of the extIPA symbols set (and later on the VoQS voice quality symbols; see Ball, Esling, and Dickson, 2000; Ball and Müller, 2005) is a good example of how insights from phonetics have influenced developments in communication disorders. However, it is also arguable that the needs of speech pathology (in this case the description, through transcription, of atypical speech) have informed phonetics. While it is true that Pike (1943) contained descriptions of a wide range of sounds (both linguistic and nonlinguistic), it is only since the development of extIPA that phoneticians seem to have recognized this range of sounds not found in natural language (for example, through the inclusion of the extIPA symbols in publications of the International Phonetic Association).

Another example of a two-way interaction between speech science and speech pathology can be found with instrumental analyses of speech. A wide range of these exist (see, e.g. Awan, 2008; Ball and Code, 1997; Gibbon, 2008; Kent and Kim, 2008; Whitehill and Lee, 2008; and Chapters 4, 12, and 13 in this volume). Some of these techniques examine speech production processes, some the acoustic signal, and others the perception of speech. While these techniques were mainly developed for the investigation of normal speech, some of them were given a special impetus through their use in the speech clinic. We can point to two of these in particular: electropalatography (EPG) and electroglottography (EGG) (also known as electrolaryngography, ELG). The work by Gibbon and colleagues on "covert contrasts" using EPG is a good illustration of this clinic–research interaction. Gibbon investigated articulatory contrasts made by a speaker that are not perceptible by the listener. For example, in Gibbon (1990) the author reports that one of two sisters is transcribed as backing alveolars to velars, but the other is not. EPG patterns recorded for both sisters had tongue contacts at both alveolar and velar positions at the onset of target alveolars, but the EPG tongue–palate contact patterns at the point of release differed. One sister released her velar contacts before her alveolar ones (thereby producing a release burst that was acoustically similar to that of the control subject), whereas the other released her alveolar contacts first and velar ones last, thereby producing a release burst that sounded like that of [g].

As Fourcin (2000) has pointed out, ELG (or EGG) can help establish links between objective measurement using laryngograph-type signals and the use of subjective auditory dimensions of voice quality description. This is because ELG measurement techniques are able to provide a way of escaping from the current clinical bias towards the utilization of data that are convenient for the researchers, because they are easy to measure (sustained vowels for example), but that are rather less relevant to real-life voice use.

Clinical linguistic research has also informed development of the application of phonology to disordered speech. As Bowen (2009) notes, insights from early phonological theory began to be applied clinically in the 1960s. Many researchers working within clinical linguistic tradition helped spread later theoretical developments within phonology to clinical situations. For example, Grunwell used Stampe's framework of natural phonology in clinical assessment (Grunwell, 1987, 1997; Stampe, 1979).

Bernhardt and Stemberger, and Gierut and Dinnsen applied nonlinear models of phonology, and more recently Optimality Theory, to disordered speech data (Bernhardt and Gilbert, 1992; Bernhardt and Stemberger, 2000; Dinnsen, 1997; Dinnsen and Gierut, 2008), and the current authors have used more functional and cognitive models of phonology for the analysis of clinical data (Ball, Rutter, and Code, 2008; Müller, Ball, and Rutter, 2008). Ball, Müller, and Rutter (2010) describe a range of phonological approaches and how these can be used to analyze disordered-speech data and also to help plan intervention.

Concrete outcomes from clinical phonology include a range of assessment instruments based on different models of phonology, or combining several such approaches. Arguably, the two such assessments most within the clinical phonology tradition are the PACS procedure (Grunwell, 1985) and PROPH, a profile developed by David Crystal (Crystal, 1982) (see Ball and Müller, 1997, for a comparison of the two profiles). Both these assessments rely on naturalistic speech data and provide profiles of the speaker's phonological abilities, using a range of phonological analyses, rather than standardized scores derived from a limited set of tokens.

1.3 Research Philosophies, and the Rest of this Book

Clinical linguistics and phonetics is far from a homogenous field in terms of research traditions, philosophies, and methods adopted by its practitioners. In fact one might go so far as to say that the one thing all clinical linguists and phoneticians have in common is an interest in data related to language or speech disorder, which in turn represents a rather wide remit, and not one that is entirely straightforward in definition (for instance, do we describe the communicative sequelae of dementia as primarily *cognitive* or *linguistic*, and indeed, what difference does it make?). Some clinical linguists would describe their work as, essentially, a branch of applied linguistics, where the application is the (eventual) translation of linguistic and phonetic analyses into clinical assessment and intervention, while others take theorizing about the nature of human language, speech, and cognition as their inspiration, and wish to investigate how impairments of speech and language inform such theories.

In all branches of science that ultimately take human conditions as their object of investigation, there is a potential tension between different scientific orientations (and at times, priorities). Thus, confronted with any one person with aphasia, one may ask numerous questions, such as, but not limited to, "what can this person's history of stroke and the effects on her language processing tell me about human language?"; "what characteristics of aphasia do I see in this person?"; "which specific language skills are impaired by a stroke such as the one experienced by this person?"; "how does aphasia affect this person's life?"; "what tools do I need to effectively assess the language skills and deficits in this person?"; "what do I need to know in order to plan effective intervention for this person?"; "what does this person have to tell me about how aphasia affects her life?", and so forth.

The starting point for research in clinical linguistics and phonetics is always going to be a person with impaired language or speech, whether he or she is a participant in a group study, or a single "case." While ethical conduct is of course a prerequisite of all good research, working with vulnerable populations such as children or people with a variety of impairments of communication and cognition imposes particularly stringent requirements. In Chapter 2 of this book, Thomas W. Powell discusses research ethics in the clinical arena, from the planning stage to the eventual dissemination of research results.

In order to situate different approaches to research in clinical linguistics and phonetics, and the role of the individual in them, it is useful to make reference to Luria's distinction between *classical* and *romantic* science (Luria, 1987a, 1987b; see Sabat, 2001, for discussion, with specific reference to dementia research). Classical science is reductionist in philosophy and approach, and aims to find general and generalizable insights. Phenomena are analyzed into component parts which are investigated using standardized procedures. A classical researcher aims at discovering the, ideally, context-free essence of the object investigated, a "truth" or general characteristic that transcends any one individual case. Classical reductionist science is typified by experimental group studies. Thus, research aiming for explanations of "the nature of," for instance, language impairment in aphasia, or Specific Language Impairment, or phonological delay tends towards experimental or quasi-experimental studies. Given the difficulty in finding large groups of people exhibiting sufficiently similar constellations of symptoms of speech or language impairment (in the absence of confounding variables, and well enough matched for the purposes of an experiment), many quasi-experimental studies in this field are case studies intended to contribute, by a process of accumulation, to a generalizable body of knowledge. Such clinical case studies have a long and proud history in medicine, psychology, and indeed the clinical speech and language sciences (see, e.g. Code *et al*., 1996, 2003).

Chapter 3 in this volume, by Vesna Mildner, is something of a *tour de force* of principles of experimental and quasi-experimental research as relevant to clinical linguistics and phonetics. Mildner discusses steps in experimental research design, the concepts of reliability and validity, the choice of appropriate design variants (including pre- and non-experimental designs), and questions of subject selection, data collection, and interpretation. May Bernhardt and colleagues (Chapter 4) use the International Classification for Function (ICF; WHO, 2007) as a framework for their chapter on experimental and quasi-experimental research on speech production and (re)habilitation. A researcher's beliefs and assumptions are what underlie that researcher's constructs of what constitutes, for example, "disorder," and how it can be investigated. Judith Oxley's chapter on experimental and quasi-experimental research on disordered language (Chapter 5) includes a discussion of nosological constructs, and of theories accounting for language development and change that drive research. At the heart of data analysis and interpretation in experimental and quasi-experimental research is the application of appropriate statistical methods, since statistical significance serves as a determinant of whether the hypothesis investigated is to be accepted or rejected. Statistical methods as applicable to clinical linguistics and phonetics are the topic of Chapter 14, by Eleanora Rossi.

With classical reductionist science, Luria contrasts what he calls *romantic* science, which is holistic in approach and philosophy and attempts to *not* reduce phenomena to abstract component parts and generalizable characteristics, but rather to "preserve the wealth of living reality" (1987b: 6). Clinical linguists and phoneticians oriented towards this goal often tend towards qualitative approaches, which involve a flexible approach to research design and the avoidance of a priori hypothesis formation. Qualitative studies in clinical linguistics are also often based on single cases, and include the layering of multiple types of data in an attempt to capture complexities embedded in, and emergent from, the real-life and individual concerns and priorities of the participant(s) (see Chapter 6, on qualitative research). Chapters 7 and 8 are dedicated to two strands of qualitative research, namely the Ethnography of Communication (by Jacqueline A. Guendouzi), and Conversation Analysis (by Scott Barnes and Alison Ferguson). Clinical sociolinguistics, which in Chapter 9 (by Martin J. Ball and Louise Keegan) is operationalized as the application of sociolinguistic methods (specifically the investigation of sociolinguistic variation) to the clinical context, is another branch of clinical linguistics that aims at capturing the complexity of the living reality of human communicative encounters; in this case, interactions with and between persons with speech and language impairments.

The core of any linguistic or phonetic analysis is a solid body of high-quality data, and many studies involve the processing of audio or video data. Chapter 10, by Benjamin Rutter and Stuart Cunningham, deals with audio and video data, the analytical purposes for which they are useful, and their recording and storage. Data recording is a first step in analysis, since the data recorded will constrain, and thereby help to focus, an analysis. Impressionistic approaches have long been a mainstay in clinical phonetics and linguistics. For such analyses, researchers employ a variety of transcription methods to transform audio or video data into a graphic source for and record of analyses. Such methods, their applicability to different areas of research, and their role in data analysis are the topic of Chapter 11, by Martin J. Ball and colleagues. While transcription-based approaches essentially rely on the transcriber's perceptual and transcription skills to filter the data into usable units, acoustic data processing methods remove this particular filter from the analysis and base interpretation on acoustic measurements. Mark Huckvale (Chapter 12) presents an introduction to acoustic measures of voice pitch, voice quality, segmental characteristics, and prosody relevant for use in clinical phonetics. A further avenue of analysis in clinical phonetics is speech imaging, that is, a variety of techniques that produce visual representations of movements of the vocal tract. Such methods, their applicability in clinical phonetics, and the technical requirements involved are the topic of Chapter 13, by Joan Rahilly. In Chapter 15, Brian MacWhinney and colleagues present a branch of research that is becoming increasingly prominent in linguistics in general, and clinical linguistics in particular, namely corpus-based approaches. Given the rapid advances in storage and processing capacity of mainstream computing in recent years, it is now feasible for researchers to access and investigate large corpora of language data without having to invest in expensive specialist computer hardware (the same is also true of acoustic analysis; see Chapter 12). MacWhinney and colleagues base their chapter on the AphasiaBank project, which to our knowledge is the largest and fastest-growing corpus of language data relating to language impairment in the world.

Doing research in clinical linguistics and phonetics is, in our humble opinion, fun while it lasts. However, it would not warrant the label of "research," nor would it warrant inconveniencing research participants, unless the ultimate goal of the research endeavor is dissemination, that is, the publication of our investigations for scrutiny by the research community, and for the purpose of contributing to the available body of knowledge in our field. Writing and disseminating research can follow many avenues, including theses and dissertations in fulfillment of degree requirements, edited books, journal articles, conference presentations, and more. The writing and dissemination of research is discussed in the final chapter of this book (Chapter 16, by Sharynne McLeod).

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2 Research Ethics

Thomas W. Powell

2.1 Introduction

The scientific method entails the collection of data to answer carefully formulated questions in a valid, replicable, and impartial manner. As explored throughout the present volume, a variety of methodologies exist for studying speech and language phenomena from clinical populations. In this chapter, basic ethical considerations will be considered relative to the planning, implementation, and dissemination of research within the discipline of clinical linguistics and phonetics.

2.2 Basic Concepts

Traditionally, the field of ethics has been characterized as a branch of philosophy that addresses issues of right and wrong (e.g. Ross, 1930). In research contexts, the term *ethics* has come to encompass policies, procedures, and practices that are intended to ensure fair and humane treatment of participants and associates throughout the investigative process (Elliott and Stern, 1997). Ethical principles also guide the dissemination of scholarly works by providing guidelines for honesty in reporting results and for impartial and fair peer review of work submitted for publication or presentation.

There have been many attempts to distil ethics down to a small number of underlying principles. Ross (1930), for example, recognized the ethical principles of *fidelity*, *reparation*, *gratitude*, *justice*, *beneficence*, *self-improvement*, and *non-maleficence*. These general principles overlap considerably with those proposed in Beauchamp and Childress's (1979) influential work, which identified four principles of bioethics: *respect for autonomy*, *beneficence*, *nonmaleficence*, and *justice*.

Research Methods in Clinical Linguistics and Phonetics: A Practical Guide,
First Edition. Edited by Nicole Müller and Martin J. Ball.

Figure 2.1 An ethics model for clinical linguistics and phonetics.

Although certain ethical principles are robust throughout the literature, it is important to consider the specific ethical issues that are germane to each discipline. Within the field of clinical linguistics and phonetics, six ethical constructs have been proposed (Powell, 2007). These constructs were identified from a review of an international sample of ethical codes from professional and scientific associations in related disciplines, including applied linguistics, speech and language therapy, and forensic phonetics:

- *beneficence*: acting in the best interest of others;
- *nonmaleficence*: minimizing risks and harm to others;
- *competence*: accepting responsibility for quality of work;
- *integrity*: avoiding conflicts of interest and communicating honestly;
- *compliance*: working in accordance with rules and regulations;
- *respect*: protecting individual autonomy and accepting differences.

These principles should not be viewed as mutually exclusive; instead, they are interdependent. For example, *beneficence* and *nonmaleficence* are complementary concepts. Thus, to act in the best interest of an individual typically entails minimizing potential risks. Similarly, *compliance* presupposes a degree of respect for governing bodies, whereas the construct identified here as *respect* emphasizes the rights of individuals (which, of course, may be protected by rules or regulations). The relationship among the proposed principles is depicted in Figure 2.1.

Ethical guidelines share certain characteristics with laws (i.e. both define standards of behavior to protect society); however, they differ significantly in other ways (Horner, 2003). Whereas laws are enacted and enforced by governments and apply to all citizens, codes of ethics typically are enacted by associations or institutions and may lack a formal means of enforcement (Irwin *et al.*, 2007). Ethical guidelines tend to be less coercive than laws, encouraging individuals to monitor their own performance. But the line differentiating ethics and laws is not always clearly drawn.

For example, many nations have codified ethical constructs into law, such as those that target conflicts of interest. As discussed in Section 2.3.3, history has documented recurrent ethical transgressions that have motivated the enactment of laws to govern research endeavors.

This chapter is organized around three stages of the research process: planning, implementation, and dissemination. Key ethical considerations are identified relative to each of these three stages. Finally, several trends impacting research ethics are examined at the conclusion of this chapter.

Section Summary

- The term *ethics* is inclusive of principles such as beneficence, nonmaleficence, competence, integrity, compliance, and respect. Investigators are bound to these ethical principles and must anticipate and address potential ethical challenges throughout the research process.

2.3 Planning for Ethical Research

Good research is painstakingly designed. Investigators develop research questions that are motivated by the literature – as well as clinical challenges – to address theoretical and applied problems. Competing methodologies should be considered and a pilot study may be undertaken to test procedures to ensure their appropriateness. At the same time, participant recruitment procedures must be developed, necessitating the identification of inclusion, as well as exclusion, criteria. As the researcher plans the study, a number of ethical issues must be considered (Irwin, Pannbacker, and Lass, 2008).

2.3.1 Rationale and Methodologies

The breadth of potential ethical issues can be daunting for both novice and experienced investigators. Therefore, the model of ethics that is depicted in Figure 2.1 may provide a useful structure for identifying major areas of ethical challenges in a systematic manner. This section begins by demonstrating such an application.

- *Beneficence*. Early in the planning stages, it is worthwhile for investigators to consider potential benefits for the participants, as well as other individuals with communication disorders. This suggestion does not imply that basic research programs without obvious clinical applications are somehow unethical; such research certainly may benefit society by increasing our understanding of the

nature of our world. However, if there are potential benefits (or therapeutic implications) that may proceed from a study, then the ethically sensitive researcher will consider those benefits while developing the research protocol.

- *Nonmaleficence*. Some research programs may require the use of invasive procedures, such as certain imaging techniques. In such cases, the researcher is ethically bound to consider alternative methodologies to minimize the potential for harm to the participant. If invasive techniques are necessary and justified, then the researcher should take steps to minimize exposure and discomfort to the participant, and to maximize safety. When applicable, infection control procedures must be developed and documented. The purview of nonmaleficence is not limited to physical risks, as research procedures may involve some degree of psychological risk (e.g. frustration, distress, fatigue). Potential risks – whether physical or psychological – need to be identified and steps should be taken to ensure a favorable ratio of benefits to risks.
- *Competence*. Research may involve the use of complex equipment or procedures. The investigator must have the appropriate knowledge and skills to undertake the project. Further, one must be competent in the research design, whether qualitative or quantitative in nature. Often, investigators collaborate with individuals whose knowledge and skills complement their own abilities. Primary investigators also may delegate certain tasks to others, but they shoulder the ultimate responsibility for addressing competence by providing sufficient and appropriate education and training.
- *Integrity*. Existing (and potential) conflicts of interest must be identified as early in the project as possible so that steps can be taken to control for investigator bias. For example, a researcher may derive benefit if certain types of results are obtained. Such benefits may be fiscal in nature, such as when the investigator has a financial interest in a product whose value may be enhanced by certain research outcomes. In other cases, the benefit may be intangible, as in enhanced status (e.g. special treatment, recognition, tenure). When conflicts of interest are identified, it is critical for the researcher to declare the nature of the conflicts and to take whatever steps may be necessary to objectify data collection and analysis.
- *Compliance*. As mentioned previously, investigators may delegate duties to others as long as steps are taken to monitor competence. Student assistants warrant special consideration to ensure that their experience is consistent with educational accreditation standards and institutional regulations, as well as applicable laws. For example, some studies involve a program of speech or language treatment that is provided by a student in training. In this type of research, the individual supervising the treatment should possess the appropriate credentials to be compliant with professional, accreditation, and legal requirements.
- *Respect*. Early in the planning stages, the research team should address issues related to participant recruitment. In some cases, speech and language professionals who work in educational or medico-rehabilitation settings may identify potential participants. As outlined above, the construct of *respect* charges us with the responsibility to empower individuals by enabling them to participate – or

not to participate – freely and without prejudice. When a trusted professional refers an individual to the research program, it is possible that the person will feel some degree of pressure to participate. Such coercion is likely to be flagged by ethics review committees (see Section 2.3.3). To minimize coercive effects, it may be preferable for a representative of the research team to describe the project to potential participants, rather than the familiar clinician. This procedure may help reduce clients' perceptions of pressure to participate in order to please the clinical specialist.

Additionally, clinical records are protected communication and are subject to confidentiality requirements. In research settings, procedures will be necessary to code participant data to protect the confidentiality and privacy of those who participate in the study. Traditionally, research records were stored under lock and key, identified only by participant codes. Access to the actual names has been restricted to the principal investigator and research associates who are directly involved with data collection. Today, many research records are digital, and therefore vigilance is necessary to ensure the safety and confidentiality of the records. Password protection should be routine, especially when files are saved to portable drives or removable media. The level of security or encryption should be sufficient to protect the files from access in case of loss or theft.

2.3.2 Informed Consent

An important tenet of research ethics is that human participants must be apprised of the goals, methods, and duration of the research program. Potential benefits and risks must be identified and explained honestly and clearly. Participants must understand that their decision to participate in the project is voluntary, and that they may withdraw from the study at any point without prejudice. Although some institutions have standard procedures for obtaining informed consent, their use is likely to be inappropriate for young children and individuals with clinical conditions that impact language or cognitive abilities (e.g. aphasia, dementia, head injury, intellectual and developmental disabilities). Such groups often are referred to as 'vulnerable populations' (Penn *et al.*, 2009).

As participant selection criteria are established, the researcher should anticipate conditions that may limit auditory and reading comprehension (e.g. aphasia, limited English proficiency). Such cases necessitate the development of special procedures for obtaining informed consent. These procedures may entail modifications to the consent form (reduced reading level, pictographic forms, and multimedia presentations), as well as the assent process (advocacy by proxy or adviser).

For participants with mildly reduced literacy skills, minor modification of the informed consent form may be sufficient to accommodate reading level. Typically, this process involves simplification of vocabulary and sentence structure (avoiding the passive voice and complex clausal structures, for example). Word processing software may provide a rough estimate of readability, typically using the Flesch–Kincaid procedure (Kincaid *et al.*, 1975).

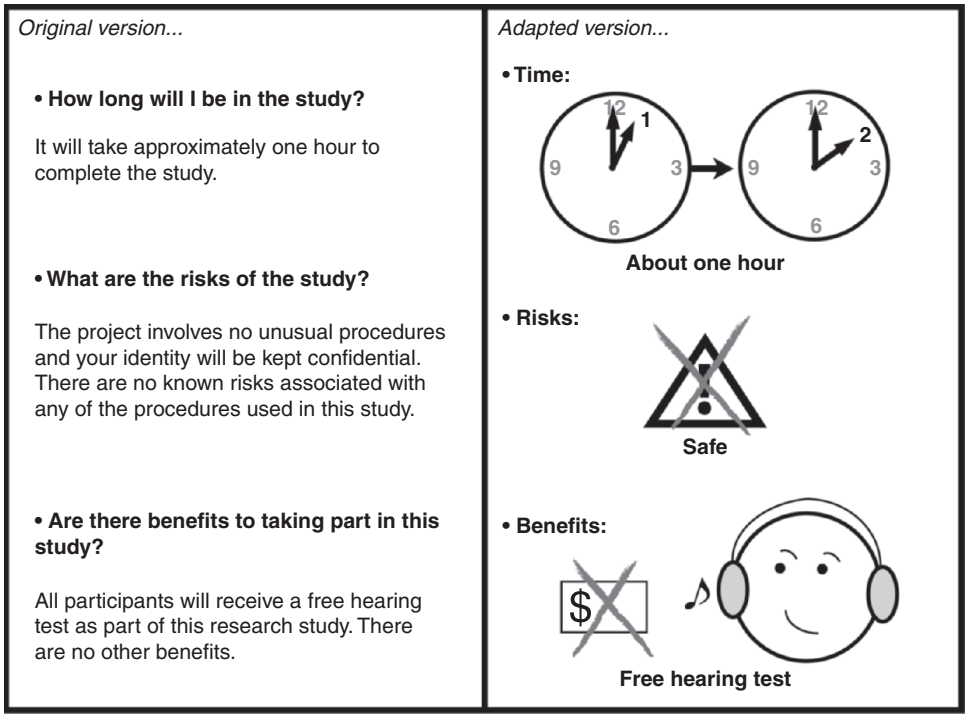

Figure 2.2 A comparison of original and adapted materials for establishing informed consent.

For participants with more severe cognitive-communicative constraints, the use of adapted materials may be appropriate. For example, Kagan and Kimelman (1995) describe procedures for use with individuals with aphasia. Their approach presents concepts such as risks/benefits and right to withdraw using pictographic symbols and a limited amount of large-print text. These adapted materials are in sharp contrast with the language used in traditional informed consent forms and will require review and approval by the relevant ethics review committees (see Figure 2.2).

A potential confound with such procedures is the issue of whether the iconic symbols communicate to the participant the specific concepts that the researcher intended. For example, some have used 'smiley faces' or a 'thumbs up' icon to signify assent (e.g. Braunack-Mayer and Hersh, 2001). It is not clear, however, that such symbols communicate 'agreement to participate' to the person with aphasia. For this reason, Kagan and Kimelman (1995) argue that the researcher must evaluate and document comprehension to validate the participant's response using, for example, a series of immediate comprehension checks consisting of simple yes/no questions.

The use of proxies or advisers has been discussed in the literature, especially in regard to patients with neurological conditions that may compromise understanding (e.g. aphasia, dementia). Individuals with aphasia may be loath to allow a proxy (typically their spouse or another member of the family) to make decisions on their behalf. Instead, research suggests that they prefer the use of an adviser who asks

questions on their behalf and discusses the pros and cons of participation, but who allows the individual to make the final decision independently (Kagan and Kimelman, 1995; Stein and Brady Wagner, 2006).

Penn *et al.* (2009) noted that participants with aphasia – especially those with severe language disabilities – challenge the researcher to develop appropriate procedures for establishing informed consent. Many variables must be considered, including severity and subtype of disorder, literacy, cultural diversity, as well as personality variables (trust, scepticism, etc.). Penn *et al.* argue against the use of generic informed consent forms and procedures; instead, they provide a model that includes procedures that are tailored to the specific needs of the participants and advocates, as well as informational materials for home use. A waiting period is recommended to allow the participant time to weigh the advantages and disadvantages of participation. Penn and colleagues reiterate the importance of assessing the effectiveness of the informed consent procedures. Comprehension and decision-making capacity must be assessed carefully (Ferguson, Duffield, and Worrall, 2010).

The challenges of establishing informed consent also extend to research with other populations with cognitive-communicative disorders, including individuals with dementia or autism spectrum disorder. The use of multimedia presentations has been successful with some higher-functioning individuals on the autism spectrum (e.g. Irwin, Glabus, and Massey, 2006). One advantage of this methodology is that it may be used to simulate the type of activity to be used in the research. Such practices may reduce the likelihood of attrition because participants have a clearer understanding of the nature of the study when assent is obtained.

Finally, the use of minors in research poses additional challenges relative to informed consent. A parent or guardian must provide informed consent on behalf of the child; however, researchers are now providing even very young children with an age-appropriate description of the research, including the voluntary nature of participation and the option of withdrawing from the study at any time. This practice may help establish rapport between the researcher and the child; it also exhorts the research team to develop engaging and age-appropriate tasks. Because children are viewed as an especially vulnerable group, special care has been given to policies governing their participation and informed consent (see, for example, Schwartz, 2006).

2.3.3 Ethics Review Procedures

History documents many abuses involving human and animal experimentation. Following World War II, the discovery of forced human experimentation by Mengele and other Nazi experimenters led to the development of the Nuremberg Code, which established many of the principles that define modern approaches to research ethics (Weindling, 2005). These principles include: voluntary participation, informed consent, minimizing of harm, and evaluating risk-to-benefit ratios. Later, the Declaration of Helsinki (World Medical Association, 1964) expanded and updated the principles of the Nuremberg Code. Nevertheless, ethical transgressions continued. A classic