

# FIVE

## Informed Consent

### Introduction

---

Most guidelines for ethical practice require participants to agree to research before it commences. They typically require consent be both informed and voluntary. Their approaches to informed consent depend on conventional Western notions of autonomy and the primacy of the individual (see Chapter 2) and are a response to a history of research practices – largely in biomedical research – that have come under intense criticism over the past 35 years.

The call for informed consent may seem relatively straightforward, but some researchers clearly do not understand what it would mean for participants to provide informed consent, while many have found it extremely difficult to gain informed consent in practice and argue that in some situations the need for such consent has damaged their research and has not been in the best interest of participants or the wider community. Social scientists have also launched deeper critiques, questioning whether an emphasis on informed consent has meant individual autonomy has trumped the principles of beneficence and justice, as well as more collective and evolving notions of community engagement, trust and reciprocity. Similarly, commentators point to the failure of researchers to engage with communities to build more meaningful understandings of how a process of informed consent might operate (Molyneux et al., 2005; Singer et al., 2008).

In this chapter, I look at some basic issues associated with informed consent – comprehension, coercion and deception – and examine situations where the question of how or whether to gain informed consent has proved problematic.

### What constitutes informed consent?

---

Informed consent implies two related activities: participants need first to comprehend and second to agree voluntarily to the nature of the research and their role within it.

## Informed

In a highly influential analysis of informed consent, bioethicists Ruth Faden and Tom Beauchamp (1986) argued research participants need to understand, first, that they are authorizing someone else to involve them in research and, second, what they are authorizing. Most commentators have concentrated on the second issue. In most circumstances, researchers need to provide potential participants with information about the purpose, methods, demands, risks, inconveniences, discomforts and possible outcomes of the research, including whether and how results might be disseminated, and data reused.

For Faden and Beauchamp, research participants can make an informed decision only if they have substantial understanding – an adequate apprehension of all information that, in their view, is material or important to their decision to grant consent (see Table 5.1). A piece of information may be material to a decision even though it might not alter the final decision. Researchers might be able to determine what they consider material as well as the kinds of things most research participants would want to know. However, it may be difficult to predict what a particular participant might want to know. Faden and Beauchamp concluded researchers must invite participants to engage actively in the exchange of information. Researchers should ‘... ask questions, elicit the concerns and interests of the ... subject. And establish a climate that encourages the ... subject to ask questions’ (p. 307).

**Table 5.1** *Terms developed in Faden and Beauchamp’s A History and Theory of Informed Consent (1986)*

Term	Definition
Substantial understanding	Someone has substantial understanding of an action if he or she has an adequate apprehension of all information that is <i>material</i> or important to a decision
Autonomous action	Acts committed intentionally, with understanding and without <i>controlling influences</i>
Informed consent	Acts of informed authorizing of a professional to involve the participant in research
Controlling influences	Influences that stop independent or self-directed actions – may result from <i>coercion</i> or <i>manipulation</i> by others or from psychiatric disorders
Coercion	One person’s <i>controlling influence</i> over another by presenting an irresistible and credible threat of unwanted and avoidable harm
Manipulation	Intentional <i>controlling influence</i> of someone by non-coercively altering the actual choices available or non-persuasively altering the person’s perceptions of these choices

Term	Definition
Material information	All information that, according to the participant, is germane to his or her decision whether to consent, including the nature of the action and the foreseeable consequences and outcomes of consenting or not consenting
Effective communication	Communication that leads to both parties having justified beliefs about the other's statements and intentions

In some cases, this may take considerable time and effort, as both researchers and participants struggle to deal with complex risks, uncertainties and problems of cultural and linguistic divides. In other situations it may be sufficient to provide potential participants with a list of their entitlements and a range of information they can choose to request. In many codes of research ethics, the default position has been for participants' agreement to take part to be recorded, by asking them to sign a form, return a survey or give consent on audio- or video-tape, though the method adopted may change according to the research.

Standard approaches to informed consent often require participants to have high levels of literacy and linguistic ability. While some people may have the competence to make independent decisions about involvement in a research project, this can be diminished if written information is unclear or constructed without sensitivity. Written consent forms can be difficult to follow and may not be helpful in guiding queries. These problems can be overcome. For example, investigators engaged in participatory research have involved participants in both the construction of information sheets and the brokering of access to peers. Other researchers have attempted to check whether potential participants understand that they are authorizing research as well as what that research might be.

However, there are limits to the degree to which a researcher can respond to tensions between the assumptions behind a Western model of informed consent and specific cultural practices. This may be because research participants have no experience on which to base a particular decision. For example, Robinson (2010) grappled with how to explain to a remote, pre-literate community in the Philippines her intention to disseminate information on the internet. Alternatively, it may be because participants have little experience of exercising or indeed knowledge of their rights (Castro and Bronfman, 1997). Participants might also not wish to hear what researchers believe is relevant. For example, action researchers investigating health service provision for Aymara women farmers in highland Bolivia encountered local aversion to risk identification which Aymara saw as 'calling evil': 'In Aymara culture, the speaker who names possible adversity may be suspected of willing it to happen' (Mulder et al., 2000, p. 105).

Particular difficulties arise if researchers and participants do not share common languages or cultures. The Kenya Medical Research Institute is a collaborative multidisciplinary research programme aimed at tackling ill health. Informed consent for various research projects is sought in local languages. However, the programme's Consent and Communication Committee identified two significant problems with its consent forms (Boga et al., 2011). First, they were poorly written, failing to understand the concerns of the local audience and missing key information generally required by regulators. Second, they were written in English and then translated into local languages, a process that did not always remain faithful to the intent of the original document. The Institute established locally relevant templates for consent forms which were written directly into local languages and concepts, and then checked for accuracy by community facilitators. The templates were accompanied by standard operating procedures for the broader process of obtaining consent.

In many circumstances, researchers are expected to negotiate consent from all relevant people, for all relevant matters and, possibly, at all relevant times. For example, a study of deviance among school students might require the consent of an educational authority, school head, parents and students. A study of an online discussion board might require the approval of members, as well as the list-owner or administrator, based on knowledge of the norms of a specific site and internet community. Quinnell (2010) avoided the need to negotiate with a list-owner by creating her own discussion boards specifically as a research tool and explaining the purpose of the website as participants arrived online. Several commentators criticize researchers who lurk in chat-rooms, reading and copying exchanges on the site. In the case of research on online sexual activity, Whitty (2003) condemned lurking as 'peering in online bedroom windows' (p. 209). Instead of lurking, Lawson (2004) pointed to the need to negotiate, through a fluid interaction with participants, a wide range of matters, including the ways in which communicative text would be used, and whether participants would be identified as authors by screen name or real name. In considering how material published on the web might be handled, Helen Nissenbaum (2010) introduced the concept of 'contextual integrity' to describe the idea of using data available on the web but keeping its use within the ambit intended by its author.

Many other researchers have also argued that consent should not be limited to the beginning of the research project but, rather, should be dynamic and continuous. This point has been made particularly forcefully by anthropologists and allows a far more nuanced and responsive approach than the default of show, tell and sign. For example, Carolyn Ellis (2007) urged researchers to 'practice "process consent," checking at each stage to make sure participants still want to be part of their projects' (p. 23). Mulder et al. (2000) pointed to the difficulty of obtaining informed consent through Andean logic in Bolivia where community members

prefer an answer of 'maybe' to 'yes' or 'no' since it always leaves open a range of options and the possibility of reconciling opposing positions. Vivien Rooney (2013) argued that in the case of longitudinal qualitative research on intimacy and the use of communication technology in Ireland, formal consent should only be documented at the end of the data-gathering period once it becomes clear exactly to what participants might be agreeing. Shamim and Qureshi (2013) reported the problems they had faced in Pakistan when they had attempted to reveal too much too quickly to potential participants who had a poor understanding of research but a fair appreciation of their limited ability to resist institutional or state power. They found a more gradual approach to introducing themselves to teachers reduced anxieties. Shamim and Qureshi argued that while the requirement they obtain informed consent might be a universal principle, it needed to be put into operation in a way that made sense locally.

In some cases, changes may occur during the research that call into question the continuing capacity of the participant to give consent – a significant problem for researchers working with people suffering from degenerative diseases. Other changes may occur between fieldwork and publication that require the researcher to renegotiate the nature of the consent. As part of work on counter-exile violence by the South African state, I interviewed political exiles in the United Kingdom in the early 1990s, providing assurances that the names of interviewees would remain confidential. By the time of publication (Israel, 1999), the government had changed in South Africa, removing the most important reasons for desiring anonymity. In addition, many of the exiles had related their stories in other fora, making it more difficult to preserve anonymity. As a result, I contacted interviewees and obtained consent to reveal their names. Of course, any threat of a return to a more repressive regime would have warranted a swift re-evaluation of this decision.

### Voluntary

Faden and Beauchamp (1986) depicted informed consent as a kind of autonomous action, an act committed intentionally, with understanding and without controlling influences resulting either from coercion or manipulation by others or from psychiatric disorders. The Nuremberg Code (1947) discussed this in terms of 'voluntariness'.

On the basis of the definitions proposed by Faden and Beauchamp, it is unlikely anyone could offer informed consent in the face of coercion or, in many cases, manipulation. For these authors, coercion occurred when someone forced another to act to avoid the threat of harm. For example, the American Anthropological Association was deeply concerned that anthropologists (among other social scientists) operating in war zones in Iraq and Afghanistan while embedded in United States military units could not possibly take consent

proffered by participants at face value. As one Marine commander concluded: 'It's a combat zone, and when you're in uniform you have all the coercive force of the U.S. government' (quoted in American Anthropological Association Commission on the Engagement of Anthropology with the US Security and Intelligence Communities, 2009, p. 50). Sudhir Venkatesh (2008) was informed by a gang leader there would be no difficulty interviewing people about the illicit jobs within a Chicago housing project: 'I'll make sure they cooperate with you. Don't worry, they won't say no' (p. 190).

Of course, in other contexts, some threats and even some punishments may be so unimportant that the person subject to them is still substantially free of controlling influences. However, researchers may find it difficult to assess whether potential participants do have freedom of action. Young people may view researchers as part of government and believe they will be punished if they refuse to take part despite emphatic denials from researchers. In some societies, once community leaders have agreed to research, it may be difficult for community members to refuse to take part. In other settings, participants may be so desperate that they invest more hope than can possibly be warranted in the research and the researcher. Nyambedha (2008) was concerned that villages in Western Kenya were only prepared to talk to him because they hoped he might sponsor AIDS orphans.

Kamuya et al. (2011) pointed out that social norms in some settings, while not being coercive, were likely to constrain voluntariness. They offered the example of a Kenyan mother who might be expected to defer to her husband when it came to giving permission for a child to take part in research. Katyal (2011) argued teachers in the collectivist, hierarchical, Confucian-heritage culture of Hong Kong were happy for principals to determine whether staff would take part in a research project, and that asking participants to sign informed consent forms was therefore superfluous. Marzano (2007) pointed out doctors in Italy controlled social researchers' access to hospitals and the conditions under which they might act. While Marzano was eventually expected to declare his professional identity to patients in a palliative care unit, he was not allowed to explain that he was engaged in ethnographic research on those dying from cancer. Marzano recognized that British review boards would not have accepted the conditions under which he was required to operate in his home country of Italy.

The problem of assessing participants' freedom of action also arises in the context of research on or in institutions, revealing how formal hierarchically offered consent may be mixed with passive resistance. For example, Rowe (2007) engaged in ethnography of decision-making and discretion in a British police service. He received formal permission from the Chief Constable and was then allocated to particular officers by the shift sergeant. Officers generally knew who he was and why he was there, but not always, and he was

occasionally mistaken for a police officer by police and civilians. While the organization had consented, individual officers could make it difficult for him to undertake his research, though given the nature of their institution it might be difficult for them to object openly.

For Faden and Beauchamp, manipulation takes place when the actual choices available to a person are altered non-coercively or, alternatively, perceived choices are altered non-persuasively, without appeal to reason. In some cases, research participants may be able to offer informed consent despite experiencing manipulation by researchers. However, the line may be difficult to draw, particularly when the manipulation comes in the form of an inducement – an offer of a reward to participate (Largent et al., 2012; Singer et al., 2008). Fontes (1998) described two Brazilian research projects that focused on street children in Porto Alegre. One group of researchers concluded that offering money to participants would compromise the ability of the children to reach an autonomous decision while a second research team decided that it would be exploitative *not* to pay the children. Dickert and Grady (1999) argued research participants might be offered a just and fair wage comparable to the amount that they would receive for similar work elsewhere, although there could be difficulties extending this argument to children. However, Molyneux et al. (2009) were concerned that even small gifts might ‘introduce new social dynamics and unexpected outcomes’ (p. 319) in their work with low income households in Africa, and chose in Kenya to offer a gift of food that would cover the basic needs for all members of the household for one day, and in South Africa to provide periodic food parcels to households depending on the needs of participants. Contentiously, Scott (2008) suggested multiple ways that offers of ten and twenty dollars to recruit intravenous drug users through respondent-driven sampling might have ‘became part of the landscape of hustles in Chicago’s most impoverished neighbourhoods’ (p. 50). In response to these types of concerns, Hammett and Sporton (2012) maintained it might be better in some situations to provide funding for community projects but that many decisions might become fraught, problematic and contested.

In some cultural contexts, offering money to interviewees may be seen as insulting and undermining the value a community has placed on a research project. Alaska Native elders told Mohatt and his colleagues (Mohatt and Thomas, 2006, p. 269) that ‘their story was not for sale ... They said that the reason they were agreeing to be interviewed was that they could give their story to the community, to help the community’. Conversely, Christie et al. (2010) observed that knowledge exchange was a significant part of Yolŋu economy in the Northern Territory of Australia and that it would be ‘unethical for university researchers to receive significant knowledge without payment’ (p. 70).

Faden and Beauchamp suggested the autonomy of an individual might be compromised by unwelcome offers that were difficult to resist. Although this

is a subjective standard depending on the circumstances and inclinations of potential participants, Faden and Beauchamp counselled researchers to restrict offers to those that were likely to be welcomed, but could also be easily resisted by participants if they wished. As a result, it might be more sensible to regard the issue of autonomy as relational rather than absolute. In sub-Saharan health research, Tangwa (2009) described the test more colourfully as: 'You know very well when you are throwing corn to feed the chicken and when you are throwing it as a bait to catch it and cut its throat' (p. S19). Joanou (2009) wrestled with the ethics of offering cameras to street children in Lima, Peru to allow them to take photographs of their lives. She was concerned the young people might find it difficult to reject access to the technology even if they would otherwise have refused consent.

Participants' autonomy may vary over short periods of time. Oransky et al. (2009) interviewed 100 ethnically diverse, impoverished, illicit drug users in New York and Hartford, Connecticut. Respondents reported that recruiting research participants through financial incentives might be 'potentially coercive during periods of intense craving' (p. 1653). However, they also considered it to be 'patronizing, offensive and misguided' if researchers sought to substitute payment with more restrictive alternatives. Faced with such an apparent paradox, Oransky et al. suggested researchers seek advice from people with experience in the particular environment.

In some disciplines, particularly psychology, several researchers have claimed the integrity of research design might have been compromised if participants were not misled in some way. Two significant experiments, one by Milgram (1974) in the 1960s and another by Zimbardo in the 1970s, have been especially controversial. In 1971, psychologist Philip Zimbardo created a mock prison at Stanford University and recruited 24 male student volunteers as guards and prisoners. The volunteers had answered an advertisement in a local student newspaper and completed informed consent forms 'indicating that some of their basic civil rights would have to be violated if they were selected for the prisoner role and that only minimally adequate diet and health care would be provided' (Zimbardo in Zimbardo et al., 1999, p. 6). The research into the effects of institutional settings was abandoned after six days when the guards subjected prisoners to physical and psychological abuse and many prisoners started to behave in pathological ways (Zimbardo, 1973). One psychologist who visited the experiment and whose intervention led to the end of the project described 'feeling sick to my stomach by the sight of these sad boys so totally dehumanized' (Maslach, in Zimbardo et al., 1999, p. 18).

Zimbardo acknowledged that the research had been 'unethical because people suffered and others were allowed to inflict pain and humiliation' (Zimbardo, in Zimbardo et al., 1999, p. 14) well beyond the point at which the experiment should have been called off. However, he also argued there



was no deception because there had been consent. While there may have been informed consent at the beginning of the experiment, it is not obvious this consent continued throughout. Although five student prisoners were released before the end of the experiment, this occurred only after one had had 'an emotional breakdown', three had 'acted crazy' and another had broken out in a full body rash (Zimbardo et al., 1999). Others may have wanted to leave but there is some evidence they believed they could not. At one point, one prisoner told the others they would not be allowed to quit the experiment. Zimbardo described this as untrue, yet recognized that 'shock waves' from the prisoner's claim 'reverberated through all the prisoners' and substantially altered their subsequent behaviour (Zimbardo, in Zimbardo et al., 1999). I shall return to the matter of deception later in this chapter.

## **The practices of informed consent**

---

Most social scientists accept that the process of informed consent forms a worthwhile part of how they negotiate their relationship with participants. However, many scholars have had difficulty when a standardized process has been imposed on all research interactions.

### **Is formal consent really needed?**

The principles of informed consent have been adopted slowly and unevenly by different parts of the social sciences. For example, the American Anthropology Association only included the matter in its statement on ethics in 1998 and Fluehr-Lobban (2000) argued two years' later that formal informed consent was still not commonly being sought by anthropologists. Part of the resistance has been directed towards the method of obtaining informed consent proscribed by institutional ethics committees. This, some qualitative researchers have claimed, has been biased towards quantitative research (Bosk and De Vries, 2004; van den Hoonaard, 2011). In contrast, researchers using open, inductive, methodologies may not have an interview schedule, nor will it be immediately apparent what the risks of such research might be.

In many countries, codes of ethics have required researchers to obtain the informed and voluntary consent of all participants except in specific, defined circumstances. Many social scientists have been concerned that the principle has been adopted mechanically by research ethics governance structures, creating an artificial, culturally inappropriate and occasionally dangerous bureaucratic process (Israel, 2004b; Schrag, 2010a).

In Canada, Will van den Hoonaard (2001) attacked the way anthropological fieldwork had been distorted by the 'hard architecture' of ethics forms imposed by ethics committees.

One can imagine many instances where the insistence on a signed consent form may be unwise or tactless. In studies of street-corner men, poachers, prostitutes, fishers, drug users, professional thieves, the homeless and, in general, those with socially defined problems, this would simply elicit an angry response. (p. 28)

Researchers have argued against consent forms on several grounds. Any requirement that participants sign their name has the potential to remove the protection of anonymity from incriminating statements. But for the signed consent form, no identifying details would have been recorded. Instead of protecting participants, such a requirement places them at greater risk (Social and Behavioral Sciences Working Group on Human Research Protections, 2004). Although the previous and current versions of the Canadian Tri-Council Policy Statement allow for oral consent (Tri-Council, 2010, Article 3.1.2), the Social Sciences and Humanities Research Ethics Special Working Committee (2004) identified a case where a research ethics committee tried to insist that a researcher undertaking fieldwork outside Canada obtained signed forms from participants who might be killed if their government discovered they had cooperated with the researcher. Will van den Hoonaard (2001) also noted that some Canadian researchers felt consent forms were obtrusive, turning an exchange based on trust into one of formality and mistrust. Criminologists in Australia reported similar misgivings (Israel, 2004b).

The form itself may compromise informed consent if written information is unclear or constructed without sensitivity. In the United States, the Committee on Assessing the System for Protecting Human Research Participants claimed 'consent forms have been hijacked as "disclosure documents" for the risk management purposes of research organizations' (Federman et al., 2002, p. 92). The use of standardized wording can affect the quality of the research data by reducing response rates because participants believe they are being tricked or because the form encourages them to overestimate the risks of potential harms. The chances of participants taking consent forms seriously can be diminished if the forms direct questions and concerns to administrators located in distant cities or countries.

When researchers exercise excessive caution in negotiating informed consent, this can be interpreted as meaning that researchers distrust participants' capacity to make their own decisions. Norwegian ethnographers, engaged in a cross-disciplinary observational study of patients and therapists in a psychiatric hospital, were required by their Regional Committee on Medical Research Ethics to offer a careful explanation of their study and obtain signatures from

patients on two different forms. One exasperated participant responded 'You know, I'm not stupid, I understand the purpose of the study' (Oeye et al., 2007, p. 2302).

In discussions with the Aboriginal Research Ethics Initiative in Canada (2008), Tester indicated situations where Indigenous communities wanted nothing to do with the paperwork demanded by the research ethics governance processes of Canadian universities. He was told that 'If we know you and trust you, we will work with you. Signing a lot of paper that talks about things we might not understand or care about, won't change that' (p. 38). The Aboriginal Research Ethics Initiative concluded that:

Respecting other ways of doing things can often lead to conflicts between what is required by officialdom and what best suits others. This experience points to the tendency of bureaucracies to build and grow in attempts to deal with every possible aspect of what should be considered. Forms, rules and regulations proliferate accordingly. Then one encounters a community or individuals that, perhaps recognizing a cultural habit that is not theirs, in a simple statement such as the one above, dispense with all of it. (2008, pp. 38–39)

In New Zealand, Helen Moewaka Barnes and her colleagues (2009) also noted that Māori researchers and participants saw written consent forms as something required by the Pākehā (non-Māori) bureaucracy rather than for the protection of participants. They portrayed forms as "something we fill in for Pakeha" independent of any expectation that the participant has about the acceptability of the research process' (p. 446). In the United States, Joan LaFrance and Cheryl Crazy Bull (2009) observed drily that in Indian Country:

Signing a paper may not be perceived as a trustworthy practice, especially in communities with a history of broken treaties and 'paper'-based promises. (p. 145)

Similar comments have been made in relation to the legacies of colonialism in other environments, including indigenous peoples in Peru (Creed-Kanashiro et al., 2005) and Botswana (Ntseane, 2009), as well as in contemporary authoritarian states such as Uzbekistan (Wall and Overton, 2006). In Zimbabwe, Muzvidziwa (2006) noted the dangers of using the form mandated by his New Zealand university which employed the term research 'informant', a highly charged word in post-liberation Zimbabwe and indeed many other places where hostility towards the state is accompanied by violence towards those who provide information to authorities.

Many agencies have explicitly recognized that written informed consent may not always be appropriate. The European Research Council's draft guidance for social science researchers acknowledged:

certain groups may be more vulnerable to harm from having information they provided be linked to them (illegal immigrants, victims of home violence, prostitutes, HIV-positive employees, etc). In these cases, standard procedures for obtaining written informed consent may be harmful to the subjects instead of offering protection and therefore need to be replaced ... (European Research Council, 2010, p. 10)

In the United States, the National Science Foundation (2008) noted that 'in most ethnographic projects a request for written, formal consent would seem suspicious, inappropriate, rude and even threatening'. Unfortunately, there are many examples where institutional review boards in the United States have followed the more traditional medically inspired forms favoured by the Office for Human Research Protections, resulting in gaps in research on the vulnerable and the powerful. The National Research Council has called for the Common Rule to be rewritten to remove any language that might suggest written consent is the 'preferred norm' (2014, Recommendation 4.2). Similar problems were documented leading up to the introduction of the 2007 National Statement among Australian Human Research Ethics Committees reviewing research to be conducted in Australia, Cambodia, India and Papua New Guinea (Czysmoniewicz-Klippel et al., 2010; Israel, 2004b).

One might hope that more research ethics committees will follow researchers and no longer view informed consent rigidly. Fluehr-Lobban (2000) argued that anthropologists should not see informed consent in terms of forms but as offering an opportunity to initiate discussion with participants about the research. Responding to strong criticism of the role played by a US anthropologist in research carried out since the 1960s on the Yanomami tribe of Venezuela and Brazil, the American Anthropological Association (AAA) commissioned a Task Force to review, among other things, how anthropologists had negotiated informed consent with indigenous peoples (El Dorado Task Force, 2002). As part of this review, Watkins (2002) called for anthropologists involved in work with indigenous peoples and related communities to move from research simply done with the consent of research subjects towards mutually beneficial collaborative and participatory practices. The Task Force supported this argument, though the Task Force's report was subsequently rejected for other reasons by the AAA membership (Dreger, 2011).

### **Whose consent should be obtained?**

---

It may be necessary to obtain the consent of organizations, groups or community elders as well as the individuals concerned. Health researchers working with economically disadvantaged communities in rural sub-Saharan Africa have discussed the importance of seeking approval from formal community leaders. For example, Tindana et al. (2006) explored the understanding of

paramount chiefs, divisional chiefs and community members in one district of Northern Ghana. They described paramount chiefs as gatekeepers: 'Consent from the chiefs in this community can therefore be a form of visa acquisition for researchers to conduct research' (p. 3). Doumbo (2005) reported that the Malaria Research Centre at Bamako in Mali used a stepped approach to gain approval from village elders, heads of extended families, groups of mothers and only then sought consent from individual families who might participate in the study. A similar approach has been advocated in Botswana by Ntseane (2009) and in China, where in the field of healthcare Zhai (2011) advocated 'informed consent with the support and aid of the family or community' in those contexts where 'family and community ties and traditional cultures are very strong' (p. 35).

Unfortunately, seeking approval from local leaders may either reinforce local patterns of exclusion, silencing particular voices, or, conversely, place pressure on members of the community to follow the decision of their leaders to take part. In a characteristically thoughtful piece, Sassy Molyneux and her colleagues (Molyneux et al., 2005) explored perceptions of consent in a rural Kenyan community. While there was widespread agreement that chiefs and elders could give permission for a research project to be conducted within an area, community members reserved the right for households and individuals to make their own decisions. However, there were differences in opinions on the basis of gender, age, status and educational attainment, particularly in relation to who should make decisions about research involving children: 'Simple comments on cultural differences between populations, or descriptions of community views as homogeneous, closed and static mask a far more complex reality.' (p. 452).

Joshua Rosenthal (2006) analysed attempts to achieve prior informed consent by anthropologists for two landmark bioprospecting projects involving the commercial exploitation of the traditional knowledge of indigenous peoples. While bioprospecting and research are distinct endeavours, with the former often entailing levels of resources and benefits inconceivable to most social science projects, Rosenthal's assessment of why one agreement with 55 Aguaruna communities in Peru succeeded while the other with the Maya people in Chiapas, Mexico, failed, is useful. Rosenthal argued that one of the most significant problems for outside researchers was the absence in many indigenous societies of a 'clearly delineated governance hierarchy' that 'formally establishes for the outside world what level of an indigenous community or nation has the authority to give consent' (p. 121). Traditional governance and authority structures may have been destroyed by colonization and contemporary governance structures may be fluid, overlap or be contested either within the relevant groups or by local or national formal political structures. In Peru, established, credible and preexisting community organizations, drawing on traditional local consensus-building assemblies, were able

to represent authoritatively local indigenous groups. In Mexico, those geographically dispersed central highland villages that supported the bioprospecting agreements were unable to defend their position in the face of a concerted political campaign by a non-representative, metropolitan-based indigenous NGO. Rosenthal's analysis was contested by a series of commentators, including Simonelli (2006) who challenged the elitism of attempting to negotiate informed consent for a pre-existing project rather than giving 'agency to those to be studied as part of an equal partnership' (p. 136).

The United Nations Declaration on the Rights of Indigenous Peoples (United Nations, 2007) affirms the belief that 'control by indigenous peoples over developments affecting them ... will enable them to maintain and strengthen their institutions, cultures and traditions' (p. 2). So, research councils in various countries have sought to recognize and protect the collective interests of indigenous communities while still protecting the autonomy of individuals. Their attempts to incorporate matters relating to indigenous peoples within their codes and guidelines forms part of a broader shift of emphasis from research *on* and *about* Aboriginal peoples to research *with*, or *by* and *for* Aboriginal peoples (Smith, 2001). For example, the revised Tri-Council Policy Statement acknowledges Aboriginal entities in Canada have emphasized 'collective rights, interests and responsibilities' (2010, p. 106). It therefore requires researchers to plan for and 'seek engagement with the relevant community' where 'research is likely to affect the welfare of an Aboriginal community, or communities' (Article 9.1, p. 110). Such engagement might involve review and approval of a proposal by community leadership. However, it might also be part of a broader collaborative and participatory approach involving structures and processes that lead to the establishment of an indigenous advisory group, or a formal research agreement so that indigenous community organizations act as a research partner and share in the leadership of a project (p. 108). Of course, authority structures governing indigenous peoples may be complex and it may therefore be necessary to work with overlapping territorial interests, a diversity of views and interests, or gatekeepers whose authority rests on custom rather than election or appointment.

The 2012 Australian Institute of Aboriginal and Torres Strait Islander Studies' Guidelines for Ethical Research in Australian Indigenous Studies (GERAIS) called for research with and about Indigenous peoples to be 'founded on a process of meaningful engagement and reciprocity between the researcher and Indigenous people' (p. 4) involving: free, prior and informed consent (Principle 6) – a formulation derived from developments relating to biodiversity and genetic resources; ongoing consultation and negotiation (Principle 7); and mutual understanding about the proposed research (Principle 8). In New Zealand, Treaty of Waitangi principles requiring respect for and protection of Māori individual and collective rights have been interpreted as granting Māori *iwi* (tribe or nation) and

*hapu* (group of families with a common ancestor) authority over their peoples' involvement in all stages of a research project (Hudson and Russell, 2009). Māori members of ethics committees (Hudson et al., 2010) have developed their own codes of ethics as have Canadian First Nations and Inuit organizations (Assembly of First Nations, n.d.; Nickels et al., 2007; van den Scott, 2012), and the San of Southern Africa (Working Group of Indigenous Minorities in Southern Africa, n.d.).

A report on homelessness in Canada (Tester, 2006) was used by the Aboriginal Research Ethics Initiative (2008) as a case study of community-initiated and directed research. The participatory action project was initiated by Inuit from a community in Nunavut, supported by advisors drawn from the community, and endorsed by the local mayor and council. It used a survey designed in and with the community, and administered by local youth trained by the project as researchers.

Many researchers have relied on consent from institutional gatekeepers, often senior management, and have not gone to the same lengths to obtain informed consent from other people present at the research site, whether the organization is a school or the police. The National Advisory Board on Research Ethics in Finland (2009) suggested participation should be informed but need not be voluntary in some hierarchical organizations, and offered the examples of participant observation of military conscripts or the observation of work processes where researchers have obtained management permission.

Nancy Plankey-Videla (2012) obtained formal consent from several levels of management and the management-aligned union president to study the workforce in a Mexican garment factory. While she introduced herself to the two teams to which she was assigned, practically it was impossible to request approval from the 1,000 workers on the factory floor. In addition, she was aware that many workers who had agreed to her research were unlikely to be in a position to refuse. Other workplace ethnographers have found it difficult to deploy the language of informed consent in negotiating the different levels of gatekeeping within complex hierarchical organizations. This has led to predictions that we might be witnessing the extinction of workplace studies in Australia (Bamber and Sappey, 2007). In response, Cordner and Thomson (2007) noted the 2007 National Statement did not offer non-participants a veto over research even if research ethics committees might have interpreted the 1999 Statement in that manner. Instead, those members of an organization not participating in research are entitled to 'the respect and protection that is due to them':

So if research in industrial sociology were to carry a risk of adverse effects ('harm') on say an employer because of his or her unfairness to employees, protection from this harm may well not be 'due' to him or her ... (p. 45)

Special procedures are often adopted when attempting to obtain consent or assent from children. The United Nations Convention on the Rights of the Child (1989) requires that the best interests of the child must be the primary consideration in all actions concerning children (Article 3). Under Article 12, children capable of forming their own views should have the right to express those views freely in all matters affecting them, due weight being given to their age and maturity. For the British Educational Research Association (2011), this meant 'Children should be facilitated to give fully informed consent' (p. 6). However, some educational researchers have been deeply reluctant to work in this way and have used adults as proxies for children's consent. As a result, Hart (1992) identified a spectrum of children's roles in decision-making. The scale ranged from manipulation, decoration and tokenism through to 'child-initiated, shared decisions with adults' and reflected not only the 'increasingly evolved capacities of children' but also the 'corresponding capabilities of adults towards encouraging the participation of children' (UNICEF Evaluation Office, 2002, p. 3).

Any understanding of the nature of children's autonomy must recognize the broader political, social and economic contexts within which decisions might take place. For example, some teachers' 'requests' may really be requirements, and consent within the classroom may therefore 'shade into coercion' (David et al., 2001, p. 351), with participation in research becoming simply more schoolwork. Gallagher et al. (2010) identified various difficulties in complying with standard ethics codes and ensuring children understood the nature of the research project. Among other issues, adults and children often had very different views of the meaning of language, and children may well lack interest in discussing methods and findings.

Several commentators and organizations have argued researchers must obtain parental consent for research on their children (Schenk and Williamson, 2005; Society for Research in Child Development, 2007). However, some researchers have challenged the need to obtain parental consent if children have already given consent (David et al., 2001). The American Sociological Association (1999) requires its members to obtain consent from both children and their guardians except where: the research imposes minimal risk on participants; the research could not be conducted if consent were to be required; and the consent of a parent 'is not a reasonable requirement to protect the child' (s. 12.04b) as in, for example, cases where the child has been abused or neglected. A similar exception is outlined in the Economic and Social Research Council (ESRC)'s Framework for Research Ethics (2010, p. 30). However, some research ethics committees have been less flexible and it can prove difficult to meet their requirements (Israel, 2004b).

Article 15 of the United Nations Convention recognizes children's right to freedom of association. In a more general context of research, monitoring and evaluation, UNICEF (UNICEF Evaluation Office, 2002, p. 2) suggested



managers of their programmes could seek children's perspectives through community, regional, national and global fora. This may fit within a wider move to augment individual informed consent for adults with community advisory boards, composed of people who may share a common identity, ethnicity, history, language or culture with participants (Kamuya et al., 2013a). Such boards can liaise between researchers and participants, helping to develop materials and providing advice for the process of informed consent. When constituted as partners rather than advisors, these boards may identify issues and concerns generated by the community for response by the board in a manner mutually beneficial to both researchers and the community. While boards have been criticized for masking lack of real community involvement, some successes have been claimed in health research in low-income settings in both developed and developing countries ranging through Kenya, Peru, South Africa, Tanzania, Thailand, Uganda, the United States and Zimbabwe (Newman et al., 2011; Shubis et al., 2009). They have also been used to good effect in research in the United States on intimate partner violence (Cerulli, 2011). On the other hand, community advisory boards comprised of vulnerable groups might veto research on the grounds that it might compromise the safety of group members (DePalma, 2010).

### **Should some research occur without consent?**

Some social scientists have maintained research should occur without consent where the research takes place in public space or concerns public officials, or the harm caused by lack of consent might be outweighed by the public benefit obtained.

There is heated debate over the degree to which deliberate manipulation of information – deception by lying, withholding information or misleading exaggeration – might be warranted in research. Deception is difficult to justify on deontological and rule-utilitarian grounds (see Chapter 2). Does potential benefit to many justify infractions of the rights of an individual participant? Act-utilitarians might argue an act of deception could only be justified if the balance of expected benefits over expected harms were greater than would be achieved without deception. However, such a case is extremely difficult to achieve. Nevertheless, deception has been justified on the pragmatic grounds that it enables researchers to control stimuli, study low-frequency events and gain information that might otherwise be unobtainable. James Korn (1997) identified a long history of the use of deception in social psychology in the United States, and concluded that social psychologists had not seen their use of deception as a serious matter for research participants, but simply as part of the typical experiences of everyday life.

However, the use of deception has been criticized on the basis that it harms participants, researchers, research professions and society overall (Hegtvedt, 2007). Korn charged psychologists with institutionalizing and legitimating the deception that 'permeates our culture' (p. 10). Indeed, the practice has been entirely rejected by experimental economists because it contaminates the subject pool (Hertwig and Ortmann, 2001), and this has led to some tension between economists and psychologists working in adjacent areas (Cook and Yamagishi, 2008).

Korn traced a decline in the use of deception by social psychologists from the 1980s onwards. However, Hertwig and Ortmann (2008) still found 53 per cent of articles published in the *Journal of Experimental Social Psychology* in 2002 had employed deception, and its use in marketing research also seems to have risen since the 1970s. Over 80 per cent of papers involving human studies published in three consumer and marketing research journals (2006–7) used deceptive practices. Smith et al. (2009) identified mood induction and anxiety-arousing manipulations, and the provision of false feedback in relation to levels of participant empathy.

The American Sociological Association (1999) only authorizes the use of deception in research where it can be justified in terms of the value of the research, and there is no equally effective alternative that does not use deception (s. 12.05a). The National Statement (National Health and Medical Research Council, 2007b) in Australia refers to a need to ensure deception does not increase the risk of harm, participants will be debriefed (see Chapter 7) and there is 'no known or likely reason for thinking that participants would not have consented if they had been fully aware of what the research involved' (p. 24). The Canadian Sociological Association (2012) has continued to recognize that researchers may have to deploy deception 'to penetrate "official," "on-stage," or "on-the-record" presentations of reality' (s. 22). Similarly, Australia's National Statement (2007b) explicitly accepts that limited disclosure in order to reveal illegal activity might be justified on the basis of a harm-benefit analysis.

Often unhelpfully conflated with deception, covert research has several alternative rationales. First, it has been justified on the basis of utilitarianism in limited circumstances where it is necessary for the research to remain secret in order to maintain access to the research setting, perhaps in the face of the desire of 'powerful or secretive interests' (British Sociological Association, 2002; Socio-Legal Studies Association, 2009) to block external scrutiny. Drawing on archived discussion group material, Brotsky assumed the online persona of a 20-year-old woman with eating disorders in order to engage with 23 pro-anorexia groups on 12 websites (Brotsky and Giles, 2007). She took part in password-protected, user-driven discussion fora, chatrooms, e-mail groups, blogs and one-to-one e-mail exchanges, justifying her covert activity on the grounds that 'pro-ana' communities had proved hostile to researchers and that the study might deliver benefits to the eating disorders clinical field. Francine

van den Borne (2007) justified the use of covert researchers posing as male 'mystery clients' in order to discover how Malawian women who bartered sex with men for money, goods or social capital, were able to negotiate condom use.

Without covert research, Pearson (2009) argued, some aspects of society, including harms and injustices will remain 'hidden or misunderstood' (p. 252) and the images that powerful groups wish to project may go unchallenged. During her research on the illegal trade in human organs, Nancy Scheper-Hughes (2004) travelled incognito in Argentina 'to enter a locked state facility for the profoundly mentally retarded ... to investigate and ultimately to document allegations of tissue, blood, kidney and child theft from the neglected, emaciated, socially abandoned and unknown, so-called "no-name" inmates' (p. 32). While researching police torture and murder in Brazil, Huggins chose to portray her work at the beginning of each interview as a 'comparative study about policemen's lives in times of conflict and crisis' (Huggins and Glebbeek, 2003, p. 375). Accurate, but clearly not the whole story. Various researchers have defended their use of covert methods to study right-wing groups in the United States (Blee, 1998), the United Kingdom (Fielding, 1982) and India (Sehgal, 2009). However, Macklin (1982) questioned whether researchers were in an appropriate position to decide which groups are bad enough to warrant covert research.

Second, covert studies have also been defended on the basis of non-maleficence, suggesting that it reduces disturbance of research participants. The argument of non-maleficence was dismissed by Herrera (1999) as failing to consider the need to protect research participants from having their interests infringed by paternalist researchers.

Third, researchers have defended partially covert research when they found it difficult to negotiate their presence as researchers because of the institutional, physical or virtual setting or the numbers of people that would be involved. For example, work on the night-time economy by a group of British criminologists (Winlow et al., 2001) involved one member of the team securing work as a bouncer without identifying himself as an academic researcher. Paweł Moczydłowski (1982/1992), later to become Director-General of prisons in post-Communist Poland, entered prisons to undertake his research by joining study groups of questionnaire-wielding students. Sallaz (2008) informed South African casino workers and their managers that he was examining working conditions for employees, but found it was not always possible to provide the same information to gamblers as this would have slowed down the games and compromised his role as croupier, without having any major impact on the risks faced by clients of the casino. In the light of this type of argument, the Swedish legislation relating to human research ethics (Swedish Research Council's Expert Group on Ethics, 2011) recognized it may not be necessary to obtain informed consent when an unreasonable amount of work might be required to achieve such an outcome, even if sensitive personal data is being collected.

Fourth, those who collect anonymized data as part of non-participant observation in public spaces have argued for a long time that informed consent is simply not required (Brewster Smith, 1979; Reiss, 1978). This argument has been extended to public areas online (Kitchin, under review) on the basis either that the data involved is publicly accessible or is perceived as public by participants. Despite these attempted distinctions, in practice it is not always clear whether or not particular internet sites should be treated as private, public (Buchanan, 2011; Markham and Buchanan, 2012) or, indeed, semi-public (Sveningsson Elm, 2009): 'what constitutes "person-based" research in cyberspace is much disputed – one person's "text-based" study is another's person-based study' (McKee, 2008, p. 106). Partly stemming from their interdisciplinary and transnational activity, internet researchers are more likely to be attracted towards situated rather than prescriptive ethics (see Chapter 2). So, Natasha Whiteman (2012) invited researchers to assess the environment, content and tacit and explicit markers of privacy when reaching a decision. She also argued that, as in the offline environment, decisions about the public nature of a site should be revisited throughout the research, as the status of sites may change:

Websites are not homogeneous, and the activities of Internet users often suggest confusion and conflicting understandings of the privacy or openness of their actions. Both offline and online, the expectations of those we observe may be in conflict with more 'objective' definitions of the status of the environment. It is therefore important to emphasise the significance of paying attention to the local detail of our research contexts. (Whiteman, 2012, p. 76)

On the other hand, many codes are concerned to protect the dignity and privacy of people even in public space while allowing covert techniques to be used in particular circumstances. Drawing on a harm-benefit analysis (see Chapter 7), Petticrew et al. (2007) defended systematic observations of smoking in Scottish pubs following a ban on smoking in enclosed public areas in Scotland. The American Sociological Association (1999) accepted the legitimacy of this practice (s. 12.01c), as have the Canadian Tri-Council (2010, Article 2.3), and the National Health and Medical Research Council (2007b) in Australia. It would seem odd were covert research to be acceptable offline but unimaginable online, but these arguments have not always run smoothly.

The 'Tastes, Ties and Time' project harvested four years' worth of demographic, relational and cultural data from the Facebook profiles of the 2006 Harvard first-year cohort and connected the data to the University's housing records. The researchers did not seek informed consent on the basis that their work was akin to observation in a public space: 'We have not interviewed anyone, nor asked them for any information, nor made information about them public' (Kaufman, 2008). Zimmer (2010) was highly critical of the project, pointing out that the data was often only available to the researchers

because they were in the same Facebook college network as the students and were therefore not subject to the blocks many students had placed on access to their pages from the outside world.

Finally, research may be covert, at least in the sense that it is undeclared, when social scientists engage in 'early musings' (van den Hoonaard, 2011, p. 252) or enter the research milieu without having formalized a research project. Spicker (2011) worked as an advisor, consultant and academic researcher, talking to officials, voluntary workers, politicians, activists and journalists:

None of these discussions has been part of a formally constituted research project ... I do not do 'covert research' in the sense of deliberately constructing research that is intended to be concealed from view; but equally, there may be no point at which it would be opportune or appropriate to make an explicit disclosure. (pp. 131–132)

Rena Lederman's 'informal fieldwork on academic cultures' (2006, p. 487) drew on her ongoing collegial relations with colleagues. She never regarded her colleagues as human subjects and was only forced to reflect on how her work might be interpreted by United States regulations when she rejoined an institutional review board and began to consider her time on the board as fieldwork. One criminologist's interest in investigating taxi drivers' experiences of crime began while talking to a driver when stuck in rush hour traffic. It would have been absurd to have cautioned the taxi driver that his views on crime and criminal justice might trigger future enquiry: 'When the conversation took place, there was no research project, no planned research project, nor indeed any envisaged research project' (Denscombe et al., 2009, p. 304).

The value of covert studies has been accepted by British, Canadian, Australian, Norwegian and Swedish national codes and guidelines in exceptional circumstances. The American Sociological Association (1999) allows members to undertake covert activities only if the research involves no more than minimal risk to participants. Similar provisions are contained in other national and professional codes such as the National Statement in Australia and the ESRC's Framework for Research Ethics in the United Kingdom. It is unclear whether such provisions might exclude the possibility of using covert research in institutions to expose, for example, state violence or corporate misconduct. It depends on whether the institution is considered a research participant. In Canada, the Tri-Council Policy Statement (2010) suggests institutions should not be protected in this way. In the United Kingdom, the Framework for Research Ethics offers space for a similar argument to be made (Economic and Social Research Council, 2010, p. 29) and this is also how Cordner and Thomson (2007) interpret the National Statement in Australia. The Canadian Statement recognizes that 'social science research that critically probes the inner workings of publicly accountable institutions might never be

conducted without limited recourse to partial disclosure' (p. 37). As a result, researchers are not required to obtain consent from those corporate or government organizations that they are researching, nor are such institutions entitled to veto projects, though private organizations may refuse researchers access to records or create rules governing the conduct of their employees that might make it difficult for those employees to cooperate with researchers. However, even in these situations, the research cannot involve more than minimal risk to participants (Article 3.7(a)), which might make it difficult for researchers to work with whistleblowers in some jurisdictions. The European Research Council's (2010) draft Guidance Note for social science researchers warned against allowing powerful figures or organizations the right to withdraw or withhold consent for fear of leaving social scientists 'without even the most basic rights to make enquiries by other social groups, such as investigative journalists, or even ordinary citizens who might confront such figures at public meetings' (p. 11).

Despite these moves by agencies to allow covert research under certain circumstances, the use of covert methodologies is in serious decline (van den Hoonaard, 2011). Indeed, some research ethics committees are even unwilling to allow researchers to analyse documents freely available under Freedom of Information legislation unless they have the consent of the authors (McKenzie et al., 2010).

## Conclusion

---

Drawing on the principle of respect for persons (Chapter 3), a requirement that researchers should obtain informed consent from participants might seem relatively uncontroversial. Designed to combat a series of appalling abuses that had occurred in human experimentation, codes of research ethics (Chapter 2) generally require researchers first to explain to participants the nature of their research and the potential consequences of involvement. Then, before research can commence, participants need to agree to taking part in the research on the basis of a fully informed and voluntary decision. As part of the consent process, researchers have developed a range of tools for consulting and communicating with potential participants and for checking that participants understand the implications of the consent process.

However, in practice, the requirements of informed consent are anything but straightforward in the social sciences. First, the formal nature of the consent process that has been mandated by national codes or local committees can compromise both the possibility of gaining genuine consent and of providing assurances of anonymity. Second, some argue the assumption of individual autonomy within informed consent protocols fails to recognize the coercive

nature of some institutional, community and family-based relationships. Conventional consent requirements also impose Western notions of autonomy on societies where communal decision-making structures have greater prominence. Finally, researchers claim requirements for informed consent are not always necessary or appropriate and that work in public spaces or involving public officials should occur without informed consent. In addition, and more controversially, some argue deceptive experiments and covert research might be justified in particular situations by reference to the balance of risk and public benefit. Although some national codes have ruled against covert research, recent Canadian, British and European regulations suggest a greater willingness on some occasions to sanction research that does not have the consent of all research participants.

In short, the regulation of informed consent could operate in such a way that it protects the interests of vulnerable groups from harmful research carried out by more powerful organizations such as government agencies. Alternatively, it could protect powerful agencies from scrutiny by independent researchers by robbing researchers of one of their most powerful methodologies, covert research. Various jurisdictions and institutions have continued to take different positions, and it is unclear in which direction future regulators will move.