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3 Informed consent

Introduction

Informed consent is a central concept in ethical research practice and is one of the key principles underpinning professional guidelines for social scientists (see for example, British Psychological Society, 2009; British Sociological Association, 2002; Social Research Association, 2003). It involves providing participants with clear information about what participating in a research project will involve and giving them the opportunity to decide whether or not they want to participate. Specifically, research participants need to be made aware of: what the research is about; why it is being conducted; who is funding it; what will happen to the results and how they will be disseminated; what their participation in the project will involve; what the potential risks and benefits of their involvement might be; and, how issues of anonymity and confidentiality will be managed. Potential research participants should also be made aware that they are not obliged to take part and that they can withdraw from the study if they later change their mind about participating.

While at first glance informed consent may appear a relatively straightforward issue, a closer examination of the issues involved reveals that the process is far from straightforward. Social researchers have to balance a number of factors in managing issues of informed consent. Obviously they have to comply with any legal frameworks and regulation as discussed in chapter 2 but additionally they have to balance a range of sometimes competing interests, such as the aims of the research, what they consider to be the best interests of research participants as well as the interests of formal or informal gatekeepers. They also have to operationalise and be reflexive about issues of 'information', 'consent' and 'competence'. This chapter explores general issues of informed consent as they apply to qualitative research across methodological approaches.

Notions of informed consent imply that participants will always be fully informed about what participating in research will involve. While recognising that intentions to 'fully inform' participants may be problematic, which is discussed below, it is also important to note that there are some research projects in which participants cannot be fully informed about the research before it takes place; to do so would render the research impossible to undertake. Various research projects in psychology, for example, explore behaviour in specific contexts that would change if study participants were made aware of the aims of the study. In research projects such as these, participants are consented to the research on the basis of limited or false information about the study aims but they should always be fully debriefed after the data have been collected and at this point be given full information about the study and have the opportunity to give full consent for their data to be used; they would be expected to have the right to withdraw themselves, and their data, from the study if they wished to do so. In the light of concerns raised about unethical experiments conducted by social psychologists in the 1960s and 70s, such as the well-known Milgram experiment on obedience to authority and the Stanford Prison experiment (see <http://www.experiment-resources.com/milgram-experiment-ethics.html>), there are very strict ethical controls on how informed consent is managed in studies when some level of deception is necessary for the research to be conducted (see British Psychological Society, 2009).

Covert research is another type of research in which informed consent prior to the research commencing is not possible. There have been some important studies which have conducted research covertly, particularly in the area of criminology. Typical examples are studies of football hooligans, of neo-Nazi groups and of corporate activities (see Scratton, 2004). Some proponents of covert research have argued that it is in the interests of the general public to expose how some organisations or institutions operate and, in some cases, the only way this can occur is through covert means. However, various criticisms of covert research have been raised including that it violates the principle of informed consent, invades privacy, betrays trust and 'spoils the field' for other researchers (for a discussion of these issues see Herrera, 1999; Homan and Bulmer, 1982; Homan, 1991; Punch, 1986; Spicker, 2011). In the face of increasing ethical regulation of research, research conducted completely covertly has become relatively rare. Nevertheless, it is still the case that much research, while not expressly covert, may take place without participants being fully aware of to what

they are consenting. The challenges to achieving informed consent in research that aims to do so are the focus of the rest of this chapter.

Providing information

The provision of information about a project is an important part of ensuring that potential participants understand what participating in a research project might entail. However, many issues need to be taken into consideration in making decisions about this; these include how much information to provide, when to provide it and how often to repeat it. In terms of the *amount* of information to provide, it is clearly important to provide comprehensive information about the project so that participants can understand what being a participant will involve for them. However, giving very comprehensive information that runs to several pages is likely to be very offputting; not only are people unlikely to read it or take it in, it also risks putting them off participating. Ethical regulation, particularly for research conducted in health care settings and subject to review by the National Research Ethics Service (NRES), may pose severe restrictions on researchers' ability to provide information in a non-standard way. The same applies to research reviewed by Institutional Review Boards (IRBs) in the US.

Consideration of *how* information is provided is also important. It is obviously crucial that information is presented in a user-friendly way. This involves giving consideration to the layout, colour, size of text, type of language and the inclusion of graphics in the provision of information. For researchers working with children, young people or groups with limited comprehension, innovative ways often need to be identified to engage with participants to enable them to understand what participating in a study might involve. This is likely to involve keeping written information to a minimum and incorporating pictures and other graphics into the information provided. Researchers have experimented with a range of ways of providing information to meet these needs including the use of photos, comic strips and video (Clarke *et al*, 2011).

A further practical issue involves consideration of *when* to provide information. In some research contexts, particularly if the research is complex, it may be appropriate to provide some introductory information to potential participants about the research and to provide full information only if they express an interest in participating. This is one way of dealing with

potential information overload for participants. In longitudinal studies or research with repeated stages of data collection it may be appropriate to provide information, and gain consent, for each stage of data collection to ensure that participants give their continuing consent to participate in the study. This approach highlights the importance of viewing consent as a process that is ongoing throughout a project rather than as a one-off event that occurs when recruiting people to a study. Some researchers, regardless of the type of study or its methodology, view adopting a model of 'process consent' as appropriate, in which consent is discussed and negotiated throughout the whole period of a study, because it ensures that participants are truly giving informed consent (Goodenough *et al*, 2004; Cameron *et al*, 2004; Cutliffe and Ramcharan, 2002). This is an approach adopted particularly by researchers working in participatory research paradigms. Renold *et al* (2008) provide a good example of this approach in their study of the everyday lives and identities of children in care in which consent was negotiated at all stages of the project:

Children's 'consent' forms (requested by the university ethics committee) were purposively constructed as open-ended, partial and provisional, ensuring that children and young people could choose how to engage in a research project. Our overall aim was to use a language that framed their participation as always negotiable. For example, they could choose whether or not they wished to sign the consent form and a designated part of the leaflet was formed in which they could outline their own expectations or desires about the project and our own role as researchers ... our approach [was] to engage in an ongoing dialogue from the outset, which involved developing personalized ethical protocols 'in the moment' with children and young people. (Renold *et al*, 2008: 443)

Underlying these practical issues of how much information to give, how to present it and when and how often to give it, are a number of challenges inherent in the research process which give rise to ethical dilemmas that impact on the decisions that researchers make about these issues. The first is the difficulty in providing comprehensive information to research participants about a study. In qualitative research the specific focus and outcomes of a research study, and perhaps even the phases of data collection, are often not known at the start of a study as study design is generally emergent. So, for example, at the outset of a study, a general research

focus or set of questions may have been designed but the number of study participants, the number of interviews to be carried out with each individual and the specific direction of the research is often dependent on the data collected and the emerging analysis. This is particularly the case for ethnographic research.

A related issue concerns the ways in which the data collected will be written up and disseminated in public arenas which is unlikely to be known at the start of a research project; indeed, the dissemination of research findings may continue for many years after the completion of a project. While researchers have varying views about whether or not consent should refer only to participation in a study rather than the way data are used in publications it is, nevertheless, an important issue for consideration in relation to consent and one which links closely to issues of anonymity and confidentiality and ownership of data. Clearly if data are in any sense 'owned' by participants (such as photographs they have taken) or if participants are potentially identifiable, then consent needs to be extended to the ways in which data are used. The point here is that the ability to give comprehensive information at the beginning of a study about what participating will involve for an individual and what will happen to the data produced is often impossible. It is also the case of course that it is impossible to know what participating in a research project will be like for specific individuals. Researchers cannot know what particular issues an individual might feel sensitive about or find distressing or what the experience of participating will be like for them. Various authors have noted that it is unlikely that participants can ever fully understand to what they are consenting and what researchers' intentions are (Miller and Bell, 2002; Prosser, 2000; Wiles *et al*, 2007). The best a researcher can do is to aim to give optimal information, to anticipate what risks could arise from the project and to inform participants of them, to consider the stages at which consent is necessary and to make plans for achieving such consent.

A second challenge inherent in the research process is that it is often difficult to provide information (and gain consent) from everyone involved in a research project. This is particularly the case when conducting research in public settings, such as at public events, in shopping malls, libraries, art galleries, schools or hospital waiting rooms. In such cases it might be possible to inform key individuals but providing detailed information to everyone who might be observed or in some way 'participate'

in a study in a public setting is likely to be impractical if not impossible. It is generally the case that researchers attempt to inform people in public arenas that research is being undertaken by, for example, putting up posters informing people about a project and when data collection is taking place. This provides the possibility for individuals to remove themselves if they do not wish to 'participate', or, if practical, request that they are excluded from data collection. Even in research in less public settings, such as in people's homes, it can be the case that others contribute, such as in cases when a spouse or friends of a research participant are present during an interview and contribute to it. It is a moot point whether or not people who have contributed in a minor, and unexpected, way to a research project should be considered as participants for whom consent is needed. In general, this is likely to depend on the level of their involvement.

A third challenge involves the role of gatekeepers to research participants. Some research projects necessitate researchers gaining consent from various gatekeepers, such as managers, head-teachers or hospital consultants, before it is possible to approach the individuals who are to be invited to be research participants. While gatekeepers may need to give permission for individuals in their employ or care to be approached, this does not negate the need to seek consent from the specific individuals being invited to participate in a study. It may be that gatekeepers view themselves as able to consent for others they are responsible for, but researchers should ensure that in addition to gatekeeper approval, approval from individual participants is also sought. This can be difficult to do in some institutions where gatekeepers view themselves as in a position to give consent on behalf of those for whom they are responsible or who are in their care as may be the case in prisons or schools. Even if approached to give consent, the extent to which consent is freely and voluntarily given in contexts in which power dynamics form part of the relationship with the gatekeeper can be difficult; schools, prisons and residential institutions are clear examples where gaining consent from participants may be difficult because of a culture of compliance. In cases where someone in a powerful position in an organisation who has sanctioned a research project will know that an individual has refused to participate, it may feel that, in effect, an individual's choice whether or not to consent is limited. The onus is on researchers to identify ways in which research participants are enabled to make decisions whether or not to participate in research, free from any influence from gatekeepers.

This will involve researchers spending time with participants to explore their wishes. It may also involve identifying ways to keep their decisions confidential from gatekeepers. Heath *et al* (2009: 33) identify a range of strategies that researchers working in educational contexts have used to enable children and young people to decline to participate in research without their teacher's knowledge. These include providing alternative activities for participants to do when ostensibly participating in research. Research with children and other (so called) 'vulnerable groups' who are viewed as lacking the 'capacity' (or 'competence') to give consent raises related but specific issues, and these will be explored in a separate section in this chapter.

A fourth challenge concerns operationalising participants' right to withdraw from research. Part of informed consent concerns giving people the right to withdraw from their participation in a study at any point. This implies the need for researchers to ensure that they have people's ongoing consent to participate in a study (as discussed above) and that they are sensitive to recognising participants' expressions of desire to opt out of a study. It is generally expected that information sheets and consent forms would state that participants have the right to withdraw from a study at any stage. However, researchers have noted that it is common, particularly for some groups, to be reluctant to state they do not want to continue being involved with a project (Alderson, 2004). So, for example, children might find it difficult to tell an adult that they no longer want to participate in a study or that they do not want to answer a particular question. The same issue can apply to people in a range of contexts because of the power relations that can exist between the researcher and the researched or simply a lack of awareness that they can say no to something to which they have previously agreed. Researchers need to be vigilant to participants' unspoken expressions of reluctance to continue to participate during data collection, such as an apparent lack of interest or irritation with the data collection (see Langston *et al*, 2004; Rodgers, 1999). In research with children and people with limited communication, some researchers have used 'stop' cards that participants can hold up if they do not want to answer a particular question or no longer want to participate (Wiles *et al*, 2005). If this type of method is to be used it is important that participants practise using it before the data collection proper commences.

In reality, wholesale promises that participants can withdraw from a study at any time may be difficult to uphold and researchers need to think through the process whereby they can manage individual requests to withdraw from a study. It may be that enabling participants to withdraw is actually time-limited. While it may be straightforward for individuals to decline to participate in a specific phase of data collection, the withdrawal of data from an individual once analysis has taken place can be difficult, if not impossible. The limits to withdrawal from a study need to be made clear to research participants.

A final challenge is that, in some areas of research, people are often keen to take part because of an interest in the topic, because they do not want to appear unco-operative by saying 'no', because they are unaware of any risks that participation might involve or because they trust the researcher. In these cases, study participants often disregard researchers' explanations of what the research will involve or are reluctant to take the time needed to read information sheets properly. It can be very difficult to be sure that participants understand what they are consenting to in such contexts. One interviewee in a study on informed consent for example noted (Wiles *et al*, 2007: 6):

We do what we can just to hold back young people's enthusiasm for taking part because on the whole most young people are very keen to take part and to be listened to... we as researchers can be sort of overwhelmed by young people's enthusiasm and just think "yeah they understand, fine let's get on"... "that's informed consent" and I, you know, I don't think it is... they just think "oh great, this sounds fun".

Encouraging participation: incentives, encouragement and acknowledgement

The issue of whether or not some form of recompense, either financial or material, should be given to research participants as part of the process of consent is a subject of some debate. Recompense can be viewed as an incentive or inducement that may offer considerable encouragement for some groups to participate in research, who might without the 'reward' offered decline to participate. On the other hand, some researchers view such 'rewards' to be a just recompense for the time and effort of being

involved in a research study. Nevertheless, the issue of payments raises questions about the role of 'rewards' when these are offered as part of the information given to participants about a study and whether this impacts negatively on the extent to which informed consent can be freely given.

It is clearly important that study participants are not out of pocket as a result of participating in research; travel expenses and any expenses relating to loss of income as a result of participating in research cannot be seen as an undue inducement. Payments, or other rewards such as gift vouchers, might arguably be viewed in a different light. Decisions about offering 'rewards' of some type are hampered by the fact that some groups, particularly various professional groups, are unlikely to agree to participate in research unless they are paid for their time. This has led some researchers to the view that, in the interests of fairness, all research participants should be paid a fee, not just those who demand it. In relation to 'hard to reach' groups, who have been traditionally excluded from research, ways need to be identified to encourage participation and these might include some form of 'appropriate reward'. Whether or not the importance of gaining insight into these previously excluded groups should over-ride concerns about incentives would need consideration and justification. There is also the issue that some researchers, particularly those working in areas of deprivation and need, may view it as important to be able to 'give something back' to participants by way of acknowledging them for their time and effort. Such 'rewards' might be personal to an individual participant or to an organisation or community. In Smyth's (2004: 53) study on segregation in South Africa, for example, food was given to interview participants and a donation made to a local organisation that worked in the community. The challenges that 'rewards' for participation pose for informed consent can be offset by not informing participants that they will be paid until after they have agreed to participate. In this way, any payment or benefit becomes a 'thank you' for participating rather than an incentive. The difficulty with this is that it is not always possible to keep this a surprise when research takes place among a bounded group of participants, as word of mouth is likely to circulate quickly so a 'thank you' can soon become an incentive.

Recording consent

The process of gaining consent involves researchers obtaining evidence that participants have consented to take part in a research project and have an understanding of the key issues involved. Consent should cover a general agreement to participate as well as confirmation that participants understand how data will be recorded, how anonymity and confidentiality will be managed and how the study will be disseminated. If specific consent is needed for the use of material owned by participants and/or it is intended that data will be archived for secondary analysis, there should be a space for participants to indicate whether or not they consent to this. Where the research design is complex or where consent is sought for a range of different activities, a consent form should include options so that participants can give or withhold their consent for each of them.

Ipohfen (2009: 74) notes that consent 'should be gained in the most convenient, least disturbing manner for both researcher and researched'. In practice it is common that researchers use signed consent forms; indeed, with the rise of ethical regulation signed consent forms have become the norm in social research. The perceived advantages of using signed consent forms are that they increase the likelihood that participants understand what participation involves and that they protect the researcher from any subsequent complaints from study participants (Coomber 2002). However, asking an individual for a signature can be problematic in some research contexts, particularly in research that relates to socially unacceptable behaviour or where participants need protection. Researchers such as Coomber (2002) and the Domestic Violence Research Group (2004) have noted that the use of signed consent forms may compromise issues of confidentiality and anonymity which are important issues where participants are in need of protection. Participants may fear that signed consent forms may make the information they provide traceable to them which may put them at risk of physical harm (in the context of research topics such as domestic violence) or vulnerable to potential investigation and prosecution by the criminal justice system (in the case of illegal activities). Coomber (2002) has noted that individuals may want to protect their identities from the researcher and expecting them to divulge it runs counter to other ethical principles. He notes that individuals involved in illegal activities who are asked to sign consent forms are unlikely to want to participate in research and, if they do so, they are likely to give a false

name, thereby making the process meaningless. Furthermore, Coomber notes that signed consent forms are not in the interests of researchers as they may force them to be complicit in the prosecution of research participants which would contravene researchers' responsibilities to participants.

Additionally, signed consent is problematic when working with people who are illiterate or have language or communication problems or indeed when working with people who do not have good command of the language in which the research is taking place. It is also the case that the need to obtain a signature in other contexts might be problematic in that it makes the process a formal one and this might be seen as off-putting for some people. Researchers have developed a range of ways of obtaining consent without the use of signatures which may be appropriate in some circumstances, such as the use of tape-recorded consent, providing marks on a consent form or, in the case of people with limited verbal communication skills, holding up red or green cards to indicate yes or no. While the opportunities to use alternatives to signed consent forms may be limited by ethical regulation, nevertheless a case can be made, in certain circumstances, for different approaches to recording consent. The challenge for researchers is to find a way to record that study participants give their informed consent to participate in a project. Signed consent does not necessarily achieve this any better than other methods.

Consent in online research

Online research raises particular challenges for consent which differ according to the specific online research method being used. More detailed information on these issues can be found in Hooley *et al* (2012), Ess (2002) and on the Exploring Online Research Methods website, <http://www.restore.ac.uk/orm/ethics/ethcontents.htm>.

In relation to online interviews with people identified through personal contacts, online forums or discussion groups, consent can be gained through the use of a consent form, either in hard copy or electronic. One difficulty raised is that in the virtual world it is impossible to know if a study participant is who they say they are. Assessing their capacity to give informed consent may be difficult and it may not be possible to ascertain their age, status or vulnerability. More significant challenges in relation to informed consent are raised by online ethnography. There are often

difficulties in identifying and providing information about research, and gaining consent, from all members of an online community who may be observed. As Hooley *et al* (2012) note, in online communities there are a small number of participants who are very active and a larger group who may interact with the community only sporadically but who remain part of the community. Maintaining on-going consent with what may be a changing group of participants is also problematic. Some researchers may view it as appropriate to observe behaviour in an online group without the consent of the participants. This might sometimes be done in the early stages of a research project when a researcher is seeking to understand how a community operates and how they might best introduce their research project to the group. This 'lurking' in online communities has been identified as unethical and potentially damaging to the group observed. While it may not be necessary to gain consent from all participants prior to observing an online group it is nevertheless essential that participants are aware of a researcher's identity and their interest in the group. Kozinets (2010: 148) has identified the central tenets of ethical research practice in online ethnography which include the need for researchers to openly identify themselves as researchers, to describe their research focus and how they will conduct their research with the group.

There are some types of information provided in online environments which are viewed as 'public' and for which consent for their use is perceived as unnecessary. This refers largely to postings for mass and public communications. There has been much debate about what is public and what is private on the internet and it is recognised that users may have varying views about the public or private nature of their contributions. It has been suggested that informed consent should always be sought for research focusing on communications which people view as private and which take place in private or semi-private forums but that this may not be essential in open access forums which are acknowledged and understood as public. The Association of Internet Researchers (Ess *et al*, 2002: 5) notes 'the greater the acknowledged publicity of the venue, the less obligation there may be to protect individual privacy, confidentiality and the right to informed consent'. See also chapter 7 for a discussion of these issues in relation to digital and e-research.

Capacity to consent

There are some groups for whom questions of capacity or 'competence' to provide consent are raised. These groups include children and young people, people with intellectual disability and people with some physical and/or mental illness and disability. These groups of people are sometimes referred to as 'vulnerable' in relation to research; however, different issues are raised in relation to consent according to the specific capacity issue that is raised. If people are not able to understand what participating in research will involve, to weigh up the risks and benefits to them of participating or to reach their own decision about this and/or other matters that affect their lives then they would be assumed to lack capacity. Specific issues are relevant for research with children and young people and these will be addressed below.

If research is being conducted in England and Wales with adults who lack the capacity to consent then the 2005 Mental Capacity Act applies. In accordance with the Act, researchers must consult with someone close to the individual to advise whether s/he would want to be involved with the study. In all cases proposals for the research need to be assessed by an approved NHS or social care Research Ethics Committee (see <http://www.ethicsguidebook.ac.uk/Mental-Capacity-Act-118>).

Assessing capacity to consent is, in many cases, a judgement made by researchers. Many researchers believe it is possible to explain research in ways that the great majority of participants, even young children and people with disabilities, can understand. This involves being sensitive to the needs of particular individuals, providing appropriate materials to help to explain the research and engaging with them in ways that suit their styles of communicating. Rodgers (1999: 428), for example, notes in her research with people with learning difficulties that 'given careful explanations, many people with learning disability can understand and make decisions'. Identifying ways in which individuals can indicate their wish to discontinue participating has also been identified as important and part of the issue of ongoing consent. This is likely to involve becoming familiar with the ways in which individuals convey assent and dissent. In relation to both of these points the ways in which this can be achieved is likely to be different for different groups and individuals.

Proxy consent, that is consent given by someone, usually a relative or carer, on behalf of someone else, is rarely used in social research. While

a proxy may be approached to assist in understanding whether an individual would be willing to participate in research, it is generally viewed as important that the assent of the individual concerned is also attained, and that this is monitored over the timeframe of the research. Certainly, ethical review committees would want a strong justification for the use of proxy consent. As noted above, many researchers hold the view that it is generally possible to explain a study in ways that someone can understand whatever (within reason) their level of 'competence'. If this is not possible, including an individual in a study raises significant ethical concerns and needs a strong justification in accordance with the Mental Capacity Act.

Research with children and young people raises a different set of issues and there is considerable debate, and some uncertainty among researchers, about researchers' legal obligations. In practice, unless there is clear guidance, interpretations of the age of competence to consent are varied. In law, children are generally seen as not competent to make decisions (in various areas of life) until the age of sixteen, although this has been challenged through the legal distinction of Gillick-competent children (see http://www.nspcc.org.uk/inform/research/questions/gillick_wda61289.html).

Gillick-competency is based on the assumption that a young person under sixteen years of age with 'sufficient understanding' can provide consent in their own right and that their parent has no right to override their wishes. The Fraser Guidelines set out by Lord Fraser in his judgement of the Gillick case in the House of Lords relate specifically to contraceptive advice but are regarded as applicable to social research. They imply that children under the age of sixteen, providing they can demonstrate an understanding of research, are able to participate in a project without their parents' permission. Masson (2004) notes that if a researcher has not sought parental permission (or consent), they are not at risk of legal proceedings brought by parents unless a claim of harm was made by the child. It is important to note that only the prospective research participant can consent to take part in research. Parental 'consent' relates only to consent to approach the child. Obtaining parental permission for the child to be approached is therefore distinct from the ethical principle of consent. Nevertheless, it may be good practice to seek permission from parents if not to do so might lead to upset on the part of parents given researchers' responsibility not to cause distress in the process of

conducting research (particularly from an ethics of care or virtue ethics perspective).

There are some areas of research in which researchers might view it as problematic for parental permission to be sought. Examples are sexual behaviour, personal relationships and drug use where young people might not want their parents to know about their involvement in specific behaviours or they might be concerned about the interest from their parents that involvement in the research might generate. Heath *et al* (2009: 27-28) provide some examples, both positive and negative, of the ways that research ethics committees have responded to researchers' proposals not to obtain permission from parents in research with young people on sensitive topics.

However, despite the Gillick ruling, many researchers do seek parental permission, as well as consent from children, for participation in research. Partly this is because establishing whether a young person has 'sufficient understanding' to give informed consent is problematic. An additional factor driving this is that institutional gatekeepers to children and young people tend to request parental permission (or consent) for children or young people to participate in research as a condition of gaining access. The advice from various guidelines in relation to research with children is that parental permission should generally be sought in order to protect children as well as researchers. However, this should always be in conjunction with consent from the children and young people themselves and parental wishes should not override those of the child; that is, if the parent gives permission but the child does not want to participate then they should be excluded from the research. A more problematic situation occurs if the parent refuses permission but the child wishes to participate.

Summary

Informed consent is not a straightforward concept. Obviously researchers must comply with any legal frameworks and regulation but additionally they have to balance a range of sometimes competing interests, such as the aims of the research, what they consider to be the best interests of research participants as well as the interests of formal or informal gatekeepers. They also have to operationalise and be reflexive about issues of 'information', 'consent' and 'competence'.

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