ETHICS AND MONO-DISCIPLINARITY:
POSITIVISM , INFORMED CONSENT AND INFORMED PARTICIPATION

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Abstract: There are a number of pressures on researchers in academia and industry to behave unethically or compromise their ethical standards, for instance in order to obtain funding or publish frequently. In this paper a case study of Deaf telephony is used to discuss the pressures to unethical behaviour in terms of withholding information or misleading participants that can result from mono-disciplinary orthodoxies. The Deaf telephony system attempts to automate multiple aspects of relayed communication between Deaf and hearing users. The study is analysed in terms of consequentialist and deontological ethics, as well as multi-loop action learning. Discussion of a number of examples of bad practice is used to indicate both the compatibility of ethical behaviour and good scientific method and that ethical behaviour is a pre-requisite for obtaining meaningful results. © 2005 IFAC.

Keywords: Disciplinary pressures, unethical behaviour, informed consent, positivism.

1. INTRODUCTION

Increasing recognition of the importance of ethical professional behaviour is illustrated by the development of ethical and professional codes of behaviour by growing numbers of professional bodies (Martin et al., 1996). The term ethics will be used in this paper, as it is commonly used to describe right and wrong conduct and motives in a professional context. However the distinction (Gluck, 1986) has been made between morality as concerned with right and wrong conduct and motives and ethics as the philosophical study of morality. One approach to analysing ethical dilemmas involves the application of different ethical theories. One of the simplest categorisations of ethics is into consequentialist and deontological (Martin et al, 1996). Consequentialist approaches are concerned with consequences and the balance between benefits and harms, whereas deontological ones focus on obligations and duties, generally regardless of consequences. One of the most commonly used types of consequentialist ethics is utilitarianism. This is

based on the maximisation of utility, generally expressed in terms of overall good, or maximising benefits over harms.

Consequentialism and deontological ethics each have both advantages and limitations. There are also serious drawbacks in the tendency to apply single ethical theories on their own to complex problems and therefore we wish to employ a multi-criteria approach that combines a number of different ethical theories, analogously to the use of multi-criteria optimisation (Hersh 2002). Ethical principles can also be classified as universalistic or absolutist and situation based. Absolutist approaches assume that a particular set of ethical principles is always valid, regardless of the surrounding circumstances, whereas situation-based ethics modify ethical principles or prioritise them differently to take account of the particular situation. Although in many ways more realistic, care has to be taken to ensure that the application of situation-based ethics is not used as an excuse to avoid hard ethical issues.

1.1 Pressures and Barriers to Ethical Behaviour

Most researchers and practitioners in academia and industry would prefer to behave ethically. However there are often pressures and barriers that make ethical behaviour more difficult. Probably the pressures most commonly thought of in this context are those relating to funding and publication. It is probably less commonly realised that disciplinary orthodoxies can also put pressures on researchers and practitioners to behave in ways that are unethical or at the very least ethically questionable. This paper will discuss the ethical dilemmas arising out of positivist pressures to withhold information from research subjects or participants. The particular case considered here concerns an investigation of attitudes to and experiences of using telecommunications systems in the Deaf community.

1.2 Deaf Telephony Case Study

The term Deaf with a capital D is used for people who identify with the Deaf Community and use sign language as their first language. A Deaf person must therefore make use of an interpreter to communicate with a non-signer. An interpreter or relay is also required when using telecommunications systems. For a Deaf user, Deaf telephony involves either a textual or video interface. Many Deaf people would prefer the use of video, as it allows them to communicate in sign language, whereas text requires them to use a second language such as English. Currently relay systems,

such as Typetalk in the UK, involve a human operator 'translating' between text and speech to allow communication between a Deaf textphone user and a user of a 'speech phone'. In our case study, the objective is to automate the relay as much as possible with text-to-speech and automated speech recognition (Tucker, Glaser and Lewis, 2003; Glaser, Tucker and Mashao, 2004). Of particular interest is to learn how to design, develop and measure the efficacy of human computer interfaces that can support the extended delays implicit in relayed communications.

Our system is built within an Internet paradigm. Deaf participants use an instant messaging client (on a shared PC situated in a Deaf community centre) to communicate with hearing users using fixed landline and cellular phones. We are not using video at this time. The system makes use of the open source Voice over Internet Protocol (VoIP) and modality conversion utilities. Due to poor 'free form' speech recognition for South African accented English, we have decided to use a human operator to relay speech to text.

Together, automated text-to-speech and human-relayed speech-to-text incur delays that can be measured in seconds. Our Deaf telephony project also attempts to automate other aspects of relayed conversation. An early prototype automatically matches up user capabilities between communicating parties upon login with user profiles (Lewis et al, 2003). Adaptation services and user interfaces are automatically assigned and linked into the communication stream, as appropriate, depending on user needs. For example, a Deaf user with good oral speech would have a profile of text in and speech out. This Deaf user would use the microphone on a PC to speak, and the speech would be sent straight to the telephone via VoIP and a gateway. When such a Deaf user communicates with a hearing user, only speech to text, and not text to speech automation would be required.

Our approach also attempts to automatically handle temporal variation in the communication process. Telephone exchanges are generally designed and implemented in a synchronous manner. However, due to the large (several second) delays involved, it is easier to conceptualize and design exchanges as chunks in an asynchronous fashion. Our current system consists of a mix of synchronous and asynchronous exchanges that we want to present to users as a seamless whole in the form of a slightly delayed and rather slow synchronous exchange. We are using the session initiation protocol in session mode for synchronous portions of the voice transfer, and page mode for asynchronous activity (Sun and Tucker,

2004). However, these system-oriented delays are only the technical part of the picture.

Other delays are due to the nature of the particular target Deaf community in Cape Town. Unlike Deaf communities in the 'developed' world, a 'developing' world Deaf community experiences more disadvantages than 'just' the lack of access to audio information or the lack of provision of signed information. The majority of this community experiences poverty, illiteracy and little or no access to information and communication technology (ICT) (Glaser and Tucker, 2004). Lack of ICT literacy in general is a huge drawback. Most participants have never used a computer before, do not own one, and must therefore use a community-based computer housed at the local Deaf community centre. This means that the time needed to travel to and from the community centre, as well as any waiting time to get on the computer or be shown how to use particular features must be factored into the delays of Deaf telecommunications. Like other new and inexperienced users, our Deaf users have poor technology skills, including slow typing speeds, further adding to the delays. There will then be the further delays resulting from text and speech being relayed by an automated, or semi-automated, relay.

Thus the proposed Deaf telephony system will be very different from the telephone experience that hearing and Deaf people in the 'developed' countries are used to, e.g. deciding to make a call and just being able to pick up a receiver or switch on a PC or textphone. Instead the process will be very slow and initially, at least, possibly also frustrating, as users learn to use the new technology. One solution to this problem of persistent delay is to employ human computer interface techniques borrowed from Instant Messaging. These techniques include awareness, presence and persistence. We are also using the opportunity of research based in a Deaf community, to engage the end-users as much as possible to enhance the design and development of the Deaf telephony interfaces to deal with these delays. This should then result in a design that is appropriate for this user community and which minimises any frustration they experience as a result of delays.

1.3   Informed Participation: An Ethical Issue for Deaf Telephony

Of course, Deaf (like hearing) users have little knowledge or interest in the mechanics of Deaf telephony or of the human computer interface techniques we wish to experiment with. However, they more than anyone else, have a keen sense of relayed communication, and the communication delays they experience in all forms of communication with hearing people. Insight into these issues can only be realized by us, the researchers, through careful and sensitive engagement with the Deaf community. Therefore, the main ethical issue that begs debate is: do we tell the Deaf community about our explicit aims of designing user interfaces to deal with macro scale delays, and if so how do we go about doing this? If we do not inform the Deaf community of our explicit aims, are we employing deception in order to achieve more 'pure' research results? We refer to the full communication of research goals to the participants as *informed participation*, which goes beyond the issues of informed consent. The remainder of this paper will examine this issue from a variety of perspectives: consequentialist, deontological and finally multi-loop action learning.

2.   THE ETHICS OF WORKING WITH HUMAN SUBJECTS

2.1 Informed Participation

Widely accepted and used principles for the ethical conduct of research with human participants include those of the British Psychological Society (BPS, 1990). These include the following main points:

- Voluntary informed consent. Investigators will inform all participants of the objectives of the investigation. They must agree voluntarily to participate in the research.
- Right to withdraw. Investigators will explain in clear terms to participants their right to withdraw from the research at any time, irrespective of whether or not payment or any other inducement has been offered.
- Deception. Withholding of information or misleading of participants is unacceptable.

Of particular importance to the Deaf telephony project is privacy of communication. Complete automation of text to speech relieves some privacy considerations, as it removes the need for the involvement of a human operator. However, we are using a human operator to relay speech to text. The participants must be aware of this, and feel comfortable with it. Other issues include destroying recordings (whether digital or analogue), and consent to the inclusion of names, images and video, for instance in website or conference presentations. Another useful approach that emphasises the importance of informed consent is Martin and Schinzinger's (1996) suggestion that

engineering should be treated as social experimentation. This requires participants:

- to have sufficient and appropriate information to make properly informed decisions.
- to participate voluntarily without any kind of coercion or deception.

A related ethical issue is recognition that new technology can have significant consequences on the lives and social relationships of both individuals and social groups. Many of these consequences may be difficult to foresee, but researchers still have an ethical responsibility to strive to reduce any negative impacts. Involvement of end-users is critical in identifying potential impacts and ensuring that they will be taken into account. Of paramount importance when conducting research in 'disadvantaged' communities is the issue of sustainability. Researchers have a specific ethical responsibility to consider and also to communicate clearly to end-users what will happen to the project and the technology when the research funding period ends. They also have an ethical responsibility to investigate other possible sources of financial support for the continuing provision of the technological and other benefits. Otherwise they are taking advantage of end-users and raising their expectations to then disappoint them.

Another important aspect of informed participation is genuine understanding of the level of risk for particular benefits. In some cases the general public has a very different attitude to risks from experts or regulatory bodies. Individuals are generally more willing to accept the risks from new technologies if they see obvious benefits. For instance mobile phones are very widely used due to the perceived benefits, despite the fact that there may be health risks (Blettner and Berg, 2000), but there is little definite information. This raises the question of how acceptable levels of risk for different activities should be determined. It also implies that present approaches by experts and regulatory bodies may be inadequate in ethical terms.

2.2 Competing Values?

It is an accepted principle in (scientific) research that carrying out measurements or obtaining information changes the system (of whatever type, including situations, industrial processes, interpersonal relationships and the positions of atomic particles) being measured. This gives rise to the problem of how to investigate the system of interest without significantly modifying it. In systems which involve people, the presence of researchers and the nature of the interaction between the researchers and participants

can contribute to modifying the system. The resulting issues of good experimental procedures and reducing distortion and error are outside the scope of this paper. What is, however, of interest here are the ethical issues arising out of situations in which it has not proved possible to find a methodology which allows the research to be carried out while both giving participants full information and not distorting the results.

There is then a potential conflict of values and imperatives. On the one hand it is clearly unethical to withhold or misrepresent information. On the other the research could have very significant benefits to society as a whole, particular groups of people or the environment. This then gives a particular representation of the old and frequently encountered ethical problem of the balance between means and ends i.e. when and whether is it justified to do wrong in order to achieve a (greater) good. In more technical terms this can be expressed as a conflict between the requirements of deontological and consequentialist ethics. Deontological ethics requires you to follow duties and obligations regardless of the consequences i.e. in this case to give all participants full and accurate information. On the other hand consequentialist ethics, such as utilitarianism, requires you to maximise positive outcomes regardless of principles i.e. to do the research and obtain the benefits even if you have to withhold information or deceive participants. A further factor is the fact that the results, whether in terms of knowledge or practical benefits to society, are to some degree uncertain. Therefore the likelihood of the expected outcomes being obtained also needs to be taken into account, leading to a slightly uncertain good outcome being balanced against definitely unethical means.

In many cases it is possible to obtain the desired results in more than one way. Therefore it may be possible to avoid the ethical dilemma by carrying out the research in another way. However, particularly when researchers are heavily influenced by disciplinary paradigms, it may be difficult to examine the research process and look for other ways of carrying out the research.

2.3 Avoiding Unethical Research

There is unfortunately a relatively long list of experiments which have ignored the rights of or been actively dangerous or otherwise damaging to the participants. Some of these experiments are well known and others less so. For instance Milgrim's (1963) study on 'memory and learning' involved

participants being instructed to administer 'painful but not dangerous' electrical shocks to a 'co-participant' (in actual fact a researcher) for incorrect answers to word matching questions. Participants who protested were pressurised to continue and told they could not withdraw and those who enquired about the painfulness of the shocks were told that there would be no permanent damage (Kamtekar, 2004).

This is a classic example of unethical treatment of research participants, who were deceived about the aims of the study (obedience to authority rather than learning), the identity of the 'co-participant', who is really a researcher and the fact that pressing a switch did not really apply an electric shock. They were also very strongly discouraged, if not physically restrained, from withdrawing from the study. The researchers apparently ignored the possibility of long term damage to the participants in terms of their self image and self confidence, resulting from the realisation that they had been willing to subject another person to painful electric shocks and do this purely in obedience to authority.

Another notorious 'experiment' which caused active harm to participants was the Tuskegee syphilis experiment (Jones, 1993), which involved a study of untreated syphilis in 399 black men by the US Public Health Service (PHS) over a period of 40 years (1932-72). The participating government doctors failed to obtain informed consent, deliberately misled participants with promises of free treatment and offered incentives such as hot meals on examination days and free physical examinations. Insufficient doses of the then current syphilis remedies were initially provided and then replaced by aspirins. The PHS took great pains to prevent the men obtaining treatment, including by getting 250 of them registered for exemptions from the draft in World War II. The US government only ended the experiment when the whistle was blown by Peter Buxton and the story appeared in the Washington Star in July 1972. However the PHS was unrepentant and claimed that the men were 'volunteers'. An out of court settlement of $10 million dollars was made to the men and their families and they received effective medical treatment for the first time. By the end of the experiment 28 of the men had died directly from syphilis and 100 from its complications, 40 of their wives had been infected and 19 children born with congenital syphilis. The participants finally received a government apology from President Clinton in 1997 (http://clinton4.nara.gov/textonly/New/Remarks/Fri/19 970516-898.html). The importance of (bio)ethics was recognised through an extension of the charter of the National Bioethics Advisory Commission and the provision of postgraduate fellowships to train bio-ethicists, particularly amongst minority communities.

In addition to the cynical disregard of the participants' human rights and rights as experimental subjects and racism in the study, it was not even good science. Scientific protocols were deficient from the start and the fact that the men initially received small amounts of syphilis medication distorted the outcomes of a study of 'untreated syphilis'. The study did not learn anything about the causes or treatment of syphilis or the control of venereal disease. This indicates that there may be a correlation between good practice in terms of ethics and good practice in terms of experimental procedure. Therefore some apparent ethical dilemmas may disappear if it is recognised that ethics is part of good scientific practice. This example shows very clearly why it is essential that all research participants (subjects) be given full information, as well as what can happen when research ethics are ignored.

The third example involves experiments about small children's responses to success and failure in which they were asked to build a tower and then one tower was 'judged' and declared the winning tower. However, although the children were given the impression that the 'judging' was serious, the decision about which tower 'won' was totally random (Apter, 1996). This is another example of deception of participants and their carers, both about the aims of the research and specific details such as the role of the 'judge'. The emotional impact on the children in terms of distress and, at least, a temporary loss of confidence on 'losing' was also ignored. In addition no attention was given to the possibility of confusion and distress resulting from the fact that the 'judging' process did not make sense, since the children were unaware that decisions about 'winning' and 'losing' were totally random, so that there was no possibility of increasing the likelihood of winning. The researchers also seem to have ignored the particular ethical responsibility to protect (small) children, as a specially vulnerable group.

Most of this research is in the domains of psychology and medicine. However the issues are also of relevance to engineering, due to the importance of involving end-users in the design, testing and development of devices, products and technologies. Any increase in involvement of end-users in the technology research and development process is in principle positive and is likely to give improvements in the resulting products. At the same time the highest ethical standards must be maintained to avoid abuses

and ensure that participants maintain their dignity and self-respect.

3. DISCIPLINARY ORTHODOXY AND POSITIVISM

3.1 Disciplinary Orthodoxy

Healthy discourse in any discipline needs to include the margins of that discipline. However, scientific gate-keeping is often used to ensure that only certain types of science and technology are given official sanction and that, if possible, proponents of unorthodox ideas are excluded from access to resources, including research grants, publication in respected journals and employment (Hersh and Moss, 2004). The prospect of paradigm shift can provoke very strong emotional reactions and a series of outraged objections, both relevant and irrelevant (Pugh, 1993). This is, at least to some extent, due to the perceived threat of a reduction in power (Johnson, 1988), with the most powerful people in an organisation deriving their influence at least in part from association with the 'constructs of power', making it very difficult for (other) members of the organisation to change or challenge paradigms accepted by the organisation.

This type of ethos is clearly not conducive to supporting original research or promoting the development of innovative ideas and artefacts. It is therefore likely to have an overall negative impact on research and can be considered 'bad' science. There will also be a tendency for new approaches to be discouraged if not actively suppressed. The exception will be paradigms and approaches which are promulgated by members of the established research community or their protégés. A resistance to the sharing of information will be an almost automatic consequence of this ethos. Thus there will be opposition to sharing information with research participants (in accordance with ethical principles), both because it may be contrary to disciplinary paradigms, but possibly even more as part of a(n unconscious) desire to retain disciplinary power. Sharing information puts research participants in a position to make decisions about their participation in the research and possibly also about the overall conduct of the research. However this could put them on a more equal footing with the researchers.

3.2 Positivism

Positivism is currently the dominant ideology in the social sciences. It was first formulated in the 1850s and has the following five main points (Dyer, 1995):

- Science is a unitary activity and research in the natural and social sciences can share the same basic assumptions, processes and procedures.
- Reality is what is available to the senses. Ideas can only be accepted as facts when tested against experience.
- The world of nature, including the social world, has strict laws of cause and effect.
- Scientific research is based on identifying the causal links which explain natural phenomena.
- Science should only be concerned with matters of fact i.e. what can be objectively measured and neutral on values i.e. what ought to be.

Positivism implies that human behaviour and experience can be investigated in the same way as natural phenomena in the natural sciences. This leads to a process of research involving the careful observation of objectively defined phenomena and quantitative measurement of variables, frequently under controlled experimental conditions. However the variability of human behaviour can complicate this approach. What is problematic in ethical terms is the assumption that science should only be concerned with facts and not values. In order to behave ethically it is generally necessary to consider values. The fact that research can be carried out in a particular way, for instance without giving full information to research participants, does not make it ethically acceptable to carry out research in this way. Thus there is a need for the reintegration of values with facts to give ethical research behaviour.

3.3 Human Centred Methodologies

One way to do this is to become more human-centred. Action research initiated by Lewin (1948), has been widely adopted in the field of information systems in order to link technology, the work process and employees. Action research prescribes iterative cycles of problem diagnosis, planning, implementation, observation and critical reflection. Sensitivity to the user community's needs and feelings is central. A variant of action research, called critical action research, has a particular emphasis on the empowerment of groups (Stringer, 1997; Carr and Kemmis, 1991). It involves supporting and encouraging change in a community by facilitating action through working together with the community members. This stress on collaboration with end users

and iterative cycles of development are also important components of the participatory design approach to (technology) development (Muller, 1991, 1998). Participatory design has been applied successfully in a range of different areas. The Scandinavian tradition of participatory design emphasizes worker empowerment through close collaboration with users of the system.

3.4 Multi-loop Action Learning

Multi-loop action learning can be used as a tool for investigating and overcoming the barriers to ethical action. Single loop action learning is about changing behaviour, rather than learning about ethics and changing values, whereas double loop action learning involves changes in values (generally of individuals) as well as behaviour (Nielson, 1996). Triple and quadruple loop action learning involve changes in the underlying tradition or ethos of the organisation and surrounding society respectively, as well as changes in values and behaviour (Hersh, 2004). In our Deaf telephony case study, single loop learning would give a change in practice to provide full information to participants without a change in values, whereas double loop learning would lead to a change in values as well as practice, for instance, to a commitment to giving research participants full information in all circumstances. This change in values is likely to increase the effectiveness of communication with participants. Triple and quadruple loop learning would lead to a change in values in our organisations and the wider scientific research community respectively. Such a change in values could include increased understanding of the importance of the participation of the end-user community in the design and development process and this would again impact on the effectiveness of the communication of information.

3.5 Combining Methodologies

In our Deaf telephony case study we have drawn on techniques from action research, participatory design and positivism and combined them in such a way as to ensure maximum transparency to participants. We wish to be entirely up front about the goals of the research – to learn how to deal with delay, in the interests of both ethics and effective research practices. Therefore, we are involving the community members in the development process for the human computer interface for the Deaf telephony relay. When they are using the system, we are automatically collecting usage metrics and delays. We are attempting to correlate the measured delays with users perceptions of these delays, as recorded in semi-structured interviews. In this way, we are constantly working the users'

feedback into the development process and also getting an objective measurement of how the users are actually using the system. The objective is to adapt the human computer interface to make the delays more tolerable to all end-users, Deaf or not.

4. CONCLUSIONS

Existing disciplinary paradigms based on mono-disciplinary research establishments, as well as these establishments themselves, can have a very powerful influence. One example of such paradigms is positivism, which may exert pressures to unethical behaviour in terms of withholding information from research participants. The importance of providing full information has been illustrated by a number of examples of the type of exploitative situations that can result otherwise. The application of multi-loop action learning shows how this problem is situated in the wider research and organisational context.

A consequentialist approach to the Deaf telephony case study might say that giving the participants full information could affect their responses and consequently the research outcomes with respect to evaluating various human computer interface techniques to deal with macro scale delay. However, this approach neglects the 'hard' science approach that an observer necessarily influences the observed system. It is better to take this as a given, especially with human subjects, and turn it to one's advantage. The deontological approach based on duties to give full information and ensure informed participation is essentially good scientific practice. For us, to fully inform the Deaf human subjects of the research goals is *both* 'right' by the subjects and 'good science'.

In our case study, the action research methodology requires careful and sensitive engagement of the target community, as their involvement is essential for the design, development and measurement of interfaces that deal with the Deaf telephony delay. However, the appropriateness of our choice is even better understood within the context of multi-loop action learning. Learning at the organisational and wider research community level could lead to a transformative shift in the way that research is carried out, resulting in a much greater involvement of the end user community and associated benefits to research in general.

In conclusion, we feel that good scientific method compels us to use informed participation – not just for the benefit of the human subjects, but for the *benefit of science*. As scientists we need to convince the

scientific community that our decisions and the resulting methods are appropriate for the experimental task. In a sense, we are asking the scientific community, or at least some sections of it, to rethink the engagement of human subjects in an ethical context. We hope we have shown that there is no incompatibility between the demands of good science and the demands of ethics and that doing the right thing in terms of ethics is what is also required by good scientific method (Bronowski 1990), namely informed participation.

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