

THE EFFECT OF CONFIDENTIALITY PRACTICE ON
PATIENTS' WILLINGNESS TO SEEK HEALTH CARE

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ABSTRACT

Although medical confidentiality is widely expected and protected, it is not absolute. Breach of confidentiality is permitted in various circumstances, but the patient perspective and the effect of reduced confidentiality on medical treatment are not well understood.

This thesis presents a qualitative exploration of patients' views about confidentiality, focusing on whether breach is acceptable when people are at risk, and possible effects on patients' willingness to seek treatment.

38 subjects from two settings (an epilepsy clinic and community mental health services) participated in interviews exploring hypothetical situations in which confidentiality might be breached with the intention of preventing harm.

Subjects valued confidentiality, but also supported breach of confidentiality for the protection of others in principle. The possibility of some patients being deterred from treatment was recognised, but this was not a major factor determining subjects' views. Confidentiality was only one component of trust in doctors.

Subjects expressed more concern for confidentiality when considering the situation relating to their own medical history. There was widespread support for discretion in responding to the situations, and confidence in doctors to make good judgements. Conversely, mandatory reporting was generally opposed, even in situations where current rules support such an approach.

Although subjects' views were largely supportive of current standards of professional conduct, there were indications that patients would prefer doctors to have more discretion than guidelines currently permit, and that greater information sharing for non-clinical purposes risks damaging the trust that patients have in doctors.

The views expressed reflected three underlying positions: appreciation of these may assist doctors in negotiating confidentiality rules with individual patients, and

policy makers in formulating policies that would have public support, while also protecting the interests of vulnerable groups.

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1 THE DILEMMA

You can trust doctors. They keep things confidential. They act in a patient's best interests.

Both doctors and patients might agree with such idealistic statements, but the reality is not so simple. It is widely, though not universally, accepted that when there is risk of significant harm, a doctor has wider duties than those to the individual patient, and that this may sometimes include a duty to divulge confidential information to others.

Determining if and when such breach may be justified raises many complex issues, but central to any disclosure is the intention to reduce or prevent the risk of harm. Yet, paradoxically, disclosure might increase the risk of such harm, if one consequence is to deter the individual patient, or a wider group of potential patients, from seeking medical help that could reduce risk.

If we accept that, in certain circumstances, risk reduction is more important than other ethical imperatives, we must still ask, does breach of confidentiality for that purpose actually reduce risk, or is there longer term damage to medical practice that, overall, will increase it? Might a policy of reporting certain things with the intention of preventing harm, actually lead to more harm? And, if so, how should that alter the threshold for such reporting?

This thesis will examine patient attitudes to some of these issues, in the context of the following clinical dilemma:

Faced with a situation in which a breach of confidentiality might reduce a risk, how should a doctor respond, how would patients react, and might that reaction lead to an increased risk in future? Is it better to reduce an immediate risk, to the possible detriment of future treatment, and possible increased risk, or is it acceptable to allow an immediate risk to go unchecked in favour of hoped-for, but necessarily uncertain, future therapeutic benefit and risk reduction?

2 CONFIDENTIALITY

2.1 A PROFESSIONAL DUTY

2.1.1 HISTORY

Confidentiality is a central feature of codes of medical ethics and practice (Gillon, 1984, 1985a; Havard, 1985a; Department of Health, 1996; British Medical Association, 1999; General Medical Council, 2009; Coggon & Wheeler, 2010), and is recognised and protected in law (W v Egdell, 1990; McHale, 1993; Z v Finland, 1997; Harbour, 1998). When confidentiality is discussed in other settings, medical confidentiality is often cited as the most familiar, or least contentious example of confidential communication (Reid, 1986; AG v Guardian Newspapers (No 2), 1988; Robinson, 1991). The Hippocratic Oath provides that:

Whatsoever things I see or hear concerning the life of men, in my attendance on the sick or even apart therefrom, which ought not to be noised abroad, I will keep silence thereon, counting such things to be as sacred secrets. (quoted in Kennedy, (1994) p637)

Of more direct relevance to medical practice in the 21st century, the World Medical Association's Declaration of Geneva includes the following provision:

I will respect the secrets that are confided in me, even after the patient has died. (BMA, (1993) p327)

However, as Gillon (1985a) has pointed out these rules are ambiguous: if some things "ought not to be noised abroad", it suggests that some others perhaps should be, and that they would not be "sacred secrets". Also "respect" for secrets may mean something less than absolute confidentiality, but in both cases the detail remains unspecified. In contrast, the World Medical Association's international code of medical ethics appears more robust:

A physician shall owe his patients completely loyalty

A physician shall preserve absolute confidentiality on all he knows about his patient (World Medical Association, 1993)

Such rules have developed not only as desirable in themselves, but as necessary for promoting effective medical practice. By enforcing strict standards of professional conduct, medical practitioners have been able to earn the trust of generations of patients, who have thereby been willing to confide in doctors details of their medical and personal histories that would not have been divulged to anyone else.

In their turn, patients have come to expect and rely on the discretion of doctors. There is considerable evidence that patients and the public expect and require confidentiality from their health care professionals (Schmid *et al.*, 1983; Appelbaum *et al.*, 1984; Roback & Shelton, 1995; Active Citizenship Network, 2002; Jones, 2003b; Sankar *et al.*, 2003). Despite some signs of reducing trust (Mills *et al.*, 1987; O'Neill, 2002b; Clark, 2006), generally doctors and other health professionals are both respected and trusted (1979; Mills *et al.*, 1987; Hallows *et al.*, 1998; Sankar *et al.*, 2003; Korts *et al.*, 2004; Mechanic, 2004; Clark, 2006; Howerton *et al.*, 2007), and belief in confidentiality is an important factor in that (Thompson, 1979; Gillon, 1987; 1995; Mechanic, 1998; Mechanic & Meyer, 2000).

There is less evidence as to whether patients are aware of the limits to confidentiality, or whether they approve of them; nor do we know what effect such limits might have on patients' willingness to seek help, or to disclose sensitive, clinically relevant, information within a consultation. Whether or not they are individually aware of current professional standards, through longstanding tradition the expectation of confidentiality is established and trust in doctors remains strong. Whether this can continue, in the face of changing professional practice, will be a theme running throughout this thesis.

Confidentiality may be breached for various reasons. Francis (1982) distinguished "convergent breach", where information is shared for purposes similar to the original consultation, for example within clinical teams, from "divergent breach",

where information is shared for significantly different purposes, such as the situations discussed in this thesis. He argued that patients generally have few concerns about convergent breaches, but generally oppose divergent breaches.

2.1.2 PROFESSIONAL CODES

While the statements above might be considered to represent ethical standards for the profession, in day to day practice most doctors will have greater regard to the mandatory rules imposed by professional regulatory bodies (in this country the General Medical Council; GMC) and by the law. The interaction between ethical, legal, and professional standards is a complex one. The legal rules will be discussed briefly in Section 2.3, but first the GMC regulations will be considered:

Patients have a right to expect that information about them will be held in confidence by their doctors. Confidentiality is central to trust between doctors and patients. Without assurances about confidentiality, patients may be reluctant to give doctors the information they need in order to provide good care. (GMC, (2009) paragraphs 2&6)

Such professional rules have evolved from the historical ethical principles quoted above, but they do more than merely restate such principles. They are strongly influenced by changes to legal requirements, but are more than guidance to lawful practice. Many of the GMC rules, including those relating to confidentiality are limited when “it is required by law”, and GMC rules have changed over time to accommodate legal changes, suggesting that its guidance is secondary to legal rulings (McHale, 2000; Crichton, 2001). But international codes of medical practice, such as the Declaration of Geneva, have been developed partly in response to concerns that “legal” practice may not always be “ethical” (Gerber, 1981; Emson, 1988; Dickens & Cook, 2000; Cordess, 2001b; Jones, 2007; Sokol, 2008a), and there is a clear role for professional standards that oppose unethical laws (Havard, 1985a; Emson, 1988; Lancet, 1995; Tur, 1998; British Medical Association, 1999). The

professional viewpoint is not always shared by others; for example the BMA Ethics Committee has:

found it difficult to convince both the government and society at large that apparently small compromises in confidentiality gradually erode patients' rights. (BMA, (1993) p37)

Codes of conduct for other professionals and in other countries contain similar provisions, although the details may often vary (Darley *et al.*, 1994; Cain, 1999). Although this thesis is couched in specifically medical terms, similar dilemmas occur for all health professions, albeit with different expectations from patients and public, which may ameliorate or exacerbate the conflicts. Differences which do occur, for example for social workers in relation to child protection issues, will not be explored in any detail here. Differences between countries are often greater than those between professions in the UK. These differences will not be explored in this thesis, although some international comparisons are drawn in Section 2.3.4 to emphasise that the current rules are not immutable or inevitable, but the result of choices, which could be made in different ways with different balances struck between confidentiality and disclosure.

2.1.3 LIMITS TO CONFIDENTIALITY

Despite being widely supported and expected, confidentiality within medical practice is far from total. Limits to confidentiality seem to be increasing (BMA, 1993), particularly in the case of release of confidential information to prevent possible harm to others (Cordess, 2001b), with growing expectation of reporting in such circumstances as:

- treatment for gunshot wounds (Houry *et al.*, 2002; Ovens *et al.*, 2009), knife crime (Hitchen, 2008) or other assaults (Shepherd, 1995, 1998; Houry *et al.*, 2002)
- treatment of illegal immigrants (Pritchard, 2001; Turone, 2009)

- non-accidental injury to children (Newberger, 1983; Berlin *et al.*, 1991; Hutchison, 1993; Bastable & Sheather, 2005; Department for Children Schools and Families, 2010; Rogstad *et al.*, 2010) or vulnerable adults (Welfel *et al.*, 2000; Department of Health, 2001)
- HIV infection (1995; Colfax & Bindman, 1998; Bayer & Fairchild, 2002), other sexually transmitted infections (Mathews *et al.*, 2001; Reddy *et al.*, 2002; Arthur *et al.*, 2005; Ryder & McNulty, 2009), and infectious diseases (Coker, 2000; Cuenod & Gasser, 2003)
- domestic violence (Shepherd, 1995; Bauer & Mooney, 1999; Department of Health, 2001; Houry *et al.*, 2002; Home Office, 2004)

There are also changes to practice such as:

- police access to records under PACE (Havard, 1983; Gillon, 1985a; Kellam, 1994; Harbour, 1998) and the use of medical data for criminal investigations (Jackson, 2000; Dyer, 2001)
- medical involvement in child protection procedures (Adshead & Mezey, 1993; Crichton, 2001; English, 2005; Department for Children Schools and Families, 2010), Multi Agency Public Protection Panels (Morris, 2003; Department of Health, 2004; Hewitt, 2004; Jones, 2007) and similar arenas (Shepherd, 1998; Barton & Quinn, 2002; Parish, 2003)
- arguments for lower standards of confidentiality for members of self-regulating professions, such as medicine, in the context of fitness to practice (Schouten, 2000; Magnavita, 2007; Peters, 2009; Adams *et al.*, 2010)
- notification in areas such as driver licensing (Morgan, 1998; Harris, 2000; Adshead, 2005; Appel, 2009; Drivers Medical Group, 2010)

It is right that standards of practice should change over time, in response to changing social expectations or to developing ethical insights (Miller & Thelen, 1987; Glancy, 1998; Clark, 2006). However the pace of change reflected above makes it difficult for doctors to keep in step with professional rules (Mahendra, 2001a). Perhaps more importantly, it also makes it difficult if not impossible for

patients to know whether, or in what circumstances, confidentiality will be breached. Evidence of patients' expectations will be discussed in Section 2.5.1, but it seems likely that many patients would be surprised by at least some of these exceptions. Patients may be as reluctant to disclose information when rules are uncertain as they would be if they knew that reporting was allowed: open-ended and changeable limits to confidentiality may be a greater barrier to trust than clear and explicit rules permitting breach in specific circumstances (Mechanic, 1998).

There are several broad exceptions to the duty of confidentiality within the GMC guidance, of which the most significant for the central dilemma of this thesis is:

Disclosure of personal information about a patient without consent may be justified in the public interest if failure to disclose may expose others to risk of death or serious harm. (General Medical Council, 2009)

We can distinguish two situations in which the GMC expects information to be disclosed. Firstly, where "required by law" a doctor is directed to follow the legal rule: no conscientious objection or "civil disobedience" in response to an unethical law is permitted, and the GMC does not appear to allow itself any professional discretion to scrutinise or challenge legal rules. Parliament and courts are given the ultimate role of resolving ethical issues¹, emphasising the GMC role as an external regulator rather than an independent professional body, and GMC guidelines have clearly changed in response to changes in law (Crichton, 2001). However we should note two limitations to this approach. Determining the precise scope and application of legal rules is not always straightforward, even for experts within a field (Gillon, 1985a; Mackay, 1990; Adshead, 1999; Jones, 2002; Huprich *et al.*, 2003; Clark, 2006). Legal rules are liable to change over time, meaning that mandated practice changes, even though ethical considerations may remain unchanged. A stark example is the way the *Tarasoff* decision fundamentally

¹ In earlier guidance the GMC accepted that "[u]ltimately the 'public interest' can be determined only by the courts"

General Medical Council (2004). *Confidentiality: protecting and providing information*. GMC, London. paragraph 26.

changed psychiatric practice in North America not because of changing ethical sensibilities within the profession but because of externally imposed legal rules (Stone, 1976; Givelber *et al.*, 1984; Appelbaum, 1988; Herbert, 2002).

Secondly, where no clear legal mandate exists, the GMC requires a doctor to undertake a balancing exercise weighing the benefits of disclosure against the value of confidentiality. No Code of Practice can cover every potential situation, and so the need for individual ethical decision-making remains (Dawson, 1994). The language of the guidelines appears to go beyond the legal rules in this area, which would suggest that disclosure should be exceptional, in response to clear and unambiguous risk, reflecting a significant public, as well as private, interest in the preservation of confidentiality (Lee, 1994; Department of Health, 1996; Harbour, 1998; Adshead, 1999; British Medical Association, 1999). Similarly, BMA guidance (1993) refers to “grave risk”. In contrast the GMC appears to envisage a lower threshold for disclosure, although where consent is actively denied the wording still refers to “exceptional circumstances” to justify breach.

2.1.4 CONFIDENTIALITY: ABSOLUTE OR LIMITED

In practice, therefore, confidentiality is clearly limited, even though the precise scope of those limits may be unclear or contentious. Most authors accept that some limits to confidentiality are both inevitable and justifiable, but a minority assert that confidentiality is a concept that cannot be subject to degrees, and that any limits to confidentiality render the undertaking meaningless (Driscoll, 1982; Nowell & Spruill, 1993).

Kottow (1986) argued that predetermined rules would leave medical practice open to being distorted for political or social ends, that allowing doctors discretion would lead to inconsistent and unpredictable decisions, and that for patients to have trust in the medical profession:

confidentiality cannot but be ... an all or none proposition.

More recently Kipnis (2006) has expressed a similar view, although a series of commentaries on his paper rejected his argument on various grounds. He argued cogently that reporting without a patient's consent adds nothing to risk management, because those patients who accept disclosure would consent anyway, and those who do not will be deterred from disclosing if reporting without consent is allowed, so that the information will not become known in the first place - a view also expressed by others (Smith & Meyer, 1984; Brahams, 1989). It has also been suggested that such rules would deter doctors from working in particular areas, or with particular groups of patients (Stone, 1976; Rudegeair & Appelbaum, 1992; Appelbaum & Zoltek-Jick, 1996; Jackson, 2000).

Bollas and Sundelson (1995) have argued, particularly in relation to psychotherapy, that absolute confidentiality is required, not only to allow patients to express feelings or concerns that might otherwise be reported, but also so that therapists are not consciously or unconsciously deterred from exploring areas that might give rise to such issues.

These arguments are compellingly made, and the principle which they advance seems attractive: how could any patient who was seriously concerned about confidentiality rely on a promise that could be unilaterally revoked at any time, and in circumstances which might cause him harm? As Bollas [quoted in Winer (2002)] expressed it:

The patient would not simply be mad he would have to be stupid.

Nonetheless such arguments seem to fail in the face of experience. Despite the very real limits to confidentiality described above, medical practice appears to continue without undue difficulty, and trust in the medical profession seems little reduced.

Some authors argue that confidentiality is unnecessary or overvalued (Fleming & Maximov, 1974; Beck, 1982; Warwick, 1989; Buckner & Firestone, 2000). Some do so from a theoretical standpoint, questioning whether it is really a required feature of medical practice. A few go further, to say that maintaining confidentiality where others are at risk is tantamount to collusion in causing harm, and that ethical

practice requires reporting, not least in order to set an example of responsible behaviour to an irresponsible patient (Samuels, 1986; Van Eenwyk, 1990; Shepherd, 1998). Although medical ethics often focuses on the relationship between a doctor and an individual patient, doctors also have wider duties to society (Adshead, 1999; Eastman, 1999): in certain circumstances a narrow focus on patient welfare at the expense of others may itself reduce public confidence in the medical profession (Wendler, 2010).

Others take a more pragmatic view, pointing out the many limitations to confidentiality that already exist, and observing that this does not seem to have altered the nature of medical practice (Shuman & Weiner, 1982; Mangalmurti, 1994; Buckner & Firestone, 2000). There are also those who, though lamenting the demise of confidentiality, argue that it is inevitably being eroded by social forces beyond the control of the medical profession, and that it is better to come to terms with that, compromising ethical standards so that treatment can continue, rather than insisting on standards that do not have the support of society (Gillon, 1985a; Weinstock & Weinstock, 1989).

There are several possible resolutions of this apparent paradox. Some patients may not present for treatment at all, and their numbers may be underestimated by clinicians who deal only with those patients who do present. Patients may censor the information they are prepared to share, and again the extent of this may be hidden from those who receive only the edited account. Such concerns may affect only a minority of patients, and the willingness of others to disclose may conceal this (Emson, 1988; Lee, 1994; Mechanic & Meyer, 2000; Jones, 2003b). Changes to the doctor-patient relationship which take place over decades may pass unnoticed: statements made by some authors in the past suggest that expectations have changed gradually but significantly (Emson, 1988; Royal College of Psychiatrists, 1990; Smith & Sutton, 1995; Mahendra, 2001a). Or there may be a tipping-point phenomenon, whereby gradual changes in confidentiality rules have little effect on patient behaviour until a critical point is reached, but once that point is passed, and trust is lost, there may be a sudden and discontinuous change which may be

impossible to reverse. If so, the medical profession needs to pay careful attention to such a possibility before the point of no return.

2.2 ETHICAL BASIS

At the centre of this thesis will be a scrutiny of what it means to behave, and specifically to practice medicine, in an ethical way. To do so, we must first consider how we can know what actions are, or are not ethical.

Ethical approaches are frequently classified as either deontological or consequentialist. Deontological ethics are based on absolute principles, with certain actions being judged to be good in and of themselves. Consequentialist ethics judge actions in terms of their effects and consequences.

Ethical positions can be justified by appeal to three different domains: theory, authority, and effect. By “theory” I refer to the existing body of philosophical and ethical thinking, much of which gives prescriptions either for specific action, or more generally for ways in which ethical behaviour is to be determined. By “authority” I refer to the many and varied rules, codes and guidelines which exist. By “effect” I mean a critical and detailed consideration of the consequences of adopting a particular position. The first two will help us to take an initial view of an ethical statement, but I will argue that it is a critical evaluation of the effect of an ethical statement that ultimately determines its validity.

Although this thesis adopts a broadly utilitarian perspective, this approach to ethical dilemmas is not without problems, and can appear to be value-free. Most people do not easily accept that “the end justifies the means” and would be uncomfortable with ethical judgements made solely on the basis of consequences. Deontological approaches will be considered briefly in Section 2.2.4: even if the utility of confidentiality is less than expected, there may be other cogent reasons for defending it.

2.2.1 UTILITARIANISM

Most discussions of this issue take a utilitarian view (Gillon, 1984; AG v Guardian Newspapers (No 2), 1988; McHale, 1993; Tur, 1998; British Medical Association, 1999; Marsh, 2003; O'Brien & Chantler, 2003; Slowther, 2006). It is argued that confidentiality must be guaranteed if patients are to speak freely and frankly to doctors, so that appropriate diagnosis and treatment can be given. If so, then failure to guarantee confidentiality will lead to non-presentation, misdiagnosis, or failure of treatment, and ultimately cause more harm than maintaining confidentiality. This concept, which I will term *deterrence*, will be central to the arguments developed later in this thesis.

Central to any utilitarian justification for confidentiality is a balancing of the risks and benefits consequent upon an action, a process which I shall refer to as the *utilitarian calculus*. Any action potentially has both positive and negative consequences, and it is central to utilitarianism as formulated by philosophers such as Bentham and Mill (Gillon, 1985b; Pettit, 1993), that the action should be chosen which leads to "the greatest good for the greatest number". There must therefore be some quantification of the likely outcomes of each action, and this approach is clearly evident in the GMC requirement to disclose where:

the benefits to an individual or to society of the disclosure outweigh both the public and the patient's interest in keeping the information confidential (General Medical Council, 2009 paragraph 37).

The potential benefits of disclosure, though difficult to quantify in practice, are straightforward in principle. It is hoped that, by disclosing information, some risk of harm will be reduced or eliminated. What potential detriments are to be weighed against this? For the individual patient there is clearly the possibility of direct harm from the reporting of confidential information. There may be negative consequences for them if others learn details of their medical history – which may include details of sexual behaviour, substance abuse, or fitness to undertake certain

activities. Even if there are no direct negative consequences, loss of privacy may itself be considered a harmful outcome.

What of deterrence? At first sight it may seem irrelevant: the patient has already presented for treatment and disclosed to the doctor. Diagnosis and treatment have, it seems, been decided. However much the patient may subsequently regret those choices, the moment for deterrence is past. There are however two ways in which deterrence remains crucial to the utilitarian calculus.

Firstly, the patient may now lose confidence in the doctor, and be deterred from seeking treatment or from frank disclosure in the future. I characterise such an outcome as *consequential deterrence*. Medical treatment is unlikely to be a single event, so consequential deterrence may impair future treatment, a negative outcome primarily for the patient, but possibly also for society, in terms of impaired public health and possibly in terms of an increase in the risk that prompted disclosure. Such deterrence may be restricted to dealings with an individual doctor who is perceived as untrustworthy, or may generalise to reduced trust in the profession as a whole. This form of deterrence is widely recognised in the literature (Kottow, 1986; Miller & Thelen, 1987; Ozuna, 1993; Hyman *et al.*, 1995; Sankar *et al.*, 2003).

Secondly, patients do not make healthcare decisions in a personal and social vacuum. The expectation of confidentiality, developed through generations of doctor-patient interactions, encourages and promotes openness. Breach of confidence by a doctor undermines that expectation, such that, potentially, many future patients may be deterred from seeking treatment or from disclosing information to doctors. I characterise this wider outcome as *anticipatory deterrence*. Clearly anticipatory deterrence will not arise from a single breach of confidence: the next section will consider whether a doctor can therefore ignore this risk, and consider only the outcome from breach on a single occasion.

Anticipatory deterrence is also discussed in the literature (Berlin *et al.*, 1991; Sim, 1996; Hodgkin, 2001; Huprich *et al.*, 2003; Crichton & Darjee, 2007), although it is less often addressed explicitly than consequential deterrence.

Deterrence, and consequent impairment of treatment, is one negative outcome of reporting, but not the only one. Less tangible harm, such as the loss of autonomy, or self-determination, could be taken into account not only by deontologists but also by utilitarians. Rarely does this seem to be the case. For example, Department of Health (2001) guidance on protection of adults advises breaching confidentiality in the patient's "best interests", but construes such interests narrowly as the protection from physical harm, rather than seeing it as being in a person's interests to have control over their own life, even at the cost of experiencing other harm. This contrasts with policy relating to consent (Department of Health, 2009), where a patient's autonomy and right to refuse treatment is given more weight than their physical health. Similarly, reporting concerns to child protection agencies is generally assumed to be in the child's interests, with little recognition that a child may also have an interest in preserving autonomy or accessing confidential treatment (Bamford & Heath, 1996; Hodgkin, 2001; Munday *et al.*, 2002).

It is crucial to recognise, as GMC guidance does, that society also has an interest in preserving medical confidentiality. Not only is it more broadly a social benefit to promote effective medical treatment for everyone, but there is also a benefit to society in ensuring that individuals receive good treatment. In the sort of dilemmas considered in this thesis, where without effective treatment a patient's condition might represent a risk to others it is important to recognise that deterrence, of either type, not only impairs treatment leading to poor health outcomes, but also potentially impairs risk management, leading in the longer term to an increase in the very risks that a breach of confidentiality was intended to reduce (American Psychiatric Association, 1984; Leeman *et al.*, 2001; Black, 2003; Chitsabesan *et al.*, 2006; Lowbury, 2006). The utilitarian calculus envisages maintaining confidentiality about current risks, at least in part, as a way of managing that risk and similar ones both immediately and in the future.

2.2.2 RULE-BASED UTILITARIANISM

Some applications of utilitarian thinking focus narrowly on the immediate situation: what will be the effect of a certain action on the outcome of this episode of treatment for this patient? However, choices made by individuals can, cumulatively, have effects which are much wider than the immediate case. If a decision-making process is valid, we must expect that similar decisions will be reached in very many similar situations, and the more appropriate question becomes; “What consequences would follow if doctors generally acted in a certain way, when faced with this sort of situation?”

Applied to the confidentiality dilemma, rule-based utilitarianism requires an assessment not only of the immediate consequences of reporting information, but also the consequences of a general policy of reporting in all equivalent situations (Gillon, 1985a; Cohen, 1990; Fisher, 1994; Huprich *et al.*, 2003; Bloch & Green, 2006). This dimension is frequently overlooked in discussions of such dilemmas: it seems likely that clinicians faced with such a situation may also focus on the particular case, rather than the general consequences.

There are parallels between rule-based utilitarianism and the “Categorical Imperative” proposed by Kant (O’Neill, 1993; Kant, 1998):

I ought never to act except in such a way that I could also will that my maxim should become a universal law.

This implies that rules for action cannot be valid if their universal adoption would undermine the conditions on which they are based: for example a rule that permits dishonesty cannot be valid, because widespread dishonesty would result in a society in which trust was lost, and the expected benefits of dishonesty would no longer accrue (Korsgaard, in introduction to Kant, 1998). Similarly, O’Neill has developed the concept of “principled autonomy”, in which an individual’s self-determination is limited by a requirement that it does not reduce the autonomy of others:

Nobody who is committed to principled autonomy can make deception of others basic to his or her life and action because deception cannot serve as a principle for all (O'Neill, 2002a, p98)

Applied to the dilemmas explored in this thesis, a rule that encompasses breach of confidentiality, overriding an earlier promise of secrecy, might be considered to contravene the Categorical Imperative, because the widespread adoption of such a rule would prevent the disclosures being made in the first place. Such a rule would therefore be self-defeating, and (in Kant's terms) *cannot* rationally be adopted as a universal maxim (O'Neill, 1989).

2.2.3 ROLE OF EMPIRICAL RESEARCH

Of the three domains identified above, theory, authority and effect, the third is the least explored, but is central to this thesis. Faced with an ethical dilemma, many authors appeal to authority, seeking to identify and interpret the rules applying to the situation, without discussing the reasons underlying them. So, many discussions of confidentiality will cite GMC rules, or legal precedents, as determinative. More thoughtful commentators often appeal to theory, examining and critiquing the basis for and effect of different standards of conduct, from a theoretical perspective, and may accept or reject the existing rules on that basis.

Relatively few authors seem to seek empirical evidence as to the actual effect of ethical rules which are applied. Particularly for utilitarians this is a counter-intuitive approach to adopt: the utilitarian calculus rests ultimately not on what theoreticians, however insightful, believe, but on what individuals involved in a situation actually do (Thompson, 1979; Kenney, 1982; Kottow, 1986; Quattrocchi & Schopp, 1993). Whether or not an individual patient, or the generality of potential patients, *will* be deterred from seeking treatment, and whether that *will* result in harm, is not a question that can be answered by theory alone. Only if there is good reason, grounded in empirical evidence, to believe that patients will be deterred by breach of confidentiality, could we be confident that the utilitarian basis for

confidentiality is justified. Conversely, evidence that patient behaviour is not significantly altered by disclosure practices would fundamentally weaken the utilitarian position.

Public policy, legal precedents and quasi-legal standards such as codes of practice and professional guidance are usually justified, explicitly or implicitly, in terms of a utilitarian calculus; that disclosure in certain circumstances is justified because overall greater benefit will result than there would be from maintaining confidentiality. Again, this utilitarian calculus is one that, in part, can be supported or undermined by an empirical enquiry into the views and behaviour of patients, but in the absence of such evidence the foundations of policy are necessarily shaky (Havard, 1985b; Whiteford, 2001; Sturm, 2002; Eastman & Starling, 2006; Pattison & Evans, 2006).

2.2.4 DEONTOLOGICAL APPROACHES

Deontological arguments for confidentiality in essence assert that it is something to be valued regardless of its positive or negative effects (Gillon, 1984; Mills *et al.*, 1987; Sim, 1996; O'Brien & Chantler, 2003). Commonly confidentiality is supported as a component of patient autonomy or self-determination: promotion of autonomy is often considered to be a fundamental good, taking precedence over other considerations (Gillon, 1985b; Seedhouse, 1988).

Warwick (1989) has argued that autonomy is a more fundamental principle than confidentiality, and derived from this an argument that, as long as a patient knows that confidentiality is not offered, and is free to determine whether or not to disclose information on that basis, there is no ethical imperative to maintain confidentiality, arguing that:

confidentiality is not a necessary component unless it has been promised.

This may serve to illustrate the limitations of a purely deontological approach: the patient's rights are unharmed, but the practical consequences may be to impair treatment, something which Warwick considered acceptable if it arose from patient choice.

Alternatively, confidentiality is sometimes justified in terms of fidelity or promise-keeping. Several authors have expressed concerns that doctors might be in the position of inducing patients to make disclosure by promising confidentiality, only to break that promise once the information has been obtained (Kottow, 1986; Herbert, 2002; Urquhart, 2008):

To use a promise of confidentiality to secure otherwise inaccessible information when it is known that such a promise may never be kept, is manifestly contrary to notions of fairness (Lee, 1994)

Therapists are placed into the disquieting position of masquerading as empathic clinicians who become undercover police agents by betraying patient confidences (Weinstock & Weinstock, 1988)

For these authors, the value of honesty and promise-keeping outweighs any benefit obtained by deception.

2.3 LEGAL CONSIDERATIONS

2.3.1 CONFIDENTIALITY IN LAW

English law recognises a duty of medical confidentiality (*AG v Guardian Newspapers (No 2)*, 1988; *X v Y*, 1988; *W v Egdell*, 1990; *McHale*, 1993; *Z v Finland*, 1997). The precise limits and purpose of medical confidentiality have been debated in various cases, but its existence in principle is never doubted.

The duty is, however, not an absolute one. There are numerous statutory exceptions, where disclosure of otherwise confidential information is required (*Hunter v Mann*, 1974; *Emson*, 1988; *Crichton*, 2001; *Hewitt*, 2004), but most situations will not be covered by statutory provision, and the common law of confidentiality will therefore apply. This was comprehensively reviewed in the case of *W v Egdell* (*W v Egdell*, 1990; *Grubb*, 1990; *Tur*, 1998), which remains the primary authority in this area, and the influence of which can clearly be seen in the wording of GMC guidance (*Crichton*, 2001). However case law has continued to develop, in particular since the introduction of the Human Rights Act (1998), and the development of the legal doctrine of privacy under Article 8 of the European Convention on Human Rights (*Morris*, 2003; *R (on the application of TB) v Stafford Combined Court*, 2006).

Other than statutory rules, which arise out of their own specific policy contexts, the legal approach to confidentiality is essentially a utilitarian one (*Samuels*, 1980; *AG v Guardian Newspapers (No 2)*, 1988; *McHale*, 2000; *Tingle*, 2002). In *Egdell* Lord Bingham clearly articulated the balance that was to be struck between the potential benefits of disclosure, and the benefits of protecting medical confidentiality. Crucially, Lord Bingham saw that there was a public as well as a private interest in preserving confidentiality, based on recognition of both consequential and anticipatory deterrence, and recognition that promoting effective treatment could itself reduce risk. He stressed that the lack of any therapeutic benefit from

maintaining confidentiality in the circumstances of that case was a significant factor in the decision reached.

In that case the utilitarian calculus was judged to come down on the side of disclosure – that is to say that the doctor, who had already disclosed and was being sued for breach of confidence, was held to have been justified in doing so. The court explicitly stopped short of identifying any duty to disclose (Grubb, 1990). More significantly, the facts of the case were quite extreme, and by indicating that the balancing exercise was still significant, the court might have been understood to be setting a very high threshold for breach of confidentiality (Lee, 1994; Harbour, 1998; Sturm, 2002; Bourke & Wessely, 2008): despite this the case has since been quoted as supporting the proposition that reporting should be considered in a wide range of circumstances, with expectations of mandatory reporting which go beyond the scope of the decision. This seems to reflect an increasing acceptance within society for reporting, and a decreasing concern for confidentiality. Current GMC guidance is that information should be disclosed when there is risk of any form of serious harm, whereas the decision in *Egdell* was only that information could optionally be disclosed in exceptional circumstances (in that case, a patient who had already committed multiple homicides).

This social change is illustrated by the Californian case of *Tarasoff* (*Tarasoff v Regents of University of California*, 1976; Blum, 1986; Felthous, 1989b; Mackay, 1990; Jones, 2003a), and subsequent developments. In that case a patient disclosed to a psychotherapist that he had thoughts of killing a specific person. Although in fact confidentiality was broken, it did not prevent a subsequent homicide and the therapist's employers were sued for failure to protect the victim. The Supreme Court upheld the existence of such a duty and the following 35 years have seen similar duties imposed across the USA (Beck, 1985; Felthous, 1989a; Felthous & Kachigian, 2001; Walcott *et al.*, 2001; Herbert, 2002; Herbert & Young, 2002; Kachigian & Felthous, 2004; Soulier *et al.*, 2010).

In a far-sighted article written shortly after the case was decided (Gurevitz, 1977) it was argued that the decision arose from social changes which still resonate today.

Although there has been much critical commentary of the original case and subsequent developments (Stone, 1976; Roth & Meisel, 1977; Carstensen, 1994; Herbert, 2002; Thomas, 2009), it has also been recognised that medical and psychiatric practice has continued without the catastrophic deterrent effect that some predicted (Leonard, 1977; Denkowski & Denkowski, 1982; Mangalmurti, 1994; Anfang & Appelbaum, 1996; Buckner & Firestone, 2000; Leeman, 2004). This has led some commentators to argue that confidentiality is less important than previously assumed (Fleming & Maximov, 1974; Denkowski & Denkowski, 1982; Shuman & Weiner, 1982).

Although duties similar to those in *Tarasoff* have been imposed in other jurisdictions, no parallel case has been brought here. There were some similarities in the case of *Palmer v Tees* (*Palmer v Tees Health Authority, 1999*), but also some significant differences, and no duty to prevent harm by the patient was found in that case. Some commentators have argued that a *Tarasoff* duty is unlikely in this country (Mackay, 1990; Miers, 1996; Morris & Adshead, 1997; Adshead, 1999) and although it remains a possibility, it would represent a significant new departure for a British court.

More significant in this country has been the introduction of the Human Rights Act (1998) and the incorporation of the European Convention on Human Rights into domestic law (*Z v Finland, 1997*; *R (on the application of TB) v Stafford Combined Court, 2006*). In recent years the right to private life under Article 8 has formed the basis of judicial activism constructing a new legal doctrine of privacy (Lee, 1994; Mahendra, 2001b; Evans & Harris, 2004). This would appear to strengthen existing legal protection of confidential information, but in a *Tarasoff* situation that might be overridden by human rights arguments based on the right to life, and the right to be protected from foreseeable harm, under Article 2.

2.3.2 MANDATORY REPORTING

While common law rules typically permit flexibility, requiring individual doctors to balance competing interests in deciding whether or not to report in a particular case, statutory rules generally define situations in which a report must, legally, be made. In such circumstances some form of utilitarian calculus has still been made, but at the level of public policy rather than a clinical encounter. Such a calculus may not be explicit, and the legislative process may not be conducive to a careful balancing of less tangible costs and benefits. The value of confidentiality, and the long term risk reduction afforded by effective medical treatment, may be trumped by the political desire to respond to a clear and present danger (Emson, 1988; Lee, 1994; Department of Health, 2001; Barton & Quinn, 2002; Crichton & Darjee, 2007).

Crichton (2001) has given a useful overview of statutory provisions in the UK. The term “mandatory reporting” is more commonly used in the US, particularly in relation to reporting requirements relating to child abuse. The policy is intended to promote the safety of children at risk, but some authors have raised concerns that the rules may be counterproductive, and that unintended consequences may increase that risk (Smith & Meyer, 1984; Berlin, 1988; Weinstock & Weinstock, 1988; Taube & Elwork, 1990; Bastable & Sheather, 2005). There is also concern that this may increase the very risks to children that a policy of mandatory reporting is supposed to reduce: (Hodgkin, 2001) said that:

it is possible that this advice is contributing to child abuse rather than preventing it. ...Do we not owe that silent majority [of non-disclosing abused children] a place where they can go to seek help about being abused in confidence?

There is also widespread evidence of underreporting, reflecting difficulties in determining the threshold at which reporting should be considered, and of frank non-compliance with regulations.

The political mood in recent years seems to have been to increase the scope of statutory reporting, with proposals to extend mandatory reporting to areas such as

gun crime, knife crime, and immigration status, but there has also been a change in the profession's view, with acceptance of public safety as a legitimate medical concern (Cohen, 1990; Ferris, 1998; Leung, 2002; Turnberg, 2003; Fleetwood, 2006).

In addition to situations covered by clear statutory rules there are various other situations in which guidance exists which anticipates release of confidential information. Such guidance is often presented in such a way as to appear mandatory, although the legal authority for this may be lacking. In the absence of clear statutory provision, the legal position remains that defined in *Egdell*, that reporting should be exceptional, based on a balancing of interests and, even in the extreme facts of that case, remains discretionary – an option to report rather than a duty. This would often not be apparent from the guidance. I will discuss four areas in more detail: child protection, driver licensing, domestic violence, and Multi Agency Public Protection Arrangements (MAPPA).

Unlike the United States, there is no mandatory reporting legislation applying to child abuse or child protection in this country. There is however central guidance, in the form of *Working Together* (Department for Children Schools and Families, 2010). Such guidance does not amount to a legally binding rule (Harbour, 1998; Jenkins, 2002; Rogstad, 2007; Rogstad *et al.*, 2010) and Butler-Sloss LJ said that “*it does not have any legal status*” (Re G (a minor) (social worker: disclosure), 1996), yet the wording of this document generally gives a strong impression that reporting is required. Section 27 of the Children Act (1989) does impose a requirement on various bodies, including health providers, to “co-operate” with child protection procedures, but even this weaker obligation is limited “except insofar as it conflicts with pre-existing duties”. At least arguably the duty of confidentiality owed to a patient is just such a duty, which would moderate even the duty to co-operate (Jones, 2002).

Despite this there is considerable expectation placed upon doctors to prioritise the interests of children at risk above those of patients, and many people assume that reporting is mandatory (Babiker, 1993; commentary to Bamford & Heath, 1996;

Dimond, 1999; Crichton, 2001; Hegarty *et al.*, 2008). GMC guidance also suggests that reporting of risk to children is expected, without using clearly mandatory language.

Munday (2002) has pointed out that the “interests” of the child may not always be best served by reporting – a child has an interest in access to confidential treatment and to autonomy just as an adult has. *Working Together* is based on a simplistic assumption that reporting is the only way of promoting the child’s interests, and while other guidance (Thomas *et al.*, 2002) does recognise the value of confidentiality to children it is not clear that this is sufficient to override the expectation of reporting. Other authors have recognised that doctors may have responsibilities to more than one person, particularly in the context of primary care, and that the “paramountcy” principle can be unhelpful and simplistic (Wainwright & Gallagher, 2010). For example Bamford & Heath (1996) reflected:

how could I, the doctor, be trusted since I had invited the social workers and police into the home? We need to re-establish the fact that a doctor’s confidentiality can be relied on

Turning to driver licensing, and reporting of medical information to the DVLA, there is evidence of change in practice and in attitudes over recent years. In applying for and receiving permission to drive, an individual undertakes to notify the DVLA of current or future medical conditions that would impair their ability to drive, and the legal responsibility for doing so rests with the driver-patient. However this is not immediately apparent from either the DVLA guidance issued to doctors, or the corresponding GMC rules.

GMC guidance (quoted verbatim in DVLA guidance (Drivers Medical Group, 2010) states that:

If you do not manage to persuade the patient to stop driving, or you discover they are continuing to drive against your advice, you should contact the DVLA immediately and disclose any relevant medical information, in confidence, to the medical advisor. (GMC, (2009) Supplementary guidance)

A straightforward reading would suggest a duty placed upon a doctor in this situation, and while it is never directly stated, given the legalistic nature of the document the reader could be forgiven for inferring a statutory duty to report which does not in fact exist (Petch, 1996; Harris, 2000). Two important issues are left unresolved: the interpretation of “should” and “relevant”, and the meaning that the GMC gives to “in confidence”. Even though the advisor is medically qualified, most patients are likely to see such reporting as a clear breach of confidence and it is disingenuous of the GMC to suggest that it is not. It is clearly an example of a “divergent breach” (Francis, 1982).

Professional opinion is generally opposed to mandatory reporting of drivers (Krumholz *et al.*, 1991; Howe, 2000; Leeman *et al.*, 2001; Black, 2003; Appel, 2009), and the American Academy of Neurology views any mandatory reporting law as inappropriate (Bacon *et al.*, 2007), although others disagree (Cremona, 1986; Ozuna, 1993; Cable *et al.*, 2000; Beran, 2002; Breen *et al.*, 2007). There is evidence that many patients do not report when they should (Maxwell & Leyshon, 1971; Maas *et al.*, 2003), and also that mandatory reporting rules are a deterrent to treatment (Salinsky *et al.*, 1992; Culshaw *et al.*, 2005).

Mandatory reporting of domestic violence has been widely debated in the United States, where it is required by a minority of state jurisdictions (Houry *et al.*, 2002; Gupta, 2007). In this country there is no clear reporting requirement, and most opinion supports maintaining confidentiality (Taft *et al.*, 2004; Jenkin & Millward, 2006; Hegarty *et al.*, 2008) although some authors have argued for overriding this (Shepherd, 1995; Davies, 2002).

Guidance is less than completely clear. *Responding to Domestic Violence* (Department of Health, 2005) basically supports the patient’s right to confidentiality, and emphasises the possibility that reporting may increase the risk. However it also stresses that “multiagency information sharing” (which is never described as a breach of confidentiality, although that is what is entailed): “offers the best opportunity for safeguarding women and children”, and that “if there is reason to suspect that children are at risk, safeguarding and protection should

always take precedence over confidentiality". Protection for confidentiality is further weakened because, in cases where dilemmas are encountered, the Department of Health recommends deferring to advice issued by the Home Office (2004); "*Safety and Justice: sharing information in the context of domestic violence*" (see also Home Office (2010)). This is written from a public safety perspective, where risk reduction is central and issues of confidentiality are seen more as problems to be overcome rather than as principles to be upheld. For example, this guidance advises not even attempting to gain consent for disclosure in circumstances where a refusal might be overridden, preferring instead to make a decision purely on risk management grounds. It seems of concern that the Department of Health is willing to devolve guidelines for medical and professional discretion to criminal justice agencies, an example of how the public safety agenda sometimes dominates professional concerns.

The Multi-Agency Public Protection Arrangements (MAPPA) were introduced by the Criminal Justice and Court Services Act (2000) and provide a forum where information can be shared about the management of certain groups of high-risk offenders (Department of Health, 2004; Home Office, 2010). The process is managed primarily by the National Offender Management Service; probation, police, and prison services are key agencies, and properly have a different agenda to health professionals (BMJ, 1974; Barton & Quinn, 2002; Parish, 2003); disclosure in this setting is another example of "divergent breach". Various other agencies, including health providers, have a "duty to cooperate" with the process, but as with similar duties imposed under the Children Act (1989), the scope of this is not entirely clear, and there is certainly a distinction to be drawn between cooperation with the process and the extensive release of confidential information which is often expected. Again, guidance is produced which emphasises the duty, while failing to make clear the limits (Morris, 2003; Home Office, 2004). The GMC (2009) requires that:

You should participate in procedures set up to protect the public from violent and sexual offenders. You should cooperate with requests for relevant information

Limits to “participation” “cooperation” and “relevant” are left unspecified, but the clear implication is that patient confidentiality takes second place to public protection. All agencies are expected to embrace the guiding principle of the arrangements, “*Working together to protect the public*” (Home Office, 2010), something which neither doctors nor patients would usually expect to be the first concern within a medical consultation. Similar provisions from the Crime and Disorder Act (1998) oblige agencies to work together to prevent domestic violence (Home Office, 2004) and to share information in Community Safety Partnerships. In other settings the medical profession has been very critical of doctors who have acted as informants to the Police (Zonana, 2005; Tuffs, 2007; Glazer, 2008), yet has accepted a similar role in this context with little resistance (Jones, 2007). Concern about this was expressed in a *Lancet* editorial:

doctors must remain responsible to their patients before all else. Once physicians become instruments of social control, no matter how well intended, they act as consulting-room collaborators threatening rather than preserving their patients’ trust (Lancet, 1995)

2.3.3 LEGAL RULES AND PROFESSIONAL GUIDELINES

There is a complex relationship between the legal duties both to maintain confidentiality and, in some circumstances, to breach confidentiality, laid down both in statute and in case law, and the standards of professional conduct imposed by the General Medical Council. GMC guidelines have been quoted with approval in a number of legal cases (W v Egdell, 1990; Lee, 1994; Harbour, 1998; McHale, 2000), and at first sight it may seem that courts have accepted them as conclusive of the legal duties which a doctor has. This would be misleading, not only because the courts clearly reserve to themselves the right to accept or reject the guidelines (McHale, 2000; Tingle, 2002), but also because the guidelines themselves have not developed in isolation, but have been intimately affected by legal decisions.

The GMC rules have changed over time. To a large extent the rules have followed legal developments, so that, while they might seem to articulate fundamental ethical principles, they are more akin to pragmatic advice to doctors on how to satisfy legal requirements (McHale, 2000; Crichton, 2001; Sokol, 2008a). Both Parliament and Courts have been increasingly reluctant to allow doctors the luxury of an entirely self-regulating profession determining its own standards (Dickens & Cook, 2000; Gladstone, 2000), and the GMC response to this has been to accommodate the political pressure by adopting changing standards of practice (Crichton, 2001).

Aspects of the current GMC guidance clearly follow the principles outlined in *Egdell*, and can be seen as having changed in response to that case. But the guidance goes beyond those principles, diluting the clear view that any breach of confidentiality should be exceptional, and the wording conceals the fact that even then reporting legally remains a discretionary option for a doctor to consider, not a mandatory duty.

2.3.4 INTERNATIONAL PERSPECTIVES

It is instructive to consider briefly the legal position in other countries, to illustrate that a range of possible approaches to the dilemma does exist, and that the balance currently struck between patient confidentiality and public protection in this country could be varied. Research has been undertaken to compare the effects of different reporting regimes in different State jurisdictions in the USA: no similar research appears to have been done comparing international differences, but in principle that could be a rich source of data on the effect of different legal rules on patient behaviour.

While confidentiality has been eroded in the United States and the UK, it seems to have been more protected in European jurisdictions (Gromb, 1997; Cordess, 2001b; Arthur *et al.*, 2005). Michalowski (2001; 2003) has compared approaches to medical

confidentiality in England, the USA, Germany and France. One aspect of her work compared the conditions under which medical confidentiality could be broken to prevent an anticipated future crime, and whether such reporting was optional or mandatory.

In France, ordinary citizens are obliged to give information to the authorities if this is likely to prevent an offence (article 434-1 of the Criminal Code), but physicians are excluded from this requirement, and are, under separate provisions of the Code, expressly required to maintain confidentiality. However Michalowski suggests that French courts may in fact allow doctors some discretion to report, particularly in the case of child abuse, where the duty of confidentiality is specifically relaxed, though no duty to report is imposed. Guedj *et al* (2009) emphasised the difference between the United States and United Kingdom, where *“it is considered legitimate to break confidentiality in some situations in order to protect other persons”*, and France where *“the emphasis in law and medical ethics is more on preserving patient confidentiality”*.

Similar provisions apply in Germany, where s138 of the Criminal Code imposes a duty on all citizens to give information to prevent certain serious crimes, but s139 explicitly excludes physicians in cases involving all but the most serious crimes (homicide, genocide and kidnapping), as long as they “seriously endeavour” to prevent the offence. The physician is however given discretion to report other planned offences, and will not be liable for breach of confidentiality. Michalowski also describes a limited exception of necessity to prevent “imminent danger” but concludes the criteria for this would rarely be met.

With respect to the USA, Michalowski concentrates on the *Tarasoff* doctrine. Most State jurisdictions impose an active duty to report, rather than a non-mandatory discretion, although many allow other protective steps to satisfy the duty without requiring confidentiality to be breached, and some States have expressly ruled out such a duty (Huprich *et al.*, 2003), although Michalowski does not explore this.

In discussing English law, Michalowski concludes that any disclosure for the purpose of crime prevention would be voluntary rather than mandatory, citing *Egdell* as

primary authority for this. She describes the GMC guidance as “*rather vague*” and stresses that disclosure is anticipated to be exceptional – as discussed above *Egdell* has not always been interpreted in that way. She does not discuss mandatory reporting regimes or other guidance, and seems to underestimate the frequency with which confidential information is released in this country.

2.4 TRUST AND CONFIDENTIALITY

Patients, and members of the wider public, trust doctors. In surveys and opinion polls physicians are consistently amongst the most trusted professions (Anon, 1979; Hallows *et al.*, 1998; Mechanic & Meyer, 2000; Sankar *et al.*, 2003; Korts *et al.*, 2004; Mechanic, 2004; Howerton *et al.*, 2007; Willison *et al.*, 2009). They trust doctors not only with their physical well-being, but also at times with their most intimate and personal information, and they do so in the belief that the information will be used for their benefit, and also that it will not be disclosed to others.

Confidentiality is widely assumed to be necessary to that trust (Thompson, 1979; Kleinman, 1991; Bamford & Heath, 1996; Persaud, 2004; Clark, 2006) but it is only one element of a complex phenomenon. Mechanic & Meyer (2000) described trust developing over repeated interactions with a doctor and suggested several components that contributed to trust. Their subjects expected confidentiality and seem to have had few concerns that it would not be provided, so other factors tended to be more significant in determining levels of trust. Gillon (1988) has also suggested that confidentiality may not be the most important determinant of trust between patient and doctor.

One consequence of this is that confidentiality, though important, may not be necessary to the maintenance of trust between doctor and patient (Warwick, 1989). Other characteristics may be sufficient to preserve trust even if confidentiality is breached. Some authors go further, arguing that confidentiality is unnecessary (Fleming & Maximov, 1974; Beck, 1982; Emson, 1988) or that potential breaches are so rare as to be of no practical significance (Sokol, 2008b). A study conducted in France suggested that members of the public were more willing to countenance breach of confidentiality than professionals (Guedj *et al.*, 2006), though that may partially reflect the more stringent existing rules in that country.

O'Neill (2002a; 2002b) has analysed changing trust within professional relationships, something which she sees as damaged by increasing emphasis on

individual rights and consumerism. For O’Neill trust is founded in an individual relationship, which may help to resolve an apparent paradox, that levels of trust in systems and institutions (which seem generally to be reducing) may not correlate with trust within an individual doctor-patient relationship (which seems largely to be preserved). O’Neill distinguishes “principled autonomy”, which permits an individual self-determination within a framework that protects the interests of all, from “individual autonomy” that is heedless of the rights of others: she argues that the former enhances trust while the latter undermines it.

O’Neill also highlights another paradox; that interventions such as audit, revalidation, and strengthened professional regulation may not increase levels of trust, even if they do, objectively, raise standards, because their existence calls the basis for trust into question:

[Such] innovations are likely to improve trustworthiness, but ... can damage rather than restore trust (O’Neill, 2002a p 131)

This may be a particular problem where external regulation is determined by an agency such as government or politicians that itself is less trusted than the profession being regulated: the focus on the mechanics of regulation can emphasize the (perceived) need, without providing reassurance that it has been resolved.

2.4.1 DIFFERENCE BETWEEN GROUPS

Although generally trust in the medical profession seems high, this may not be true for all groups of patients. In particular, those who have most to fear from reduced confidentiality may be less likely to have such trust than a “typical” patient. This may be true for whole populations of patients – Mechanic and Meyer (2000) found that concerns about confidentiality were more common, and were more likely to impair trust, in subjects with mental health problems, and many studies have shown that concerns are higher in adolescents and in subjects with particular

health issues, such as HIV infection. It is also likely that some individuals will be more concerned about privacy and confidentiality than others, for reasons unrelated to their health status.

People may be more likely to underestimate the damage resulting from breach of confidentiality where the medical condition involved is seen as something which only happens to other people, where a condition is stigmatised, and where the person can more easily imagine themselves in the position of the third party at risk than the patient. For example, responding to a question about notification of drivers with drug dependency, a subject may see drug abuse as something that “other people” do, may see drug users as to blame for their choices, and may picture themselves as a road user at risk from a drug-impaired driver, rather than as a patient whose confidentiality is in jeopardy.

These considerations are important for the utilitarian calculus, because while a majority of patients may be relatively relaxed about breaches of confidentiality, it is possible that there is minority who are much more concerned. If they are disproportionately the ones whose health care is likely to give rise to confidentiality dilemmas, and if they are likely to be deterred from treatment where other patients would not be, then it is their sensitivities and behaviour that have to be incorporated into the calculus. The views of other people who are not directly affected do not have a direct impact on the balance of risks and benefits resulting from decisions affecting those who are.

2.5 PREVIOUS RESEARCH

There is no shortage of views expressed about the importance of confidentiality in medical practice (see Roback (1995) and Sankar (2003) for useful reviews). Most are in the form of individual opinions expressed by an author, in some case supported by sophisticated philosophical analysis, more frequently based on clinical experience or personal perspective. Often the need for confidentiality, and its utilitarian value, is assumed and sometimes it is explicitly argued. Less commonly is it directly challenged or rejected.

An extremely wide range of opinions is expressed, from authors who argue that an absolute and unyielding standard of confidentiality should be enforced (Driscoll, 1982; Kottow, 1986; Nowell & Spruill, 1993; Bollas & Sunderson, 1995; Kipnis, 2006), to those who argue that confidentiality is unnecessary and should be abandoned (Warwick, 1989; Koeting, 2001). Between these extremes, most authors attempt to find some balance (Slowther, 2006), accepting that confidentiality may be breached in certain circumstances, but should be maintained in others: the point at which this balance is struck varies enormously. In general these authors express concern that confidentiality is being eroded (Havard, 1985a; Gillon, 1987; Emson, 1988; Lancet, 1995; Adshead, 1999; Cordess, 2001b; Appelbaum, 2002), although whether this is a view held by professionals in general, or only by those who feel motivated to write about it, is less clear.

Most authors agree that reduced confidentiality will deter patients from seeking health care, or from full disclosure within consultations. Often this is asserted as an obvious truth that underlies the utilitarian argument for confidentiality, or is assumed with little or no discussion or justification (Adshead, 2005; Bastable & Sheather, 2005; McPherson, 2005; Crichton & Darjee, 2007). Sometimes it is explored in more detail, and a few authors doubt the reality of deterrence, or consider it to be of little practical relevance (Slovenko, 1988; Brosig & Kalichman, 1992b; Ferris, 1998; Houry *et al.*, 1998; Paton, 2009).

Similarly, informing patients of the limits to confidentiality is generally considered to be good practice, whether for reasons of utility, fidelity, or patient autonomy, but it is also recognised that this may itself deter patients from disclosing information to doctors (Faustman & Miller, 1987; Kremer & Gesten, 1998; Rogers, 2006; Sokol, 2008b). For some this is an argument against giving patients such information (Roback *et al.*, 1996).

2.5.1 EMPIRICAL STUDIES

Utilitarian arguments are open to empirical study: how does the behaviour of patients alter when presented with different standards of confidentiality? (Schmid *et al.*, 1983; Sturm, 2002; Jenkins *et al.*, 2005; Eastman & Starling, 2006) Surprisingly, such empirical evidence is not readily available (Appelbaum, 1985; Singer *et al.*, 1993; McNeil *et al.*, 1998; Pattison & Evans, 2006), perhaps because ethical questions are commonly considered to be better answered by appeal to theory rather than by practical testing (Tancredi, 1995). It is usually assumed that patients consider confidentiality to be important and that they would be less likely to seek treatment if this was not assured (Havard, 1985b; Kottow, 1986; Lancet, 1995; Hodgkin, 2001; Bastable & Sheather, 2005; Crichton & Darjee, 2007), but few studies have asked patients directly, and some authors have explicitly challenged the assumption (Beck, 1982; Buckner & Firestone, 2000), although again with little empirical support.

There has been a limited amount of empirical research into issues of confidentiality and deterrence (see Brosig(1992b), Sankar(2003), Feder(2006) for reviews). The studies in the following discussion report data on the views of the public, professionals, or patients rather than the opinions solely of the author, and are summarised in Appendix 1. They are only explicitly referenced in the text where necessary to illustrate a specific point. They include findings from various countries and clinical settings over more than 30 years, a period during which rules and norms of behaviour have changed significantly. While these differences will not be

analysed in detail, it should not be assumed that findings will necessarily reflect the current situation in the UK.

Several methodological issues should be borne in mind when interpreting studies of attitudes to confidentiality and disclosure. Subjects may support confidentiality when asked in the abstract, but be more willing to support breach when presented with a specific situation: evidence of this phenomenon will be discussed in Section 4.1. Studies of the public, often selected for reasons of convenience, may underestimate the concerns felt by patients currently receiving health care, and patients not directly affected by a scenario may underestimate the concerns of those who are. Also, responses to hypothetical situations are likely to be different to the actual behaviour of patients confronted with a situation (Brosig & Kalichman, 1992b).

Professional views may be misleading in two ways. Some authors have suggested that confidentiality is a preoccupation of professionals (Samuels, 1986; Emson, 1988; Guedj *et al.*, 2006), and that the concerns that doctors may have, that patients would be deterred from treatment if it were not confidential, may be unfounded. Conversely, professionals may tolerate breaches of confidentiality, for example sharing information within teams, that patients may find unacceptable (Jenkins *et al.*, 2005; Slowther, 2006). Either way, views expressed by doctors may not predict disclosure choices made by patients.

There is a concern that professionals' reporting of their own attitudes and behaviours may not reflect their actual practice. This is likely to be more marked in areas where legal or professional guidelines mandate particular behaviour and professionals may be reluctant to admit to practice that does not follow such rules. This may be most likely in controversial areas, where acute dilemmas or conflict of views occur, precisely those areas in which such data may be most needed.

At first sight it would seem that studies which seek the views of actual patients are superior to those that use patient-analogues such as college students. In some ways this will be true, but there is also one significant drawback to studies of patients. When we are interested in revealing factors that might deter potential patients

from seeking treatment, the views of those patients who have chosen to accept treatment might be misleading. The very people in whose views we are most interested may have selected themselves out of any clinical sample that can be accessed. Consequently, such samples will underestimate the importance of confidentiality, and the possible effect of lack of confidentiality in deterring people from seeking medical help (Rodriguez *et al.*, 2001a).

Confidentiality in general

Public views

There have been a number of studies (Appendix 1; Table 1) in which views about confidentiality have been examined in non-clinical samples.

When adults are asked about confidentiality in the abstract, there are usually high levels of support for absolute confidentiality. Subjects are typically less sure that doctors will maintain confidentiality, although most express confidence in their own doctors. The picture seems to change when subjects are presented with examples of situations in which information might be reported to protect others: between 40% and 80% of subjects have supported such reporting in various circumstances. This view seems to be maintained, even when subjects recognise the risk that reporting might deter patients from disclosing information.

Studies which have investigated subjects' own willingness to enter treatment or to disclose information have usually been carried out on clinical populations. When such questions have been put to non-clinical samples it has generally been found that lack of perceived confidentiality would deter significant numbers of potential patients from treatment.

Professional views

There are a number of studies in which the views of a wide range of professionals have been explored (Appendix 1; Table 2). Generally, support for absolute confidentiality is low, but in situations where reporting of confidential information

is expected (by legal or other standards), actual reporting seems to be less common than the rules require, suggesting that professionals substitute their own, more restrictive, standards for those imposed externally.

A small number of studies have presented both public and professional subjects with identical situations. Lindenthal & Thomas (1982b) found that, although doctors do not support absolute confidentiality, they report less than patients fear they will. In contrast, Kearney (1998) and Weiss (1982) found that doctors were more willing to breach confidentiality than patients anticipated, at least when presented with a hypothetical situation. This has particular importance for the utilitarian position, since it suggests that factors other than actual disclosure practice influence patients' expectations, and therefore the likelihood of them seeking or avoiding treatment. Changes to practice may not result in the predicted changes in patients' care-seeking behaviour, if potential patients are unaware of them.

Patient views

As with the general public (above), studies show that patients attending a range of clinical settings (Appendix 1; Table 3) also believe that medical consultations should be confidential. If anything, this expectation is higher amongst patients, with reported rates typically between 80% and 100%. Belief that consultations will in fact be kept confidential is generally lower than this, between 60% and 80%.

Attitudes to public interest reporting

Public views

Although studies typically find a large majority of the general public support a more or less absolute standard of confidentiality, when presented with situations of risk to others a significant number also support some form of reporting. Typically studies (Appendix 1 ; Table 4) find that between 50% and 80% of subjects would support disclosure in the case of child abuse, homicide, or serious violence, but that rates are lower, typically 30% to 50%, in the case of other risks such as impaired drivers, domestic violence, or other offending.

Professional views

Over a range of professions and situations, professionals generally seem to support some form of discretionary reporting of confidential information (Appendix 1; Table 5a). They generally oppose, however, the development of mandatory reporting: perhaps not surprisingly professionals would prefer to be the decision-maker in these situations. In various studies professionals have reported failure or refusal to follow guidelines (Appendix 1; Table 5b). Professionals who are more reluctant to breach confidence also tend to anticipate more damage to therapeutic relationships if confidentiality is not maintained, but how important that perception is in determining their behaviour is unclear.

Patient views

Although patients are typically concerned about their own information being kept confidential, they continue to support breach of confidence in the public interest at levels not greatly different to the general public (Appendix 1; Table 6). The exception to this seems to be adolescent patients, who generally report low levels of support (less than 50%), even in cases of child abuse where others are at risk. It seems likely that most patients do not perceive these issues as impacting on their own situation: possibly adolescents feel more directly affected, in line with studies which suggest they have higher levels of concern about confidentiality than adult patients.

Deterrence

Public views

Only a minority of studies have explored the issue of whether breach of confidentiality would deter potential patients from seeking help (Appendix 1; Table 7). When this issue is raised, most studies find that a majority of non-patient subjects will recognise the possibility of such deterrence. The actual proportion expressing this view varies widely between studies, from as low as 33% to as high as 88%: these differences partly reflect the nature of the medical problem being

discussed, and the characteristics of the subject group, but may also be due to methodological differences in the way these issues were raised or discussed.

Professional views

A number of studies (Appendix 1; Table 8) have shown that professionals anticipate that failing to maintain confidentiality would lead to avoidance of treatment, damage to the therapeutic relationship, or withdrawal from treatment. The frequency with which these concerns were expressed varied widely, up to 50% in some studies, but as low as 20% in others. Levels of concern about damage to therapeutic relationships was also higher in studies which focussed on actual clinical experience, or case vignettes, as compared to studies that asked more general questions without clinical examples.

A small number of studies have asked about actual clinical experience in cases where confidentiality has been breached. Typically about a quarter of cases have had a negative outcome – usually the termination of treatment by the patient. Asked hypothetically about the same issue, professionals typically anticipate a negative outcome in 30 – 40% of cases.

Patient views

Studies in various settings (Appendix 1; Table 9) have found that patients recognise a risk that others might be deterred from seeking treatment by lack of confidentiality, or that they would be so deterred themselves. Typically 15%-30% of subjects report that they have actually been deterred either from seeking treatment or from disclosing certain information: this may reflect the tendency of patient subjects to view the issues as applying to others rather to themselves, as discussed above, and the possibility that potential patients with the most anxiety about this have already opted out of treatment, and are underrepresented in studies. These concerns seem to be more common in studies of adolescent patients, for example 59% of adolescents attending a family planning clinic said they would stop using the service if mandatory parental notification was introduced (Reddy *et al.*, 2002).

Studies of mental health patients have found that between 20% and 40% of patients would consider terminating treatment or limiting disclosure if their confidentiality was breached. Mechanic & Meyer (2000) found that confidentiality was a more important component of trust for mental health patients than for other groups.

Three population-based studies (Gielen *et al.*, 2000; Rodriguez *et al.*, 2001b; Ferri *et al.*, 2002) have shown that subjects who have not presented for medical help are more likely to have concerns about confidentiality than those currently in treatment, suggesting that some degree of deterrence has already taken place.

Experimental studies

Appendix 1, Table 10 summarises studies which have examined the actual disclosure of subjects provided with different assurances or levels of confidentiality, in what were in some cases highly artificial situations. In 8 of the 11 studies, subjects offered a lower level of confidentiality disclosed less personal information, or gave more socially conforming answers, than others. In the other 3 studies no differences were demonstrated. An interesting study from the United States (Singer *et al.*, 1993) interviewed people who had failed to complete a census return: although few subjects reported concerns about confidentiality, those who did were significantly more likely to be non-returners. Singer *et al.* (1992) highlighted a potential problem with confidentiality assurances. When provided with “elaborate” assurances of confidentiality subjects became less willing to participate in a survey, presumably because the assurances implied that the subject matter would be intensely personal or intrusive.

2.5.2 DIFFERENCES BETWEEN GROUPS

Section 2.4.1 discussed the possibility that some patients may be disproportionately affected by issues of privacy. The hypothesis that many subjects do not perceive the issues as relating to them, even in studies which draw on clinical populations for

study, is supported by findings from studies of attitudes to domestic violence in which the views of women who had experienced abuse were contrasted to women who had not: most have found that survivors of abuse are significantly less likely to support mandatory reporting of domestic violence, suggesting that, when patients who are directly affected are studied, attitudes are different.

In a study of 1218 Emergency Room attendees, Rodriguez *et al.* (2001a) asked about attitudes to mandatory reporting of domestic violence. Of those who had suffered domestic violence, 56% supported such a policy, whereas 71% of other patients supported it, suggesting that patients directly affected did place a higher value on confidentiality. Gielen *et al.* (2000) reported similar findings. In a study of general medical in-patients (Lindenthal & Thomas, 1982a), patients were less likely to support reporting of confidential information than non-patients. In Slade *et al.* (2007) patients, carers and mental health professionals were asked about disclosure of information to family members: patients expressed higher levels of concern than other groups. Fehrs *et al.* (1988) investigated the increase in uptake of HIV testing under anonymous conditions, and concluded that it was greatest in high-risk groups, suggesting that they had been more deterred from seeking testing under earlier name-based arrangements. Merz *et al.* (1999) showed that patients whose records contained items of sensitive information were less likely than others to consent to standard disclosure and information sharing agreements.

Systematic reviews (Sankar *et al.*, 2003; Feder *et al.*, 2006; Hegarty *et al.*, 2008) have concluded that victims of domestic violence are generally more concerned about maintaining control of their health information than other groups. Despite this the professional views in this area seem generally to support disclosure (Shepherd, 1995; Bauer & Mooney, 1999; Bledsoe *et al.*, 2004; Ferris, 2004). Some authors do recognise the risk of deterring patients from seeking help but support reporting despite this (Glancy, 1998; Sachs *et al.*, 1999; Haggerty & Hawkins, 2000), but some see either deterrence (Hyman & Chez, 1995; Rodriguez *et al.*, 1999; Taft *et al.*, 2004; Sullivan & Hagen, 2005) or autonomy (Ingram, 1994; Ellsberg & Heise, 2002; Jenkin & Millward, 2006) as grounds for opposing reporting. In a commentary to Shepherd (1995), Adshead suggested that:

crime prevention is a dangerous (and impossible) extension of the medical professional role.

Mandatory reporting has been introduced piecemeal in the United States, though still in only a minority of States (Houry *et al.*, 2002; Bledsoe *et al.*, 2004), and in this country there is a legal requirement for health agencies to cooperate with criminal justice agencies under the Crime & Disorder Act 1998 (Home Office, 2004). This is supported by Department of Health guidance which sees reporting as automatically being in the patient's best interests (Department of Health, 2009), giving little apparent weight to the views of the patients affected, who seem to see their interests differently.

In a focus group study (Sullivan & Hagen, 2005) victims of domestic violence overwhelmingly opposed mandatory reporting, which was clearly perceived as a deterrent to seeking help. Other studies with varying methodologies find similar results (Rodriguez *et al.*, 1996; Gielen *et al.*, 2000; Hegarty & Taft, 2001; Rodriguez *et al.*, 2001b; Rodriguez *et al.*, 2002), although one study (Coulter & Chez, 1997) found much higher support for reporting.

2.5.3 ACTUAL BEHAVIOUR

Most of the empirical studies described have asked subjects about confidentiality in a hypothetical situation or have described behaviour in an artificial experimental setting. As discussed above, patients directly affected by a situation are likely to have different views to others, however carefully matched, considering a situation that does not apply to them. However it also recognised that it is difficult to access those patients most suspicious of medical services and most likely to be deterred from seeking treatment, so that any clinical sample is likely to underestimate such concerns. A few studies (Appendix 1, Table 11) have addressed these problems by reporting patients' actual behaviour in the context of "natural experiments"; observational studies of situations in which confidentiality rules have varied. These

include situations where different reporting rules exist in places with otherwise similar social characteristics, such as US States with differing laws, and situations where a new procedure or legal rule has been introduced, allowing a before and after comparison.

Salinsky *et al.* (1992) compared patients attending epilepsy clinics in two US States: in one physician notification to the driver licensing authority was required by law, in the other patients were required to notify, and reporting by the physician was discretionary (similar to the current UK rules). Patients reported that they were 4 times less likely to discuss issues that might impair driving with their physician in the doctor-reporting State, although absolute numbers were low in both places (16% vs. 4%). The authors calculated the proportion of patients in each State who would be driving without abiding by the notification procedures: this was 53% in the doctor-notification State, compared to 33% in the other. This calculation did not take into account the lost opportunity for effective treatment, which would be expected to increase that difference.

In a similar study, McLachlan (1997) compared two Canadian provinces with different driver notification laws, and confirmed that reporting rates differed significantly, although it was not clear what effect this had on the number of impaired drivers who remained licensed.

Berlin *et al.* (1991) reported data from a well-established sex offender treatment programme, in a US State where mandatory reporting of child sexual abuse was introduced in 1988. The rate of spontaneous disclosure of past abuse by participants in the treatment programme fell from 20 cases per year to none following the change in law. Self-referral of offenders to the programme dropped from 7 per year to zero. The authors make the point that, at least in the context of a treatment programme, the change in law designed to protect children was in fact likely to have the opposite effect.

Fehrs *et al.* (1988) reported data from a sexual health clinic which introduced anonymous testing for HIV. They reported a threefold increase in self-referrals for HIV testing, an increase that was greatest in high-risk patients. This suggested that

name-based testing had previously been a significant deterrent for some patients who were willing to seek testing under the new arrangements. Similarly, Meehan *et al.* (1997) reported from a State which introduced HIV testing and treatment without parental notification for adolescents. Both attendance rates and willingness to be testing increased, so that the total number of tests taken over a two year period more than doubled, while no change was noted in rates for 18-22 year olds who were not affected by the change.

Kassler *et al.* (1997) reviewed the changes in HIV testing in counties in North Carolina which withdrew, and then reintroduced, anonymised HIV testing, and those which did not. Although testing rates increased over time under all conditions, the rate of increase fell when anonymous testing was withdrawn. When anonymous testing was reintroduced testing rates did not return to previous levels, which may suggest that, once trust has been damaged, a simple change of policy is not sufficient to restore it.

Lothen-Kleine *et al.* (2003) reported data from a study of alcohol abuse in adolescents. Because of regulatory changes, study procedures changed part-way through, so that subjects were informed that thoughts of suicide would be reported whereas previously they had not been. Although participation rates and characteristics remained constant, the frequency of reporting of suicidal thoughts dropped from 8% to 1%.

Single case reports may have less validity, but can give a vivid account of dilemmas missing from larger studies. Bamford & Heath (1996) did so in describing a case in which reporting of child abuse led to a breakdown of trust with the family involved. From the patient's perspective Baker-Brown (2006) described his experience of schizophrenia, including the feeling that he "*felt more 'policed' than cared for by my psychiatrist*".

2.6 EXAMPLES FROM PRACTICE

In what sort of situations might a doctor have to consider disclosing confidential information in order to reduce risk to others? Are they exceptional, and limited to particular areas of practice, or are they common and widespread? What follows are some examples illustrating the wide range of clinical situations in which the dilemma may arise. Implicit in each case is a potential for deterrence, and the possibility that that might increase risk. References are given to some real-life examples.

- A patient states the intention to continue driving, without notifying the DVLA, after being diagnosed with a condition that might impair their performance (Duncan v Medical Practitioners Disciplinary Committee, 1986).
- A patient states the intention of driving home following a minor procedure during which benzodiazepines were given.
- A patient has a hereditary condition which may affect other family members: the patient does not want the family informed (Leung *et al.*, 2000).
- Police demand details of patients attending a needle exchange scheme (Jackson, 2000).
- A patient attends for treatment for a sexually transmitted disease and refuses permission to contact sexual partners.
- A patient who works with machinery is prescribed medication which may impair his concentration but does not want to take time off work.
- An offence is committed near to a psychiatric unit – the police ask for details of patients on leave at the relevant time (Kellam, 1994).
- An adult patient discloses suffering sexual abuse as a child, but does not want to make a formal report (David, 1998).
- A patient refuses permission for their details to be included in an audit, which may invalidate the data and prevent services from being improved.
- A patient requests referral for anger management counselling, saying that they are often violent to their partner.
- During a Multi Agency Public Protection Panel meeting a doctor is asked to disclose details of a patient's medical history, treatment, and prognosis.

- A doctor presents for treatment for a condition that might impair their judgement and fitness for practice (Stephenson, 2008).
- A patient with an infectious disease refuses to cancel their cruise holiday.
- DNA samples are taken during a population-based research study. The Police seek details to match to a crime scene (Watson & Levine, 1989).
- A patient with a chronic degenerative condition asks for information on painless ways to commit suicide.
- A prisoner tells a prison doctor how drugs are being smuggled into the prison (Soliman, 2010).
- A patient suffers complications that might be important for other patients' treatment but refuses permission for the case to be reported.
- An autopsy reveals a previously undiagnosed congenital condition that represents a treatable risk to other family members (Elger *et al.*, 2010).
- A patient with symptoms of anxiety and depression is worried that their status as an illegal immigrant will be discovered (Pritchard, 2001).
- During a home visit large quantities of boxed electrical goods are seen, suggesting the person is handling stolen property.
- During routine enquiry a patient reports moderate use of illicit drugs.
- A patient refuses permission for information to be shared with a family member who cares for them (Slade *et al.*, 2007).

These examples demonstrate that potential dilemmas arise in all branches of medical practice: by virtue of the doctor-patient relationship doctors obtain access to information that is not available to others, yet which potentially has great value for non-clinical objectives, many of which are of clear social value. Equally, confidentiality may be necessary for engagement in the doctor-patient relationship, promoting effective treatment which itself is a social benefit.

2.7 THEORETICAL CONTEXTS

2.7.1 RISK PERCEPTION

It is tempting to think of the utilitarian calculus as a strictly logical and dispassionate balancing of risks and benefits, but in reality people's choices and behaviours are not governed by precise, or even approximate, statistical calculation of risks. People object to nuclear power or mobile phone masts because of fear of cancer, yet continue to smoke.

If appreciation of risk is not rational, is there any way of predicting behaviour in response to those risks, or is the utilitarian calculus destined to be unknowable? Fortunately there is a large body of work that suggests that while risk perception is not logical, it is in many ways predictable. People consistently overestimate some risks and underestimate others, or (a parallel but not identical construct) are willing to accept some risks while being reluctant to take others which may objectively be smaller. Current theories of risk perception built on studies of "decision making under uncertainty" by Tversky & Kahneman (1974; 1981), and have been well-summarised by Gardner(2009) and Schneider(2003).

For example, risks that are unavoidable, man-made, or unfamiliar are perceived as more dangerous than others that are freely chosen, arise naturally, or are familiar. Possible outcomes that can easily be brought to mind are overestimated, compared to similar risks that are hard to visualise. Some of these factors are more or less strongly associated with the scenarios presented in this study, for others the association may depend on details within the scenario. There are opportunities to manipulate some of the factors to explore the response of subjects: there are also risks of introducing confounding biases into scenarios.

2.7.2 CULTURAL COGNITION THEORY

Cultural cognition theory has been developed from original work by Douglas and Wildavsky (Douglas, 1978; Douglas & Wildavsky, 1983; Gross & Rayner, 1985), largely by Kahan, Slovic, and their collaborators (Slovic, 2000; Kahan & Braman, 2006). They have identified two variables termed “group” and “grid”, to describe cultural views: “group” reflecting orientation to individualistic or communitarian views, “grid” to hierarchical or egalitarian views. Communitarian subjects strongly support group or community based action, and measures which support social structures, and oppose individual rights which undermine this. Individualistic subjects support individual responsibility and self-reliance, and reject interference with this for the good of the group. Hierarchist subjects tend to support defined social roles, including racial and gender roles, and to defer to authority. Egalitarian subjects tend to support social mobility, equality of opportunity, and oppose hierarchical or deferential systems.

Cultural cognition has been used to analyse socio-political views, and Kahan and others have claimed that, within the US context, it is a better predictor of position on topics such as gun control and abortion than socio-demographic status or political party affiliation (Kahan & Braman, 2003; Gastil *et al.*, 2005). It has also been used, in particular by Slovic, to explore variation in risk perception between individuals (Slovic, 1992, 2000; Kahan & Slovic, 2006; Kahan, 2008a).

Central to this thesis is the idea of the “utilitarian calculus” – that we can in some meaningful way judge the outcomes of various potential actions and objectively choose the one which leads to “the greatest good for the greatest number”.

Cultural theory suggests that this approach is not merely simplistic, but is seriously flawed (Kahan & Slovic, 2006), because the judgements conceal more fundamental cultural beliefs. In this view the debate is less about how much good or bad results from a particular action, rather it turns on the nature of what is considered to be desirable, which reflects cultural beliefs that are not changed by, or amenable to,

empirical evidence. The judgements are less about probabilities, and more about values. As Kahan *et al.* (2009) express it:

Culture is prior to facts ... Because facts are cognitively derived from culture, the need to choose between moral principle and utilitarian efficacy, for most people simply never arises.

The utilitarian calculus seems to be vulnerable to cultural input at three points. Firstly individuals with different cultural beliefs will value different outcomes as “good” or “bad”. Secondly, even where there is some basic agreement that particular outcomes are good or bad, these will not typically be perceived to lie at different points on a common scale that can be directly compared. Different cultural views will value specific outcomes differently, with no universally shared “exchange rate” between them. Thirdly, cultural beliefs will fundamentally affect the way in which supposedly empirical evidence is perceived, assimilated, and whether or not the risk to be evaluated is considered to be significant or not (Kahan & Braman, 2006; Kahan, 2007, 2008b).

Individuals consider situations within different, mutually incompatible, frameworks of social and cultural values and constructs, and consider different costs and benefits in the utilitarian calculus. Even if they can agree on the potential good and bad outcomes they will attach very different weightings to the various results, so their conclusions are likely to be different. Even providing empirical data is unlikely to resolve their differences. Not only will they be selectively receptive to data that supports their position, the data only has meaning within their different cultural frameworks (Kahan & Braman, 2003; Kahan & Slovic, 2006; Kahan, 2008b). For example, all could accept data that provided a precise probability of a bad outcome, but whether that probability is considered to be reassuringly low, or worryingly high, and the weight it is given within the calculus, will depend on pre-existing cultural positions.

3 RESEARCH QUESTION

3.1 CRITICAL ISSUE

Having completed a wide-ranging review of issues relating to confidentiality, the issues to which I return are whether or not patients are really likely to be deterred from seeking medical treatment by actual or potential breach of confidence, and the effect this would have on treatment, and on risk management. The research question focuses not on whether confidentiality should be maintained at the expense of public safety, but whether public safety might be better promoted by maintaining confidentiality, rather than by breaches in individual cases that might consequently lead to deterrence from treatment.

As a secondary issue, I am also interested in whether or not patients recognise these concerns, and would adopt a utilitarian calculus that would prioritise effective treatment over more immediate forms of risk management. This is of interest partly because it may indicate what patients may find acceptable, and partly because it may indirectly suggest an accommodation that society as a whole would be prepared to adopt. Ultimately however, the utilitarian calculus does not depend on what people want, but on what they actually do: whether maintaining confidentiality in risk situations would ultimately increase or decrease risk is in principle subject to empirical determination irrespective of whether or not society is willing to adopt policies based on that knowledge.

3.2 THE QUESTIONS

This study is not primarily hypothesis-driven. It has been conducted to produce evidence to illuminate the following questions:

- Do patients value confidentiality in medical consultations?
- Do patients recognise the possibility of deterrence resulting from breach of confidentiality?
- How do patients balance conflict of interest between patients and the public?
- What features of confidentiality dilemmas determine whether patients prioritise patient or public interests?
- Do patients consider that increased risk resulting from deterrence is a valid factor in reaching that decision?
- Can the likelihood of deterrence be estimated?

4 METHODOLOGY

4.1 LIMITATIONS OF THE QUANTITATIVE APPROACH

The utilitarian calculus is ultimately a quantitative one, balancing the amount of good and the amount of harm resulting from various courses of action, so it should not be surprising that most of the empirical work reviewed in Chapter 2 is broadly quantitative in nature. Despite this, there are some significant limitations to quantitative methods and the methods adopted in this thesis are qualitative in nature.

Quantitative methods are good for analysing phenomena that can be identified in advance, but are less appropriate for exploring areas in which the significant issues have not yet been identified (Greenhalgh, 1997). Until it has been established which factors patients consider in reaching decisions about confidentiality and disclosure, quantitative methods entail a significant risk of overlooking crucial variables.

While quantitative methods can be useful in defining the views held by subjects, they are relatively poor at uncovering the reasoning underlying those views: at best they will reveal *what* subjects think, without leading to understanding of *why* they think it. This often makes it difficult to predict what effect these views might have on behaviour, something which is crucial to the sort of critique of the utilitarian hypothesis proposed in this study. A related issue is that quantitative methods have poor sensitivity to subtle differences between situations, which may be crucial to the way in which people reach decisions.

In complex ethical dilemmas people are likely to express ambivalent or inconsistent views. Quantitative methods generally require a reductionist approach that classifies views unambiguously, rather than reflecting the complexity of ethical judgements, whereas qualitative methods can preserve that complexity and use it as a source of deeper understanding of the underlying attitudes.

As seen above, dilemmas of confidentiality and reporting can arise in a wide range of clinical situations. While there are some important similarities between all of these, there are also differences. While quantitative methods would aim to reflect the differences arising in different situations accurately, the lack of explanation would make it hard to generalise any findings from the particular facts of a situation to a wider understanding that could be generalised to other situations.

All of these limitations suggest that quantitative methods would be more appropriate at a later stage of investigation, once qualitative studies have identified the factors that subjects focus on when reaching decisions, and once it has been determined which similarities and differences between situations are most significant in determining people's views.

Several of the above weaknesses can be seen in the pilot study carried out prior to the current project (Jones, 2003b). In that study subjects expressed clear support for confidentiality as an abstract principle, but when presented with dilemmas in clinical situations generally endorsed breach of confidentiality. The nature of the study meant that those contradictions could not be resolved, and it was not possible to understand which of those views best reflected subjects' opinions, or how they were able to reconcile the apparent contradictions to their own satisfaction. Similar contradictory responses have been a feature of other quantitative studies in this area (Morris *et al.*, 1985; Collins & Knowles, 1995; Eisenberg *et al.*, 2005): as Ormrod & Ambrose (1999) commented:

when given a straightforward choice people seem to want greater confidentiality from their professionals, yet when given real-life situations with which to grapple many seem quite comfortable with the possibility of breaking confidences.

Even if it had been possible to determine subjects' views in the pilot study, the rationales supporting the views remained unspoken. Although the study demonstrated different opinions in different clinical situations, it was not possible to identify which variables or factors were important in producing those differences, and which were not.

4.2 QUALITATIVE METHODS

In response to the problems identified in the pilot study, the current study was designed from the outset to utilise qualitative methods in an attempt to reach a deeper understanding of the beliefs about confidentiality and deterrence held by the subjects, and the ways in which that understanding could contribute to the utilitarian calculus. In particular, the qualitative approach of grounded theory was selected as useful in the present context.

Grounded theory (Strauss & Corbin, 1990; Charmaz, 1995) is a qualitative analysis method which is generally recognised as being particularly appropriate for exploring complex inter-personal process (McCann & Clark, 2003) and in areas where there is little existing knowledge on which to base hypotheses (Greenhalgh, 1997; Brown & Lloyd, 2001; Mason, 2002; Stanghellini & Ballerini, 2008). Described as an inductive method (Strauss & Corbin, 1990; Charmaz, 1995; McCann & Clark, 2003), in which general principles are derived from specific instances, it explicitly aims at developing theory which is “grounded” in data, with attention paid to ensuring that the data is analysed with as few pre-conceptions on the part of the investigator as possible (Britten, 1995; Charmaz, 1995; Mays & Pope, 1995; Greenhalgh, 1997).

Grounded theory also permits a high degree of contextual sensitivity and interpretation (Strauss & Corbin, 1990; Silverman, 1993; Priest *et al.*, 2002), and can exploit differences in the views expressed by subjects as a source of richness and deeper understanding of the emerging theoretical concepts, rather than seeking to reduce complex phenomena to simple categories, producing “depth” rather than “breadth” (Patton, 1990; Whetten-Goldstein *et al.*, 2001). It aims to develop depth, nuance and complexity in the understanding of complex phenomena, and “thick description” of them, rather than simple correlations between pre-identified variables that may not accurately represent the lived experience (Mason, 2002). It adopts the insider perspective, rather than imposing pre-conceived views of the researcher (Smith, 1995; McCann & Clark, 2003). In an area with little existing

research, this can help ensure that subjects are able to introduce issues that had not been anticipated by the researcher.

In common with other qualitative methods, grounded theory acknowledges the role of the researcher as an active participant in the research process. This introduces a subjective element into the collection and interpretation of data that potentially undermines the credibility and value of any conclusions drawn. It is therefore particularly important that the methods adopted provide transparency, so that the influence of the researcher on the process can be identified and allowed for, and that clear connections are drawn between the original data and the conclusions. In the following sections the methodology adopted will be described in detail, with particular attention paid to points at which the researcher influence is potentially greatest.

Qualitative methods typically rely on triangulation to enhance methodological rigour and reliability (Patton, 1990; Miles & Huberman, 1994; Britten, 1995). This is usually achieved by demonstrating consistent findings from different data collection methods, or different subject groups, implying that they are reflecting a genuine phenomenon, rather than a methodological artefact. Previous work in this area (though largely quantitative in approach) has provided a degree of triangulation, by obtaining views from different groups, including patients with a variety of conditions, professionals from different fields, and the public. Some studies have directly compared more than one group; in other cases comparisons can be made between studies.

In this study there has been no attempt to utilise different methods, and although two distinct subject groups were sampled, the differences between them were minimised. The decision not to attempt triangulation, for example by seeking the views of professionals to compare with those of patients, was a deliberate one. The fundamental aim of the study is to determine the views of patients, and that is a construct to which the patients themselves have privileged access: views from another source, whether confirming or contradicting those expressed by patients, would not have equivalence that would allow comparison to be made.

A limited degree of triangulation can be achieved by comparing the data obtained with findings from previous literature. This should not preclude openness to the possibility of novel results, or of new insights arising from detailed analysis absent from previous work, but if the views expressed are substantially different from previous findings, this would raise the possibility of unreliability arising from some specific methodological flaw.

4.3 SUBJECT GROUPS AND SETTINGS

Although the views about confidentiality of the public, or of patients in general, would be of interest, it is the views and behaviour of patients who may be directly affected by the issue that are of greatest relevance to the utilitarian calculus. It was therefore decided to focus on subjects who might be expected to have concerns about this issue, and to explore their views about a clinical situation relevant to them.

Previous research suggests that subjects who perceive a dilemma as applying to their own situation may have different views to subjects who do not. It was therefore decided to identify two groups of subjects who might have concerns about confidentiality, and to explore their views in the context of one clinical situation which might arise in their own care, and in others less directly relevant to them. Various potential subject groups were considered, for whom a confidentiality/reporting dilemma could be identified, which would be likely to be familiar or easily understood by patients for whom it was not immediately relevant. Two groups were selected for study; patients with epilepsy, and patients with mental health problems. Two further scenarios were devised, in order to compare the responses of subjects from each group to neutral scenarios that had no immediate connection to their situation.

4.3.1 EPILEPSY

The first group identified was patients with epilepsy, and the associated dilemma was a patient continuing to drive against medical advice, with potential reporting to the DVLA. This group was chosen because the dilemma is one that is widely discussed in existing literature, and is likely to be familiar or understandable to other groups.

4.3.2 MENTAL HEALTH

The second study group comprised patients with mental health problems, and the associated dilemma was a patient making threats against a third party. Again, this is a clinical situation much discussed in the literature, particularly the US literature relating to the *Tarasoff* doctrine. Risks supposedly represented by mental health patients in the community is a common theme of discussion in the media, and therefore likely to be familiar to subjects. Confidentiality may be particularly important in mental health settings (Beigler, 1984; Bollas & Sunderson, 1995; Cordess, 2001a) and to mental health patients (Mechanic & Meyer, 2000). It was decided to recruit subjects without specifying a particular diagnosis, and the scenario similarly referred to non-specific “mental health problems”, despite the association of violence with specific mental disorders, because most debate in this area does not distinguish between diagnostic groups, and policy decisions are likely to apply to patients irrespective of diagnosis.

4.3.3 CHILD SEXUAL ABUSE

The first “neutral” scenario related to a man seeking psychological treatment for sexual thoughts relating to children. This is also an issue much debated in the media, and likely to be familiar to subjects, although some may perceive this as a criminal justice rather than a health issue. In the pilot study a scenario was presented in which abuse had taken place, and there was widespread support for reporting: in this study the scenario was changed so that abuse had not occurred, in an attempt to make the dilemma more balanced, and this also introduced the dimension of treatment seeking/avoiding.

4.3.4 DOMESTIC VIOLENCE

The second “neutral” scenario concerned a woman suffering domestic violence, but who was opposed to reporting. This allowed the dimension of risk to patient/other to be introduced. Mandatory reporting of domestic violence has been introduced in some US jurisdictions, but remains controversial, and this is an area where there is considerable evidence that the views of patients directly affected by the issue may differ from those of others (see Section 2.5.2).

4.3.5 SAMPLING ISSUES

How many subjects are needed to achieve coverage of the range of views within the groups? This question can be approached both theoretically and practically. Although statistical power is not a necessary attribute for a qualitative methodology, a small sample may be insufficiently representative to allow meaningful generalisation. In the extreme case, a single case report may generate interesting data, but is unlikely to lead to any conclusions about patients in general. This is not to argue for a purely quantitative approach to the methodology, where sample size and statistical power is all, but to recognise that for qualitative analysis to be valid and meaningful, the study design has to provide a reasonable expectation of sampling the relevant range of opinion. On the other hand, the qualitative methods employed depend on the detailed explorations of subjects’ beliefs, and practical constraints mean that a large sample size will result in more superficial data from each subject.

Qualitative studies sometimes address the issue of sample size by means of purposive sampling – selecting subjects in a way intended to produce maximum variation, so that all potential viewpoints are accessed. However this depends on an initial judgement, based on previous work, or on *a priori* assumptions, about the characteristics that will predict that variation. In this study no such characteristics were known, so subjects were randomly identified from within the two groups.

While it is not possible to find an example of every minority view that might be held by a few patients, it is important to sample widely enough to identify the most commonly held views. The utilitarian calculus of “the greatest good for the greatest number” requires some estimate of what that number might be. A policy that would deter 1% of patients from seeking treatment would be very different, in utilitarian terms, to one that would deter 50%.

An attitude that was held by as few as 10% of the population, if it significantly affected their willingness to seek treatment, would be of considerable importance for an understanding of the issues, and for the utilitarian calculus. Given the number of patients involved, attitudes held by 5% or less of the population might still be important for policymakers. Certainly an attitude that was held by 20% of the population would be too important to overlook. The empirical studies reviewed in Chapter 2 generally found that between 10% and 20% of subjects reported having already been deterred from seeking health care, and that between 30% and 60% of subjects recognise this as a possibility, either for themselves or for others. This suggests that sample size needs to be large enough to give a reasonable chance of detecting views held by between 10% and 20% of the population

The likelihood of NOT obtaining at least one example of a view that is held by a proportion of the population, P , in a sample of size n is given by $(1 - P)^n$. For the chosen sample size of 20, the possibility of failing to sample a view held by 10% of the population is therefore 12%, or about 1 in 8: the possibility of failing to sample a view held by 20% of the population is about 1%. This was felt to be an acceptable compromise between breadth of sampling, depth of interviewing, and practical constraints on the study.

In a more pragmatic way, evidence that a sample has accessed the full range of variation within the population is demonstrated by saturation. Initial subjects will raise many new issues, but as sampling progresses there will be fewer new issues arising, and increasing repetition of those already covered. In the limit, further sampling produces no new material at all, although in practice this point may never

be reached. Evidence that few or no new issues are being introduced will provide reassurance that adequate sampling has been achieved.

4.3.6 RECRUITMENT

Three inclusion criteria were imposed: subjects had to be over 18, able to participate in the English language interview, and able to give valid consent. No variables suitable for stratified or purposive sampling were identified, so subjects were identified within each target population without further selection. All potential subjects were identified and contacted initially by a clinician working with them, and given information about the study. Only those patients who chose to make contact were identified to the investigator, who provided additional information at this stage if required. Those subjects who agreed to participate were then offered an interview following their next regular clinic attendance, or at an alternative convenient time.

Subjects for the epilepsy group were recruited from a specialist epilepsy outpatient clinic. The consultant neurologist identified patients who satisfied the inclusion criteria, and who were interested in participating in the study. Subjects for the mental health group were identified by staff from two local Community Health Teams. People attending for some form of outpatient contact were chosen, to maintain comparability with the first group, and to minimise concerns that subjects may lack capacity to give valid consent. Subjects were attending a variety of services, including routine appointments with a psychiatrist or community nurse, a service-user facilitated support group, and specific clinics for patients receiving depot medication or clozapine therapy.

4.4 VIGNETTE DESIGN

There is an inherent difficulty in studying a concept such as deterrence in relation to breach of confidence: if it exists then by definition a subject will be deterred from talking about it to a researcher, just as they would be deterred from discussing the relevant issue with a doctor. It can be seen in studies such as Lothen-Kleine *et al.* (2003) that research subjects can be inhibited from frank disclosure to researchers by concerns for confidentiality. For this reason it was decided to use hypothetical clinical situations in this study, as a way of enabling subjects to talk about situations in which disclosure of actual personal experience might have adverse consequences. The hope is that in this way subjects who do have direct experience of such a dilemma might feel more able to discuss that, by locating the issue in a fictitious scenario rather than their own history.

There are further benefits to using standardised situations as a basis for research interviews: it enables the researcher to explore attitudes to confidentiality in a range of clinical settings that will be outside the experience of some or all subjects; it enables comparison of responses between situations which have direct personal salience to the subject and those which do not; and it enables each subject to be presented with the same situation, so that comparisons can be made between subjects' decision-making. In addition, it allows the researcher an opportunity to define variables that might be expected to influence support for reporting or not reporting, and to design scenarios that manipulate or demonstrate those variables in specific ways, rather than relying on these emerging during a less structured interview.

Numerous studies of attitudes to confidentiality, summarised in Appendix 1, have utilised clinical vignettes (for example Lindenthal & Thomas (1982a), Beran (2002), Brosig & Kalichman (1992a), Guedj *et al.* (2006)) as a way of exploring these issues, either to illustrate a clinical situation, about which questions are then asked or to manipulate experimental variables. In the latter case, groups of subjects would be presented with vignettes in which specific details, such as a child's age, had been

varied, to explore the effect this might have on, for example, a therapist's willingness to report a case of child abuse. More widely, vignettes have been employed by qualitative researchers as a way of introducing "real world" issues in a systematic way (Alexander & Becker, 1978; Strauss & Corbin, 1990; Miles & Huberman, 1994).

There are also potential drawbacks to the use of vignettes. By presenting a particular clinical situation the researcher is setting the terms of the ensuing discussion, which may inadvertently bias responses, or focus discussion on areas considered relevant by the researcher rather than by subjects. Selection of the variables related to reporting decisions entails similar risks, and there may be other variables, unrecognised by the researcher, that subjects would have raised if the scenarios had been worded differently. Finally, there is a risk that a vignette that is too detailed may close down discussion, by giving a piece of contextual information that effectively determines the subject's choice: conversely, a vignette lacking in sufficient detail may make it difficult for a subject to reach a conclusion in a situation that is insufficiently defined. Drafting vignettes that balance these concerns and facilitate access to the complexity of subjects' views without undue distortion or restriction was a significant challenge.

It is likely that subjects' responses to questions of disclosure will vary depending on whether they are posed in the abstract, or in the context of a clinical dilemma, as was the case in Jones (2003b). If so, then considering a specific clinical issue is likely to lead to responses that are closer to the actual behaviour of patients in a similar situation, in comparison to the responses to a general statement of principle (Ormrod & Ambrose, 1999).

Four brief vignettes were written, to illustrate the four clinical settings described above. They were kept brief, between 72 and 92 words, with a minimal amount of detail, to encourage subjects to explore possible variations that would influence their view of reporting. Each vignette ended with a question of the form "Should the doctor report this to X". There was a risk that this would limit discussion, by encouraging subjects to reach a conclusion immediately, but it also had the benefit

of focussing the subject on the central dilemma to be resolved. Where subjects did respond with an immediate “yes” or “no”, which was uncommon, subsequent questioning was able to explore the reasons for the decision, and the variables which might alter it.

Several potentially relevant dimensions were identified from previous work in the area, and from reflection and supervision discussions during the study design phase. The situations chosen, and the detailed wording, allowed comparisons to be set up between situations where:

- The person at risk was the patient, an identifiable third party, or unidentifiable third parties
- The patient actively sought help, or rejected it
- The patient cooperated with or defaulted from medical management of the risk
- The potential harm was intentional or accidental
- The patient was or was not concerned about the risk
- Harm had already occurred (and may or may not be repeated) or was a potential future risk
- Treatment may potentially reduce risk or may have little effect (or may potentially increase risk)

The wording of the four vignettes, and the rationale underlying it, is given in Appendix 2. Initial drafts were discussed during supervision sessions, and preliminary versions were given to clinical colleagues, who were asked to identify the main factors relevant to reporting and whether the situation gave rise to a perceived dilemma, rather than a clear-cut response with little alternative.

4.5 DATA COLLECTION

4.5.1 INTERVIEWS

Prior to initial contact with the investigator, subjects were given an information sheet explaining the purpose of the study and the nature of the interview. This, and the interview schedule that was followed, are presented in Appendix 3.

Both in the information sheet and in the preamble to the interview subjects were given clear instructions that they were not required to discuss any information relating to their own case unless they wished to do so. Each subject was first presented with the scenario relevant to their subject group (DRIVING or THREATS), and reminded that personal disclosure was not required.

Subjects were prompted with the question “How do you think the patient might be feeling in this situation?” Further discussion was primarily structured in response to the topics raised by the subject, but two further prompts were given, if subjects did not spontaneously address the questions, “How do you think a doctor should deal with this?”, and “If doctors did report this sort of thing, what effect would that have on patients?”

Subjects were then presented with the other three scenarios, in a random order achieved by shuffling the three cards, and the same prompt questions asked. At the end of the fourth scenario, subjects were asked “In general, how important do you think it is that doctors keep most things confidential?”, and were offered an opportunity to give any other comments or reflections on the issues raised. They were then asked to confirm that they remained happy for their interview to be used in the study, and for their comments to be quoted.

Later interviews took place in parallel with the coding of earlier interviews. This resulted in a degree of refinement to the focus of later interviews, with issues and concepts raised by earlier subjects being presented to later subjects. As the initial

coding framework was developed (see below), the conceptual links being identified within the data were also tested for validity in later interviews.

4.5.2 RESEARCHER AS INTERVIEWER

All interviews were carried out by the researcher. Some of the weaknesses of this methodological choice are discussed in Section 4.8.2: some benefits are discussed here.

In addition to the pragmatic benefit of not requiring additional research staff, there are several benefits from the direct involvement of the researcher in every interview. The design of the study involved a detailed review of previous literature and of theoretical writings on confidentiality and medical ethics. The researcher was therefore familiar with numerous subtleties and ramifications within the brief scenarios presented, and was able to be sensitive and alert to nuances that might have been less apparent to another interviewer. Ideally, this will have resulted in an exploration of issues that gets as close as possible to the central dilemma being studied.

Personal familiarity with the content of the interviews also proved useful in later analysis, allowing a greater contextual awareness of the interview from which comments arose, and repeated comparisons between the interview itself, review of the audio recording, and reading of the written transcript. Coding could therefore be based on a deeper familiarity with the content in different modalities that would not have been possible if different individuals had carried out different parts of the process.

Direct involvement of the researcher in the interviews also allowed the reflexivity described above; insights derived from reviewing and coding early interviews could be fed back into the interview process with later subjects, allowing concepts to be verified and understanding to be enhanced. Overall a complex interaction could be developed between different stages of the research process (Figure 1):

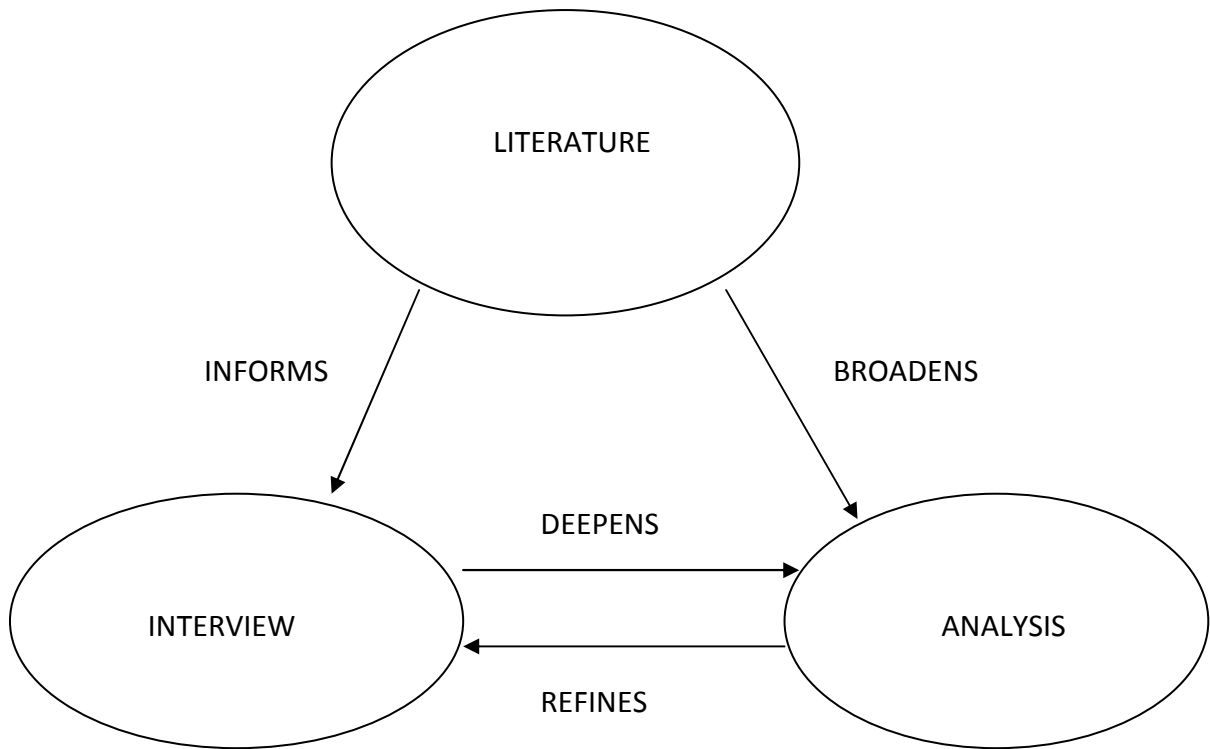


Figure 1: Iterative interview process

4.5.3 TRANSCRIPTION

All interviews were recorded on a digital recorder, and subsequently downloaded and saved as a computer .WAV file. Interviews were then transcribed by an experienced medical secretary. Interviews and transcripts were reviewed by the interviewer, and a small number of corrections were made, and some brief gaps filled in. To avoid introducing bias on the part of the researcher, any remaining ambiguities were left unchanged. Brief comments were added in places where context or tone of voice indicated a meaning not immediately apparent from the transcript alone.

Edited versions of the transcripts were saved, and imported into NVivo 7 for further analysis.

4.5.4 ASCERTAINING FUNDAMENTAL CHOICES

In reviewing the transcripts, and indeed in conducting the interview, the researcher was already exposed to the views expressed by subjects, so the coding phase, described below, was not undertaken blind to knowledge of those views. Although all subjects expressed some degree of ambivalence, or recognised that their view might change depending on further details that were left unspecified in the scenario, in almost all cases subjects had a clear preference either for reporting or for not reporting in the situation described. In a small number of cases the subject seemed genuinely undecided or equipoised between the two alternatives, and in another small number the subject had not expressed a view either way, but 95% of the subject/scenario combinations were identified as supporting one of the two options. During the review phase, the researcher decided to make explicit his judgement as to the subject's fundamental support for reporting, or for maintaining confidentiality in each scenario, which was recorded for further analysis (Section 5.2).

This judgement did not entail any consideration of why or how subjects reached their decisions, and was not thought likely to prejudice the later detailed analysis, since the researcher was already familiar with the content of the interviews. Although such a classification is necessarily simplistic, it allowed comparison of the different approaches taken by subjects and some broad comparisons between groups, which were further explored through detailed analysis of interview content.

4.6 DATA ANALYSIS

4.6.1 DEVELOPING THE CODING FRAMEWORK

All text from the interview transcripts was initially coded at one of six nodes: one for each of the four scenarios, one for introductory remarks, and one for final reflections and comments after the final scenario. This allowed the occurrence of particular concepts within the interviews to be analysed by scenarios. Interview transcripts were then re-read and coded in NVivo², with the content being allocated to free nodes. Interviews from the two groups were initially coded alternately, but because of different rates of recruitment in the two groups, after the first 24 interviews had been coded (12 from each group), all remaining mental health interviews were coded before the rest of the epilepsy interviews.

The first eight interviews were coded entirely using free nodes. At this point a preliminary tree structure was created, grouping nodes which related to connected concepts, although some coding remained as free nodes at this point. Tree nodes were grouped under ten headings as in Table 1.

In addition two further groupings were created. One, labelled “Practical or process issues” related to observations on the interview rather than direct subject comments, such as points where the subject re-read or clarified aspects of the scenario, appeared to misunderstand or misinterpret details, or where the interviewer directly challenged the subject’s view. The second, labelled “Scenario-specific issues” contained four sub-groups, in which references to factors specific to one of the four scenarios were held.

² NVivo qualitative analysis software, QSR International Pty Ltd version 7.0.281.0, ©2007.

GROUPING	RELATING TO
ACTION OR DECISION	The action to be taken by the doctor.
AUTHORITY	External rules or authority appealed to.
CONFIDENTIALITY IN ABSTRACT	Expectations of medical confidentiality, and its value or lack of value.
DETERRENCE	Recognition of the possibility of patients in the scenario being deterred from health care, and the consequences of this.
DOCTOR BEHAVIOUR	Factors relating to the doctor's decision-making or experience of the dilemma.
FOREWARNING	Whether doctors would inform patients in advance of breaching confidentiality, and the consequences of this.
ORIENTATION	Perception of degree of risk, importance of confidentiality.
PATIENT EXPERIENCE	The patient perspective on the dilemma, including the relationship with the doctor.
REPORTING	Support for breaching or for maintaining confidentiality.
SELFDISCLOSURE	Subjects revealing aspects of their own experience, or identifying with the patient in the scenario.

Table 1: Initial tree node groupings

At this point some nodes remained free nodes, because their place within the structure was unclear. As coding progressed, and the structure was extended, these were gradually incorporated into the tree. Some nodes were reorganised within the structure during this phase of the procedure, but no nodes were deleted or combined, even when similar nodes had been created which covered similar concepts. The total number of nodes therefore increased monotonically, and the rate of increase could be used as an indicator of saturation, as described below.

The first cycle of coding ended after 33 interviews (12 epilepsy and 21 mental health) had been coded. A reasonable degree of saturation was achieved, as described in Section 4.7, and therefore further work was undertaken on the coding framework, with the final five interviews being left uncoded at this stage.

The framework was edited, with some nodes relating to similar concepts being merged, and the tree structure being further refined. Because nodes had been added to the framework incrementally, it was clear that some concepts identified and coded in later interviews had been present, but unrecognised, in earlier interviews. A second phase of coding was therefore undertaken, with particular attention being paid to the earlier interviews. A smaller number of new nodes were

identified during this phase, usually arising from subdivision of existing nodes into more specific concepts. The number of additional nodes coded to each interview was used as a measure of coverage.

New nodes added during the second phase were recorded, and a more limited third phase coding undertaken. In this phase no new nodes were created, and only nodes which had been added since the interview was coded in phase two were considered. In this way each interview was examined at least once for examples of all concepts contained within nodes created by the end of phase two.

At the end of phase three the tree structure contained 289 nodes (not including higher level groupings, which did not link to interview content). The broad groupings had remained unchanged from those created after the first eight interviews (above), although various subheadings had been added.

The 289 nodes were then simplified and consolidated by merging those relating to similar concepts, and by deleting a small number of nodes which did not appear relevant (these were typically nodes identified during early coding, often with no further examples emerging, and which were peripheral to the main issues identified). 211 nodes remained, of which 71 related to the “scenario specific” factors described above. These were then merged with non-specific nodes covering similar material, with four new nodes being created for data which did not fit comfortably in an existing node: scenario-specific nodes were retained for analysis and validation of the vignettes to be undertaken (see Section 5.3) but were not used for further analysis.

The final five interviews, all of epilepsy subjects, were then coded using the 144-node framework. At this point it was predicted that, if adequate data saturation had been achieved, the framework would allow complete coding of the content of those interviews, with no significant new concepts emerging. In fact one new concept emerged, which seemed significant even though it had only emerged in one interview, and was added to the framework. The final coding framework, comprising 145 nodes, plus associated headings and subheadings, and the 71 scenario specific nodes, is reproduced in Appendix 4.

4.6.2 FROM NODES TO CONCEPTS.

The initial coding framework was developed by grouping comments thematically in order to facilitate consistent use of nodes. For example comments relating to the patient's experience were grouped together, separate from nodes relating to the doctor's experience, even when they discussed similar concepts.

Subsequent development of the framework kept some of those pragmatic groupings, but also introduced higher-order concepts which appeared to have explanatory value, and which linked nodes from different headings which related to the same concept. In the restructuring and simplification of the coding structure new categories were developed with a theoretical organisation rather than a pragmatic one, and the resulting framework represented a combination of the two approaches.

The clearest example of this process comes from the "scenario specific" nodes. Comments arising from each of the four scenarios were grouped together, which greatly facilitated coding, but resulted in separate nodes coding essentially similar concepts within two or more scenarios. In the final recoding all of the scenario-specific nodes were reorganised into the main theoretical framework. The content coded at these nodes was therefore regrouped with similar material from the other scenarios, and from elsewhere in the framework.

Several key concepts emerged from this process which will be examined individually in detail in the following sections. The modelling tools within NVivo were used to explore connections and overlapping content between the nodes relevant to each concept, and within each concept several themes were identified which summarised the issues emerging. Where necessary further levels of sub-themes were included within the models. The first three levels of this model are tabulated in Appendix 5. Further analysis based on those models led to the proposed theory developed in Chapter 6.

The themes and sub-themes within each model in Appendix 5 represent individual nodes from the coding framework. However whereas the hierarchical organisation of the nodes shown in Appendix 4 remains partly pragmatic, the allocation of those nodes within the model represents a more theoretical organisation of the same data. It would be possible for the coding framework to be further reorganised along similar lines, and if ongoing data collection and analysis was envisaged this would be a useful step. However for the purposes of this thesis the coding framework has been “frozen” at the pragmatic stage, with the derived models used to take forward the theoretical analysis. The tabulation in Appendix 5 is also “frozen” at an intermediate stage, before the derivation of the proposed theory. This provides some transparency, so that the modelling process can be evaluated. However it means that the structure of the early stages do not fully reflect the structure of the later models derived from them, which may give the impression that the two are less closely connected than is the case.

Any such selection and ordering of data entails a degree of subjectivity. By documenting the process, and providing details of the coding framework and models developed, I aim to demonstrate that the decisions made are justifiable and reasonable, and that the proposed emergent theory derived is a valid one.

4.6.3 STORY OF A NODE

To illustrate the processes described above, we can follow the progress of a particular concept through the process of coding and analysis.

The node **Need to have clear rules known in advance was first created** between coding the 5th and 8th interviews. By the time the 8th interview was coded, it was one of 173 free nodes, and contained 2 references taken from a single source. At this point the first tree structure was created, and it was grouped under the heading FOREWARNING, with 4 other nodes. It grew during the first phase of coding, ending up with 19 references from 7 interviews: at the same time FOREWARNING expanded to include 13 other nodes.

During the reorganising of nodes, FOREWARNING was subdivided, and the node was allocated to a subheading INFORMING PREDISCLASURE. Further reorganisation led to three other nodes, **Confidentiality needs to be negotiated** and **Advance warning or knowledge of rule**, both of which had been part of FOREWARNING, and **Need for clear rules**, which had been part of the AUTHORITY heading, being merged into the node.

At this point the node had expanded further, containing 36 references taken from 11 interviews, and 3 further references came from one of the final five interviews. At this point the final coding framework was completed, and the node **Need to have clear rules known in advance** can be seen in the framework in Appendix 3.

The node was included in the NVivo modelling process, and remains in the Forewarning model (Figure 12) as a component of “Informing pre-disclosure”, and from there it appears as a sub-theme in the model in Appendix 4 (shortened to “Need to have clear rules”). Content coded to this node is then quoted in Section 5.9.1, and those concepts are reflected in the discussion of “Rules in advance” in Section 6.1.1. Throughout this process the classification of the various nodes has been checked against the interview content coded there, to ensure a good fit between subjects’ statements and the concepts being derived and analysed.

4.7 SATURATION

The qualitative methods employed in this study entail small sample sizes, and a resulting risk of failing to reflect the full range of opinions held by patients (see Section 4.3.5). One safeguard against this is to ensure that the data sampled achieves saturation: that is, to reach a point when additional sampling gives rise to minimal new perspectives or concepts. Saturation was assessed at various stages during the coding procedure.

During the first coding phase 33 interviews were coded, resulting in a total of 312 NVivo nodes. The first interview coded resulted in 61 nodes, but after this the number of new nodes identified in successive interviews dropped off rapidly. No other interview produced more than 33 new nodes (from the fifth interview) and 24 interviews, including all of the last 21, produced fewer than 10 new nodes. This pattern is shown in figure 2.

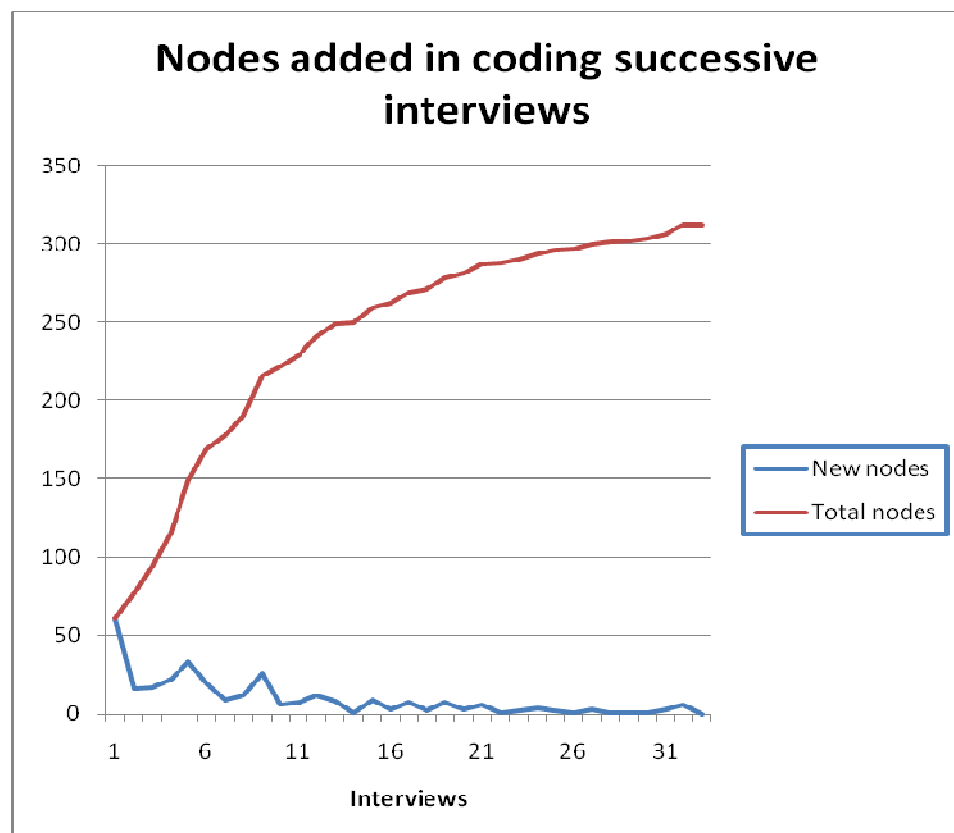


Figure 2: Accrual of nodes in first coding phase

The ninth interview coded seems to have generated more new nodes than the overall pattern predicts: there was a gap of several months between coding the eighth and ninth interviews, and it may be that some new nodes coded here duplicated existing coding due to lack of familiarity with the framework. However it was also the longest interview (over 56 minutes), and after the final consolidation of the coding framework that interview remained the one coding the most nodes, so it is more likely that it was a particularly rich source of data

Following review of the coding frame, the second phase of coding was undertaken on the same 33 interviews. Figure 3 shows the number of additional nodes coded to each interview during phase 2. Most of these were not entirely new nodes, but were nodes created during the first phase, further examples of which were identified within a particular interview in the second phase. Although more variable than the addition of new codes during phase 1, this also shows the expected decrease in new material as coding progressed.

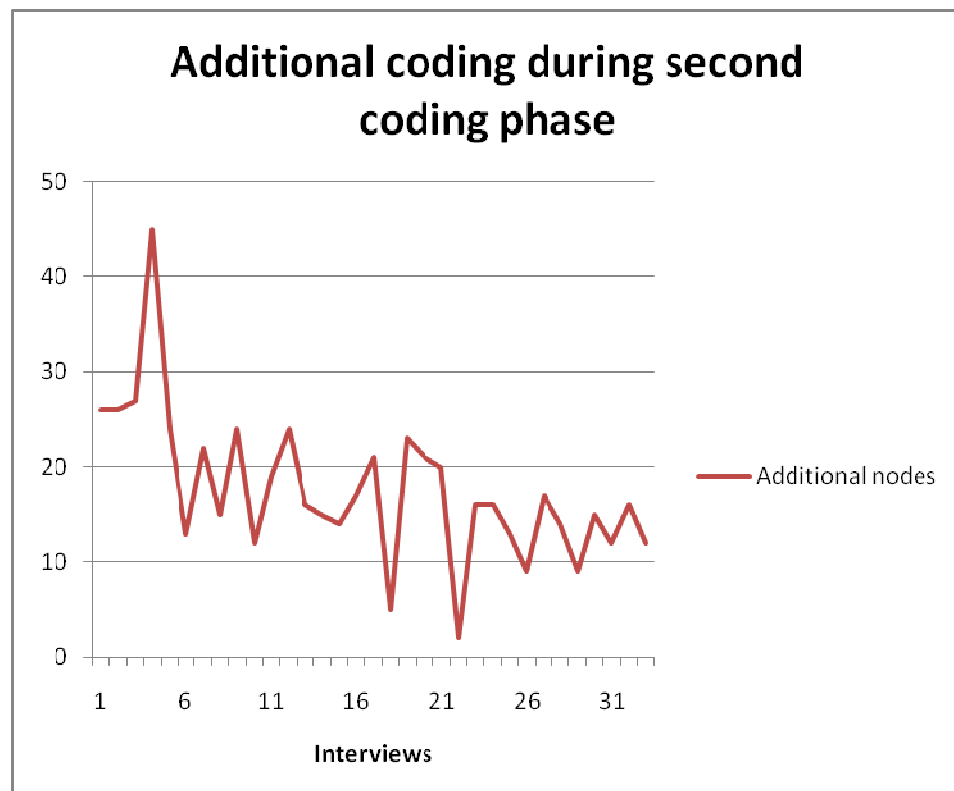


Figure 3: Accrual of nodes during second coding phase

At this stage the coding frame had 211 nodes (including the scenario-specific nodes). The 38 interviews were coded at an average of 67 (range 34-93) distinct nodes, many occurring more than once in a given interview. The 211 nodes each appeared in an average of 10 interviews (range 1-37). Other than the scenario-specific nodes, which often coded very narrow concepts, the 145 nodes occurred in an average of 15 interviews (range 1-37), with only three nodes represented by a single interview, and 114 (78%) of nodes occurring in at least 6 interviews.

Taken together these figures demonstrate that the data collected and the coding frame developed were adequate to provide reasonable sampling of the breadth of opinions within the population, and also to give depth to subsequent analysis, by providing multiple examples of each concept. Obtaining an average of 67 distinct concepts from interviews lasting less than 40 minutes also suggests that the interviews were rich sources of relevant data, and that the methodology enabled subjects to express complex and multifaceted views.

4.8 LIMITATIONS AND WEAKNESSES

The methodological choices outlined in this chapter have some significant benefits for addressing the study questions but, as with all such choices, they also have some limitations and weaknesses which it is important to bear in mind when interpreting any results.

4.8.1 GENERAL WEAKNESSES OF QUALITATIVE METHODS

Two features of qualitative methods make them particularly vulnerable to charges of subjectivity. Firstly the (relatively) small number of subjects and often large bodies of data means that it can be easy to select both subjects and data that support a particular pre-determined view, and it can be difficult for an external observer to tell whether or to what extent this may have happened. Secondly the detailed nature of the analysis involved can lead to a researcher becoming too close to the data source and losing a degree of objectivity. This is exacerbated by the tendency of qualitative methods, and qualitative researchers, to utilise researcher involvement in the process as a way of generating depth of understanding. This can be a source of great richness in qualitative research but is also a potential source of bias. At its best, “reflexive” involvement of the researcher with the data produces insights that could not be obtained in other ways, but at its worst it serves to reinforce preconceptions and distorts data to fit the researcher’s prejudices.

Because qualitative methods tend to be time-consuming and seek depth rather than breadth in sampling, they are also vulnerable to producing studies that are narrow in scope. This can be reflected in findings that are too unrepresentative of the phenomenon being studied credibly to support the conclusions, or in findings that have credibility in a narrow context, but lack sufficient generalisability to have any wider application.

The following sections consider how these potential weaknesses arise in the context of the current study, and how they might be reduced or eliminated.

4.8.2 THE RESEARCHER PERSPECTIVE

Although grounded theory attempts to develop a theoretical framework from data, with as few preconceptions as possible, no research is conducted in a theoretical vacuum, or without some initial concepts about the area of study. To ensure that these distort the conclusions as little as possible, it is important to be explicit about decisions made in advance of data, and about external influences on the design and conduct of the study, so that their impact can be assessed.

One source of preconception is the experience and beliefs of the researcher³. This study examines issues relevant to all doctor-patient interactions: I am a practicing doctor with over twenty-five years experience, and have also been reading and thinking about the dilemmas associated with medical confidentiality for much of that time, so it is inevitable that my view of these issues will affect the design of the study, the conduct of the interviews, and the analysis of the data.

I am concerned about what I perceive as the erosion of confidentiality between doctor and patient. This predisposes me to recognise the risk of deterrence, and perhaps to give it more weight than would most patients. I have a genuine desire to understand what patients think about these issues, but I also have an expectation that reflection on the possible consequences of deterrence will lead some subjects who initially support reporting to re-evaluate that.

At the same time, my clinical practice as a forensic psychiatrist is one in which, more than most doctors, I am continually reminded of the need to consider not only the interests of my patients, but the wider perspective of safeguarding the public from risk. This also explains in part why I am interested in resolving

³ This section deals with the impact of the researcher's own perspective on the research process. It is therefore written in the first person, to emphasise the reflexive nature of the qualitative research process.

confidentiality dilemmas, and the associated conflict of interests, since they form a backdrop to most aspects of my day-to-day. I routinely share sensitive information about my patients with agencies such as the Ministry of Justice, the Prison Service, Probation, and MAPPA panels, and face the consequential effects on my relationships with patients. Not uncommonly I am surprised by the willingness of patients to share information with me, even when they have actual experience of repeated disclosures that are directly adverse to their interests. Perhaps deterrence is not a significant problem in practice – although it is never possible to know what additional information might have been disclosed under different conditions.

Part of my motivation for undertaking the study is a concern that policy decisions have increasingly prioritised public protection over patient privacy, and a belief that this has been possible in part because of a lack of compelling evidence for the value of confidentiality. While I do not discount the possibility that patients in general, or even those directly affected by confidentiality dilemmas, may not share my views, there is a risk that I may introduce bias into the design, conduct and interpretation of this study by privileging my own perspective over that of subjects. I hope to have minimised that by reflexive and self-aware conduct of the study, and to demonstrate this by transparently documenting my own contribution to the project. The reader can also play a part, by critically evaluating that process.

The other source of information in advance of data is the existing literature both theoretical and empirical, reviewed in Chapter 2, and my own thoughts and observations arising from that. That literature suggests factors that are likely to influence subjects' perceptions of confidentiality, risk, and disclosure, which should be reflected in the study design.

4.8.3 SPECIFIC WEAKNESSES OF THE CURRENT STUDY

Because of limitations of scale and funding all stages of this study, literature review, study design, interviews, data analysis, and conclusions, have been carried out by a single researcher. Advantages in terms of familiarity with the data, and reflexivity

between the various stages have been described in Section 4.5.1. There was no opportunity for detailed discussion between co-researchers to discuss issues of research questions, methodology, coding, and analysis, to promote objective decisions, and although academic supervision provided external scrutiny of assumptions and decisions, this inevitably took place at some distance from the process itself.

Several steps have been taken in an attempt to limit these problems. Choices regarding methodology and process were discussed repeatedly in supervision sessions, and the rationale for choices made is presented in this thesis: hopefully the reader will be persuaded by those arguments but, if not, the process is at least transparent, and the consequences can be assessed. The interviews themselves are potentially open to bias, although the use of semi-structured questions ensured that all subjects were asked about key issues. Data will be presented to show that subjects were not unduly compliant with suggestions made by the interviewer, and some transcripts were scrutinised by the academic supervisor for leading questions and for bias. These were found to be rare, and countered by the interviewer prompting for alternative arguments in most transcripts.

The coding of data from the interviews, to identify emergent concepts, is in part a subjective process, but the density of codes obtained from interviews and the wide range of concepts identified within the coding framework do not suggest that substantial issues raised by subjects were ignored. The organisation of the coding framework and the categorisation of concepts could undoubtedly have been done differently by a different researcher, but this does not in itself invalidate the structure that emerged.

The analysis of data and construction of an emergent theory will be described in considerable detail in the next chapter. While quotations taken from 25 hours of interview will always be selective, substantial amounts of direct quotation from subjects will be given to exemplify the points made. It is necessary for the credibility of any resulting theory that it arises out of the data, but this does not imply that it represents the only conclusions that could be drawn. If a theory is credible,

internally consistent, and clearly linked to the data from which it emerges it is less critical whether or not other aspects of the data might support other conclusions, and no claims are made that the results presented here have exhausted the richness and subtlety of subjects' views.

One final observation may serve to emphasise the integrity of the research process. Since the researcher had strong pre-existing views about the issues explored, there are grounds for concern that those views might have taken precedence over the true opinions of subjects. In fact the results presented and the conclusions drawn will be seen to contradict the researcher's views outlined in Section 4.8.2, providing significant evidence that it is the subjects' voice, not the researcher's, being heard most clearly.

4.8.4 LIMITATIONS OF SAMPLE

The sample size in this study is limited primarily by practical considerations arising from the desire to analyse deeply the positions held by subjects, and by the limited resources available. No claims for statistical significance will be made for the results, and no estimate of the frequency with which, for example, a particular view is held in the general population, could be made with any degree of precision. Results will be presented descriptively in terms such as "many", "most", "a few", but it should be recognised that even these indications are at best a preliminary indication of relative frequency. It is not possible to be sure that all possible attitudes are represented in the findings: approaches to addressing this concern have been described in Section 4.3.5, but this implies that some views, particularly less commonly held ones, may have been missing from the sample.

Perhaps more critical than the absolute size of the sample studied is whether it is typical of a wider population. The study recruited subjects from only two settings, although as Section 2.6 demonstrates dilemmas of confidentiality arise in very many areas of medicine, and there is no compelling reason to believe that patients from the settings chosen are similar to patients as a whole. In fact one of the

settings, mental health was selected partly because there is some pre-existing evidence that it is NOT typical, but that mental health patients may have different concerns to other patients (Mechanic & Meyer, 2000). To the extent that similar opinions are expressed by both groups we might tentatively conclude that this is an indication of how patients in general feel about the issues, although with a large proviso that further work may show that the groups chosen in this study are not typical or, if they are, that some other specific groups are different. However for aspects in which the two groups studied differ it will be difficult, if not impossible, to determine which, if either, might be more representative of patients as a whole and which might be atypical.

It is also important to note that all of the epilepsy subjects were recruited from the practice of a single neurologist: if that doctor is particularly skilled at negotiating confidentiality and promoting trust (or indeed, particularly unskilled), then subjects selected from his caseload will be atypical. Mental Health subjects were recruited from several settings within two distinct community teams, but even so with small numbers it is possible for practice in one particular area to distort the picture, and there may be other unrecognised characteristics of the populations sampled that would limit the generalisability of any conclusions.

No attempt was made to obtain a sample that reflected specific socio-demographic characteristics such as age, gender, social class or educational level. One specific issue is that Norfolk has a low proportion of black and minority ethnic groups compared to most areas of the UK. Therefore, even if the sample is typical of the local population, extrapolation to other areas and different communities requires particular caution.

These weaknesses can be partly countered in two ways; by careful attention to the meaning of the data obtained, and caution in extrapolating beyond the point justified by the sampling techniques, and by recognising that the method is intended to represent the *range* of position adopted by subjects (and, within limits, by patients more generally) more accurately than the *relative frequency* of those positions. Conclusions about the range of position commonly adopted will

therefore be more robust than conclusions about the frequency with which they occur: given the small sample size, any such estimate of frequency would anyway be very imprecise.

It is also concerning, if unavoidable, that all the subjects in this study have volunteered to take part. Since the topic of interest is related to patients' willingness or otherwise to trust doctors and cooperate with health services, a volunteer sample presents obvious limitations. Conclusive investigation of this area would require attempts to be made to access the views of patients who had less trust in doctors, perhaps by adopting an explicitly non-medical approach to sampling and interviewing, and, if possible, the views of people who have chosen not to present to health services at all. That this has not been attempted in the current study should be seen as a limitation, rather than a weakness, but it does imply that any conclusions reached should be seen as applying primarily to those who are relatively positively disposed to health professionals.

5 RESULTS

5.1 SUBJECTS AND DEMOGRAPHICS⁴

In total 38 subjects were recruited and interviewed, 21 in the Mental Health group and 17 in the Epilepsy group. Male subjects were more frequent than female in both groups (59% in Epilepsy, 62% in Mental Health). Subjects were classified into 4 age bands: 18-30, 31-45, 46-60, >60. In both groups the 46-60 age band was the most common, as shown in Figure 4.

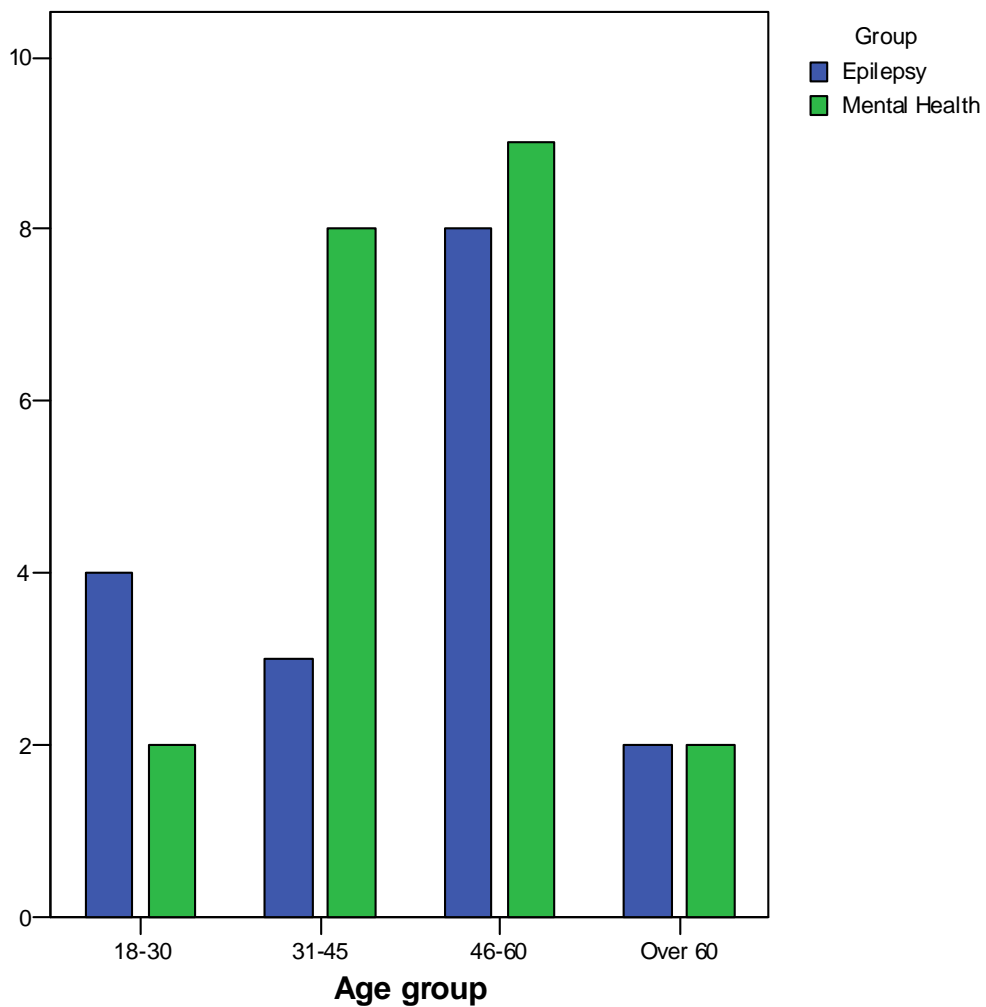


Figure 4: Age of subjects

⁴ Descriptive statistics quotes in this section have been generated within NVivo and calculated in SPSS 12

Interviews lasted between 22 and 56 minutes, with an average length of 37min 57 sec. There was no significant change in the length of interviews over time, but the mental health interviews were considerably shorter than the Epilepsy interviews, with an average length of 34 min 29 sec compared to 42 min 14 sec as shown in Figure 5. 13 (62%) of the Mental Health interviews were shorter than the shortest Epilepsy interview.

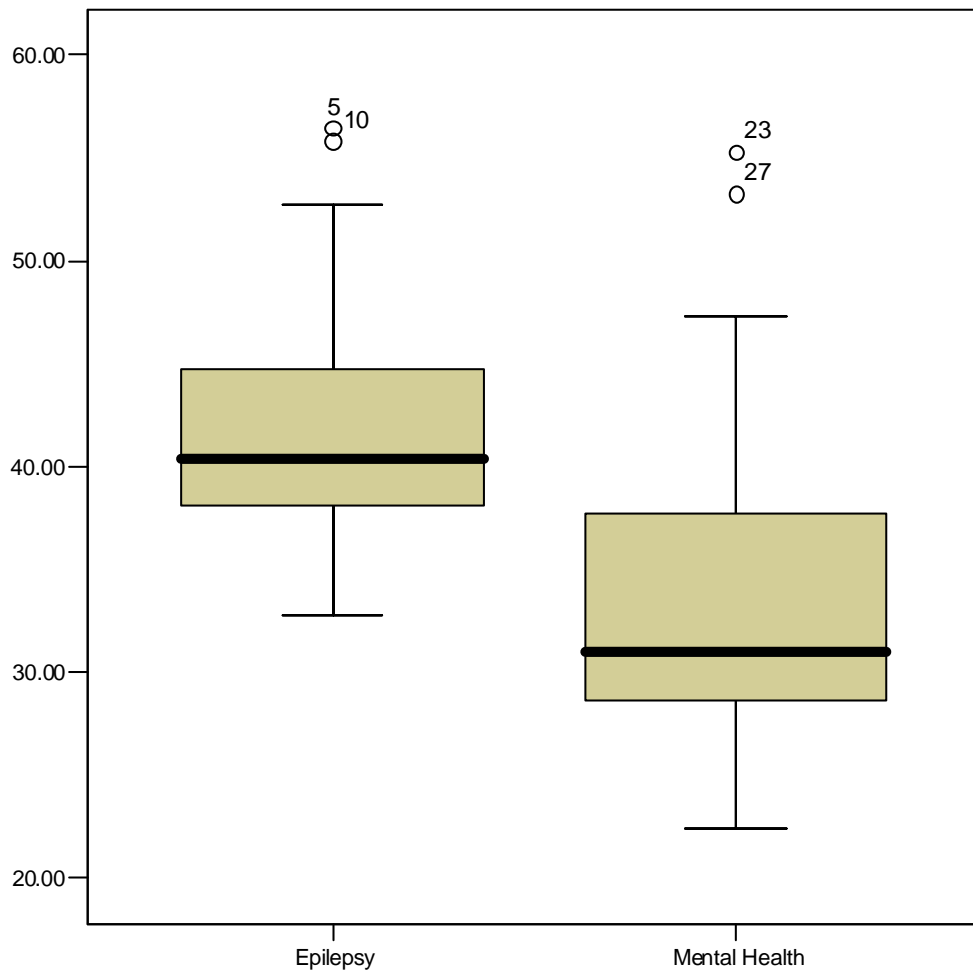


Figure 5: Boxplot of interview length (minutes)

The Epilepsy interviews each coded to an average of 60 discrete nodes (range 29 – 79) producing 172 (80 – 223) separate references. Although shorter, the number of nodes coded within the Mental Health interviews was on average only 10% less (53) with a very similar range (34 – 75), and total references showed a similar pattern (average 155, range 87 – 216). The number of nodes per interview is displayed in Figure 6.

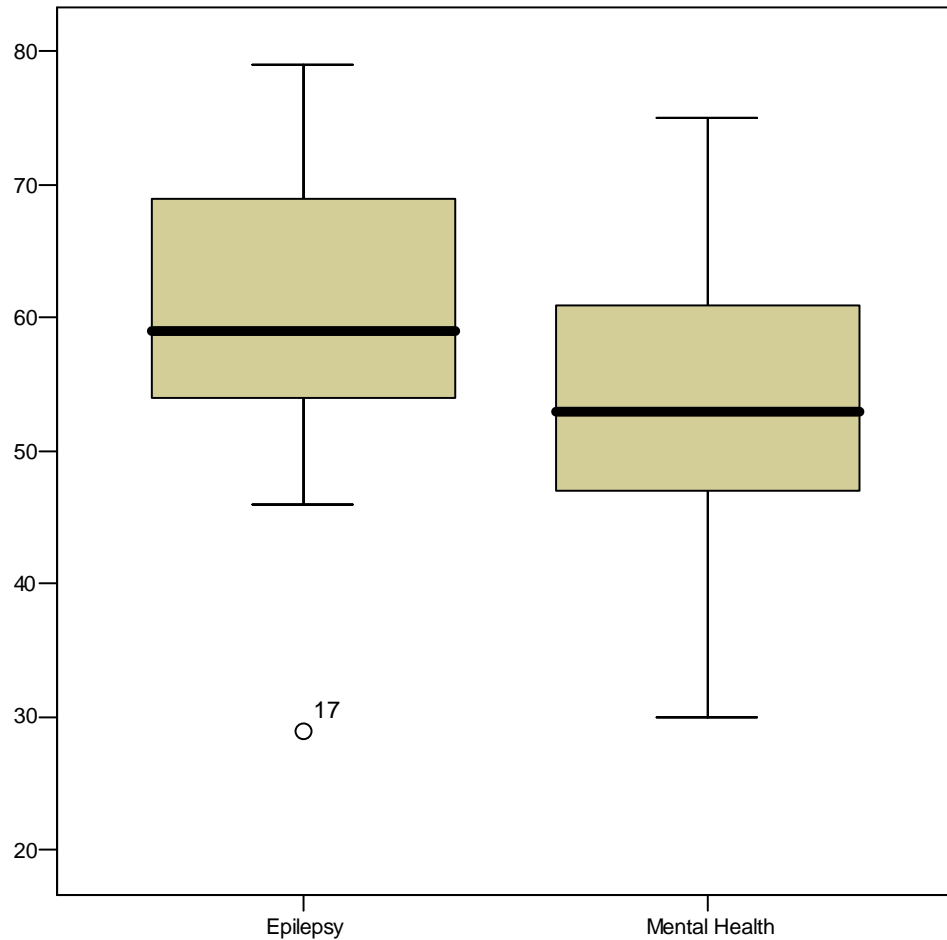


Figure 6: Boxplot of nodes arising per interview

Why were the mental health interviews substantially shorter than the Epilepsy interviews? Two possible explanations are suggested. It may be that a greater proportion of the Epilepsy interviews was uncoded, perhaps being irrelevant or inconsequential. This was not the case: 76% of all text within the Epilepsy interviews was coded by at least one node (range: 50% - 85%), as was 75% (range: 60% - 86%) of the Mental health interviews. Figure 7 demonstrates the lack of appreciable difference in coverage between the two groups.

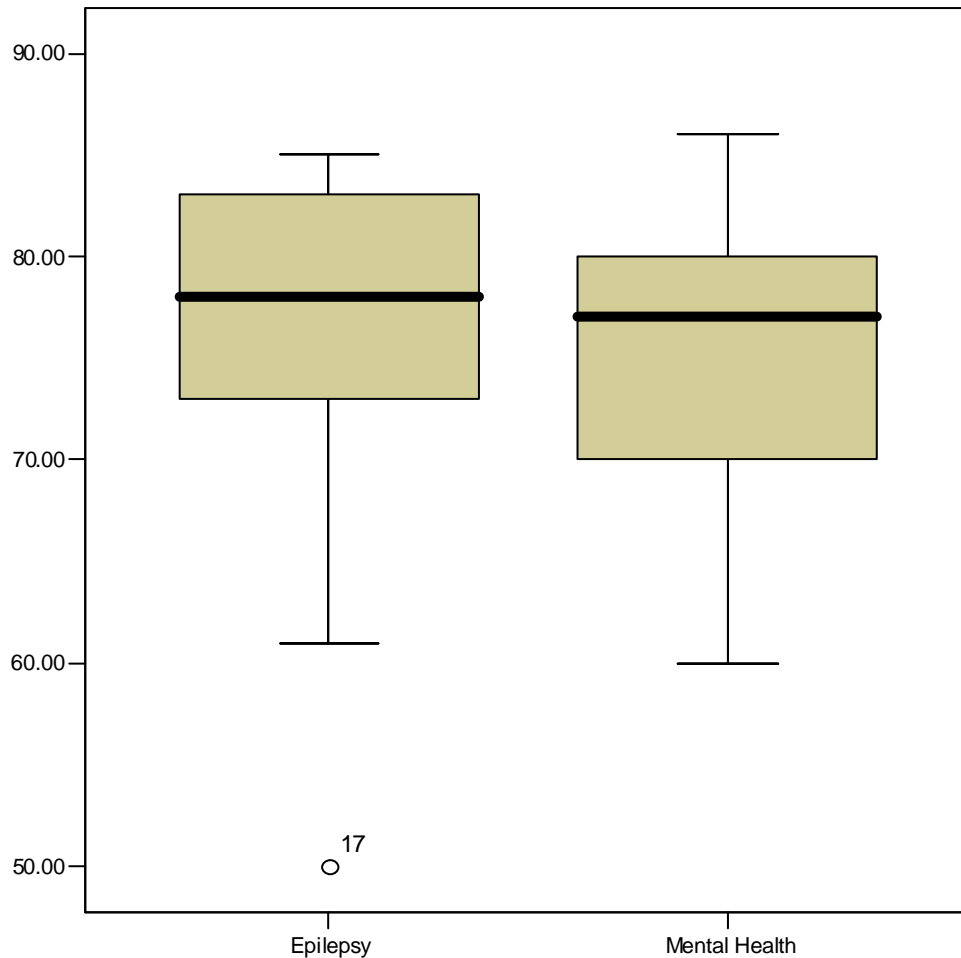


Figure 7: Boxplot of percentage of interviews coded

A more convincing explanation is that, although both groups of subjects raised similar breadth of issues, the Epilepsy subjects discussed them in more depth, or at greater length. This is in accordance with the researcher's perception of the interviews: although there were examples of very sophisticated and detailed discussions with subjects from both groups, there appeared to be more examples of relatively superficial discussions, or of subjects who failed to engage with the issues being raised, within the Mental Health group. This may reflect differences in characteristics such as educational level or socio-economic status, but no such data was collected to demonstrate or disprove this. Levels of health literacy are known to vary between patient populations, with lower levels in mental health patients (Wolf *et al.*, 2005), and associated with various markers of social disadvantage

(Department of Education, 2006) and may mediate differences in depth of exploration.

This may also reflect differences in the clinical characteristics of the two groups: the Epilepsy group were generally attending for routine but infrequent monitoring of their condition, which was not significantly affecting their level of function. Several spoke of being employed. In contrast, Mental Health subjects were typically attending at least weekly sessions, and probably had significantly greater levels of morbidity and disability. Data was not collected to assess this directly.

5.2 FUNDAMENTAL CHOICES

As described in Section 4.5.4, a preliminary judgement was made as to each subject's support for confidentiality or reporting in each scenario. This simplifies complex views into a simplistic yes/no dichotomy, and does not reflect the full complexity of opinion, but may give a general indication of the attitude each subject had. With those caveats in mind, there are some general observations that can be made, and some conclusions drawn, from this data.

There was more support overall for reporting concerns than for maintaining confidentiality. Of the 152 subject/scenario combinations, reporting was supported in 92 (61%) with 52 (34%) supporting non-reporting, and 5 (3%) and 3 (2%) being ambivalent or expressing no opinion respectively. Subsequent analysis is based on the 144 responses where a preference was identified.

The balance in favour of reporting was greatest in the DRIVING scenario (75%:25%), and lower in the other three (THREATS, 67%:33%; DOMESTIC VIOLENCE, 55%:45%; SEXUAL THOUGHTS, 59%:41%).

Mental Health subjects supported reporting more frequently (72%) than did Epilepsy subjects (54%), and females (72%) supported reporting more than males (58%). Support for reporting was commoner in younger subjects: those aged 18-30 supported reporting in 83% of cases, those between 31 and 45 in 68%, those between 46 and 60 in 68%, and subjects over 60 supported reporting in only 50% of cases.

There is some evidence that subjects from the two groups responded differently to the scenario that was directly relevant to them, although these results need to be interpreted with caution: because of the small numbers in each group, a consequence of the qualitative methodology adopted, these estimates are not statistically robust, and percentage responses are given below (Table 2) for comparative purposes only.

	MH SUBJECTS	
	Support reporting	Support confidentiality
Driving	89%	11%
Threats	71%	29%
Sexual	70%	30%
DomVi	62%	38%
Overall	72%	28%

	EP SUBJECTS	
	Support reporting	Support confidentiality
Threats	63%	37%
Driving	59%	41%
Sexual	47%	53%
DomVi	47%	53%
Overall	54%	46%

Table 2: Proportion of subjects supporting confidentiality/reporting in the four scenarios

Within each group, support for reporting was similar in the two scenarios not directly relevant to either subject group, although higher in absolute terms in the mental health group, who supported reporting more frequently than the epilepsy subjects in all scenarios.

In the THREATS scenario, Mental Health subjects supported reporting at about the same level as for the neutral scenarios, whereas in the epilepsy group, support for reporting the mental health patient was considerably higher. The views of the Epilepsy subjects suggest that a disinterested subject would support reporting more frequently in the THREATS scenario than in the neutral ones: Mental Health subjects did not respond in this way, suggesting that their views are different (less supportive of reporting) when the scenario is relevant to their situation.

In the DRIVING scenario, this pattern was reversed. Mental Health subjects, not directly affected by the scenario, were substantially more likely to support reporting in this case, compared to the neutral scenarios. In contrast Epilepsy subjects were much more likely to support confidentiality, at a level not very different to the neutral scenarios. Again, the subjects directly affected by the scenario appear to be less inclined to support reporting than others.

Across all four scenarios, 15 of the 38 subjects supported the same basic decision in each (6 supporting confidentiality each time, 9 supporting reporting each time). The other 23 reached different conclusions in different scenarios (including 7 who were undecided in at least one scenario). Only 5 subjects supported reporting in two scenarios and maintaining confidentiality in 2. While recognising that these views were contingent on details of the situations presented, there is some support here for the proposition that subjects have differing sensitivity to risk and concern for confidentiality that are consistent across the scenarios.

5.3 VIGNETTE CRITIQUE

Since the intention was to create scenarios that would address different dimensions of the dilemma, it is useful to compare the issues that arose in the interviews with those initial intentions. In each scenario subjects generally did raise the expected issues, but also introduced others which had not been anticipated. In later sections of this chapter those themes will be developed further, and observations from the four scenarios combined to allow broader conclusions to be drawn.

5.3.1 DRIVING SCENARIO

The variables deliberately included within the scenario were recognised by subjects. The patient had had a long seizure-free period while on medication, establishing a low baseline risk, and several subjects identified this:

But then at the same time she could be a danger if... but then she hasn't had any seizures for over 10 years so it's pretty well controlled.

(Epilepsy subject; DRIVING scenario)

It was potentially significant that the patient was voluntarily raising the issue with her doctor, although this was less strongly worded than in the SEXUAL THOUGHTS scenario. In fact only one subject commented on this, suggesting that it was not seen as significant, perhaps because of the patient's subsequent rejection of medical advice:

Oh definitely yeh, yeh. The fact she has actually gone to the doctors.

(Mental Health subject; DRIVING scenario)

One subject commented that a patient in that situation may have raised the issue of pregnancy without realising that driving might be compromised, in which case her willingness to raise the issue may not suggest ongoing cooperation is likely:

I think that she's gone to the doctor for advice about getting pregnant, perhaps not realising that the driving might be an issue.

(Epilepsy subject; DRIVING scenario)

Some subjects queried whether the advice to stop medication was appropriate:

I know these sort of things happen because there is a great ignorance about epilepsy in the medical profession. From my personal experience. Certainly shouldn't advise her to stop taking the anticonvulsants because there is more chance of the baby being damaged if she has a seizure.

(Epilepsy subject; DRIVING scenario)

Others felt the advice to stop driving was over-cautious, and that continuing to drive might be acceptable:

Well he can suggest that she drives and if she feels weird or funny she pulls up and stops driving and has a day off from driving and stuff like that cos with me, I don't suffer from epilepsy, but I suffer with fits.

(Mental Health subject; DRIVING scenario)

There was also criticism of DVLA rules in relation to epilepsy, and some subjects felt that other, less stigmatising, conditions, were treated more leniently. Where this view was expressed, subjects anticipated that patients would be less likely to comply with rules that were seen as unfair:

But with epilepsy you're, how can I say, you're put out on a limb. Now someone with a heart condition, there are more people suffering with heart conditions and they're driving. But once you've got epilepsy you're victimised in everything you do.

(Epilepsy subject; DRIVING scenario)

Most subjects assumed that reporting to the DVLA would automatically lead to loss of driving licence, but a couple of subjects queried whether the DVLA rules may permit some flexibility: the long period of stability without seizures was seen as crucial to this:

DVLA would have noted it I would have thought, not took her licence away.... It's not black and white, no.
(Mental Health subject; DRIVING scenario)

One concern may be that, even if reporting does lead to a licence being withdrawn, some patients may continue to drive anyway, in which case reporting may have little protective value:

the other worrying thing is if you're told not to drive they could possibly drive and then they've got no insurance
(Mental Health subject; DRIVING scenario)

It was potentially significant that the patient was willing to stop driving in some situations, suggesting a degree of compliance with advice that might be extended by discussion, but none of the subjects commented on this or saw this as a positive factor helping to reduce risk. Many subjects expressed concern about the risks inherent in driving, and some specifically mentioned the fact that the patient, and potentially her unborn child, would also be at risk:

Apart from anything the mother, potential mother, has got to think if she has an accident. It's not just another person she could injure. There's herself and then there's also the unborn child. So that may make her think much more carefully about whether she thinks it's a wise thing to do or not
(Epilepsy subject; DRIVING scenario)

A number of subjects reflected on the difficulties caused by being unable to drive, often drawing on personal experience of such restrictions. However the view was also expressed that it was reasonable to expect someone to stop driving, given the risks involved:

I was allowed to drive in South Africa but when I came to UK I wasn't allowed to drive. My licence was taken away and it has affected my life drastically.

(Epilepsy subject; DRIVING scenario)

She'd hate it. I can't drive at the moment and I hate it. It's just a pain - having to get lifts everywhere and ask favours off everybody and you get a bus which doesn't turn up when the weather's changing.

(Epilepsy subject; DRIVING scenario)

Several subjects raised the issue of the patient's own duty to report medical details to the DVLA. Some stressed that this responsibility lay with the patient, and saw this as absolving the doctor from responsibility, but others saw the patient's failure to report as reducing the patient's entitlement to confidentiality. Two subjects commented that, in applying for a driving licence, a driver agrees for medical information to be shared with the DVLA when necessary, but a similar consideration, even if not explicitly formulated, may have underlain other subjects' views.

A common theme explored by subjects was the patient's refusal to comply with the medical advice, and it was widely recognised that this was a plausible scenario, and that non-compliance with such advice is common:

I do know people who suffer from epilepsy who haven't informed the DVLA, because they are breaking the law and of course they wouldn't be insured. If they suffer a seizure at the wheel and ran somebody over it would be their fault but insurance wouldn't cover it.

(Epilepsy subject; DRIVING scenario)

Yeah. I think people take the chance. They get up in the morning, "oh I feel alright, take the chance".I mean you're going to try and do it, drive a car when you've been told not to.

(Epilepsy subject; DRIVING scenario)

She would carry on driving anyway.

(Mental Health subject; DRIVING scenario)

5.3.2 THREATS SCENARIO

By stating that the patient had been attending outpatients for some time, it was intended to highlight the importance of an established relationship between doctor and patient, and the possibility that this might assist in risk management. Only a few subjects picked up on this issue, but did consider it important (the value of the doctor-patient relationship more generally came up in all scenarios):

No if they've got a good relationship with the doctor I think they would probably feel quite secure because that can be quite comforting seeing a doctor.

(Mental Health subject; THREATS scenario)

The intention in the vignette was to establish that the patient was responding to beliefs that were clearly delusional or irrational in nature. Most subjects did interpret the vignette in that way, but there were several subjects who were willing to accept the possibility that the beliefs may be true, or needed further investigation. These subjects sometimes saw the patient as welcoming Police involvement as protection for him against the neighbours:

perhaps he becomes ill because they are poisoning his water then you know maybe he does need help from the police because he's having trouble.

(Epilepsy subject; THREATS scenario)

More commonly, subjects viewed the patient as irrational, and saw this as reducing the options for negotiating with him, and as justifying intervention. Irrationality was also seen by some subjects as reducing the risk of deterrence, because an irrational patient would not make such a nuanced calculation; in contrast other subjects felt that a patient who is already suspicious and paranoid is more likely to be deterred from future health care by reporting:

It's difficult when it's a mental health problem because you've almost got to get inside their mind ... because if he's got mental health problems I suppose it all depends on what health problems they've got. As to whether they trust the doctors again or not. Perhaps the doctor just needs to assess how mentally able they are as to what was the next step whether to see the police or not.

(Epilepsy subject; THREATS scenario)

Would he be worried about [police involvement] though? Would he know what is going on because obviously he thinks the neighbours are poisoning his water.... He thinks everything's going AWOL. He thinks everything's sort of going against him anyway so the police coming in is not going to be any different is it?

(Epilepsy subject; THREATS scenario)

One significant variable in managing risk is timescale: the THREATS scenario was intended to present a risk that was potential rather than immediate, the phrase “if it doesn't stop” suggesting some delay before possible action. Similarly the phrase “I'll sort them out” was deliberately non-specific. No subjects raised this variable directly, although there were some comments that the degree of risk was hard to predict, and that this might influence reporting decisions:

I think it should be kept. I don't think that's right serious enough. Cos you don't know what's going to happen do you if you inform the police. ... Not certain enough to actually report it to the police.

(Epilepsy subject; THREATS scenario)

Conversely, for one subject the fact that this was not a response to an immediate situation implied a more calculated threat, and therefore higher risk:

he's actually giving out threats while he sees the psychiatrist. It's not like he say seen his neighbour outside in the garden going “if you keep poisoning me I'll sort you out once and for all”. You know while they've had an argument or something. He's actually saying it in the office with him there rather than in the heat of the moment kind of thing.... like he really means it.

(Epilepsy subject; THREATS scenario)

One important difference between the THREATS scenarios and the others was that, although the patient was attending an appointment, he was refusing treatment,

whereas other patients in the other scenarios were compliant to a greater or lesser degree. This was a commonly identified factor that subjects relied on in justifying breach of confidentiality: the possible ambivalent meaning of “more” medication (“additional” vs. “any more from now on”) did not seem to be a confounder. Issues of degrees of compliance did arise in each of the scenarios, but were most marked in this one:

Well with the others it was the fact that the first three had bothered to go and ask for help. ... and the fourth is where he is ... refusing any medication or becoming an inpatient in hospital so that they can try and help him.

(Epilepsy subject; Final reflections)

It's quite frightening actually cos it doesn't sound as though you'd persuade him in any way to accept help.

(Mental Health subject; THREATS scenario)

A few subjects recognised that the patient's attendance at the clinic suggested he was at least partially engaged with treatment and that this was a risk-reducing factor, although generally it did not outweigh the clear refusal of treatment:

Because he is coming to the outpatient and he is sort of talking about things even if he is saying some things that are a bit irrational he is willing to tell people how he's feeling.

(Epilepsy subject; THREATS scenario)

Another significant difference in mental health settings is the possibility of compulsory admission under the Mental Health Act. A number of subjects mentioned this, and it is potentially a significant confounder, since admission may be seen as a way of reducing risk without the need for breach of confidentiality. In the wider context, however, compulsory admission is sometimes seen as another intervention that might reduce trust and deter patients from seeking health care. Both of these issues were raised by subjects:

He needs some help. If he's been violent in the past, the psychiatrist I would say has the duty for the sake of the general public to actually force treatment or to have the person committed under the Mental Health Act.

(Epilepsy subject; THREATS scenario)

So if that was me I'd be worried that they were going to think that you'd be told that you'd probably end up being sectioned 9 times out of 10.

(Mental Health subject; THREATS scenario)

The scenario ended with a statement that the patient had been violent in the past. This is well-recognised by professionals as a key factor in risk assessment, and this perception was reflected by subjects:

...it certainly sounds like a risk to me especially with a history of violence.

(Epilepsy subject; THREATS scenario)

Well if he's been violent in the past, that's the thing that gets me.

(Mental Health subject; THREATS scenario)

Only one subject wanted to understand further the history of violence, suggesting that not all previous violence would suggest increased risk in the current circumstances:

All it says "he's been violent in the past". It doesn't say he's been violent to neighbours, it just says he's been violent. That could have been a bloke after a night on the beer or something like that.

(Epilepsy subject; THREATS scenario)

5.3.3 DOMESTIC VIOLENCE SCENARIO

One feature of the DOMESTIC VIOLENCE scenario was that the patient had not raised the issue of domestic violence, injuries being noted by the doctor during a consultation. Several subjects took the view that the patient was seeking help, and that the consultation was some form of "cry for help":

I mean why would the doctor notice bruises? Is it a cry for help? I mean she could wear a long sleeved sweater and a polo neck or something like that. Unless she has a black eye of course, I don't know. Yeh it may be a cry for help.

(Epilepsy subject; DOMESTIC VIOLENCE scenario)

I think in the end she'd be grateful. I think so, yeh, I think so. And she's actually gone to the doctors hasn't she with the bruises, and he's sort of noticed them and whatever, I think in a way she's asking for help.

(Mental Health subject; DOMESTIC VIOLENCE scenario)

A common theme in responses to this scenario was the perception that intervention might depend on the severity of the abuse, either in degree or duration. Many subjects felt uncomfortable about this, being at some pains to explain that they did not condone less severe abuse, but feeling that life-threatening or long-standing abuse might require a different response. The scenario was worded to suggest ongoing and frequent abuse ("her husband often hits her"), but subjects did not seem to focus on this particular detail:

if it got too far then obviously if she'd had loads of broken bones or anything like that, if it got too far then I think it's important that he does report this.

(Epilepsy subject; DOMESTIC VIOLENCE scenario)

A thought that was going through my head was that it depends on how bad the violence is, but any violence is bad isn't it? ... It depends on the level of violence. I don't know if that's nice for the woman though is it, a gauge for her bruises.

(Mental Health subject; DOMESTIC VIOLENCE scenario)

A few subjects recognised that, whatever the severity of existing injuries, escalation might occur unpredictably, and the situation was one that was unlikely to resolve without intervention:

Well, in my opinion it's true as regards the, erm, that domestic violence, they do say that it can lead to an awful lot more ...Situations like that never improve do they? Quite honestly ... I say yeh [to reporting] in reality because he could end up killing her for instance. From what I've known of it, well it's never got any better. That's what I've known.

(Epilepsy subject; DOMESTIC VIOLENCE scenario)

I think, how do I put this, I think in a way he should report it actually because that could get really out of hand.

(Mental Health subject; DOMESTIC VIOLENCE scenario)

A number of subjects raised the issue of the husband's need for help or treatment for his alcohol abuse, and some saw this as a way of protecting the patient.

Although not explicitly discussed, the particular dilemma of a GP, who is likely to owe a duty of care to several people within a family, whose interests may not coincide, was an aspect of this:

But I think they should offer them both help first. Cos he's got a drinking problem.

(Epilepsy subject; DOMESTIC VIOLENCE scenario)

In this vignette the patient was the person primarily at risk, and this raised the issue of whether she should have control of reporting decisions. Although this issue came up in other scenarios the specific issue here was that the person at risk was willing to accept that risk:

In a way it should be if it's her at risk, it's not the public at risk, it's her at risk but then she's probably old enough to make her own decisions really you should respect her wishes really. It is her choice really, isn't it?

(Epilepsy subject; DOMESTIC VIOLENCE scenario)

However other subjects recognised that victims of domestic violence may find it difficult to protect themselves, and may need professionals to take the initiative on their behalf:

But you think of people in this situation, they are under the control of somebody else, they don't make many of their own decisions so the fact that that has already been decided for them, that it will be passed on to the authorities is probably a lifting of the weight off their shoulders.

(Epilepsy subject; DOMESTIC VIOLENCE scenario)

One significant concern in this scenario is that reporting might have little protective benefit, and might exacerbate the risk – this is part of the patient's anxiety about reporting, and was shared by a number of subjects:

but then she'd probably go home and she might well say something to him like "I went and saw the doctor today and he asked me about my bruises" and then something that could well create a situation.

(Epilepsy subject; DOMESTIC VIOLENCE scenario)

The only trouble with that [reporting] is that of course he can beat her even more because she's told the doctor

(Epilepsy subject; DOMESTIC VIOLENCE scenario)

Although not specifically cued in the vignette, several subjects discussed alternative courses of action. Reporting was usually assumed to mean police involvement, but subjects also recognised that counselling, advocacy, refuges, or other supportive help might be available, and these options were seen as less intrusive or unwanted than reporting to the police:

Yeh I think that's a good idea, give them somewhere confidential. Possibly offer her some sort of respite possibly if there's anything available in her area....Yeh rather than actually report it, put her in touch with groups.

(Mental Health subject; DOMESTIC VIOLENCE scenario)

Another aspect not specifically mentioned in the scenario was the possible presence of children in the family. A few subjects identified this as a factor that would change the balance of the reporting decision. Of the six subjects raising this issue, only 2 had considered the SEXUAL THOUGHTS scenario before the DOMESTIC

VIOLENCE one, so it does not seem that consideration of that scenario issues had sensitised subjects to the child protection issues:

I think the other thing is it depends on whether there are children in the household who might be involved as well.

(Epilepsy subject; DOMESTIC VIOLENCE scenario)

Erm the GP could just mention to the social workers and you have to, if there are children involved, you have to anyway. It is his duty of law to actually advise children's services. So it's going to escalate anyway and she has to know that.

(Epilepsy subject; DOMESTIC VIOLENCE scenario)

5.3.4 SEXUAL THOUGHTS SCENARIO

Perhaps surprisingly, a common theme in discussing the SEXUAL THOUGHTS scenario was to query the seriousness of the potential risk. The vignette was deliberately written to provide positive features, the lack of past abuse and the active wish to seek help both acted to balance the seriousness of the potential risk, so as to leave subjects with a genuine dilemma to resolve:

I think as long he hasn't done anything with the child, I think in that case it's a harmless situation at the minute with him only being sexually attracted to the child,

(Epilepsy subject; SEXUAL THOUGHTS scenario)

However other subjects took a very different view, seeing high level of risk, in some cases even without physical abuse occurring:

Yeh and he's working with people's children and I think he should be reported yeh. Because he could do anything at any time couldn't he? ... Cos like I say someone could hurt, someone could get raped. And that's the last thing you want to happen, so like I said, before it's too late.

(Epilepsy subject; SEXUAL THOUGHTS scenario)

One variable left unspecified was the age of the pupils involved, which some subjects explored. Some subjects felt uncomfortable about condoning such

behaviour, even with older pupils, but a few clearly saw such attraction as understandable, and not necessarily problematic:

I mean just some of his pupils that could be a first school or something which is disgusting. ...But it could well be, he could be a teacher of my age, or she [rereading scenario]- no he - could be a teacher of my age and attracted to someone who's ten years younger than them which isn't actually that big a deal.

(Epilepsy subject; SEXUAL THOUGHTS scenario)

The vignette was written to suggest possible risk to multiple pupils, and also to the patient's own children. This was not widely discussed, and when it arose the lack of attraction to his children was generally seen as a positive factor, rather than an additional area of risk:

That's er...he feels that his thoughts are starting to get stronger. He says he never has these thoughts about his own children. Which is a good thing isn't it?

(Mental Health subject; SEXUAL THOUGHTS scenario)

5.3.5 CREDIBILITY OF SCENARIOS

Another measure of the validity of the vignettes is whether subjects were able to recognise and engage with the clinical situation presented, either as something that may potentially affect them, or that they could envisage affecting other patients.

Although subjects were advised several times that they were not expected to reveal details of their personal case, many did so spontaneously:

Well I can understand how she feels with stopping driving because just over this last month and a half I've had to stop driving because unfortunately I've had my epilepsy back again after a year and a half. So I can understand how she feels

(Epilepsy subject; DRIVING scenario)

Well I've done it. ...Stopped my medication. I've experimented.

(Mental Health subject; DRIVING scenario)

Well that's exactly the situation, I'm not trying to get pregnant, but that's the situation I'm in

(Epilepsy subject; DRIVING scenario)

This was not limited to the Epilepsy subjects in the DRIVING scenario or the Mental Health subjects in the THREATS scenario: many of the Mental Health subjects reported experience of driving restrictions, and subjects from both groups referred to experience of domestic violence:

But that is funny you asked that question cos that near enough happened to me.

(Mental Health subject; DRIVING scenario)

Well I've had to um, I've had to write to the DVLC to say that I'm on lithium ... And um they sent me a letter and they went into all my history with the doctor, everything, and they went back and said they will only give me a three-year licence and then I'll be reviewed again. And also I've now found out I've got diabetes and I've had to inform them that I'm taking medication for that.

(Mental Health subject; DRIVING scenario)

Even where they did not have direct experience of the situation being discussed, many subjects indicated that they knew of similar situations arising in relation to other people, or could imagine patients or themselves being in that situation, providing further evidence that the scenarios were credible and plausible:

People are going to lie. If they know it's going to be reported they won't tell the exact truth. It's my opinion and how I hears people speak. What I've learned over a period of time with people.

(Epilepsy subject; DOMESTIC VIOLENCE scenario)

I do have a friend who didn't inform the DVLA. I didn't say anything to him because that's none of my business.

(Mental Health subject; DRIVING scenario)

Some subjects were at pains to emphasise that they themselves would not act in the way attributed to the patient. Generally this did not imply that such behaviour was unrealistic, but rather served to distance themselves from behaviour that seemed plausible but not desirable:

Well my schizophrenia's been pretty bad but I tell you I've never done any sort of drugs. ..., I've never been in trouble with the police and I've never been violent

(Mental Health subject; THREATS scenario)

I don't know really. I never had a problem with children so...I don't understand people like that I'm afraid cos I don't have a problem myself. That's the last thing I want to do is do that to a child.

(Mental Health subject; SEXUAL THOUGHTS scenario)

Although these subjects were distancing themselves from the patient in the vignette this does not necessarily mean that their responses are less valid. Where subjects are discussing irresponsible or even illegal behaviour, there will be a tendency for them to minimise their own recognition of such things: by relating the discussion to another, fictitious, person, subjects may feel more able to give answers that genuinely reflect their own, unacknowledged, experience. Although we cannot know whether this has happened, this phenomenon of distancing supports the arguments made for the utility of the vignette method.

There were no examples of subjects rejecting the situation presented in the vignettes as implausible or unrealistic: overall there seems to be good evidence that the vignettes presented credible clinical situations that resonated well with subjects' own personal experiences and their expectations of others.

5.3.6 POSING A GENUINE DILEMMA

Many clinical encounters raise no significant dilemmas of confidentiality. Usually this is because there is no need to consider breaching confidentiality; less commonly a need may arise, but the patient is willing to consent to reporting of information; less commonly still, a situation may present such clear and present danger that the need to breach confidentiality is unquestionable. In this study the aim was to present subjects with situations that did give rise to a dilemma, where the decision whether or not to report was a finely balanced one, and in which a detailed consideration of costs and benefits was likely to be needed.

There is considerable evidence from subjects' responses to show that they did consider the issues raised to be difficult to resolve. In many cases a subject's initial response on reading the scenario was to comment on this:

That's a difficult one that is

(Epilepsy subject; THREATS scenario)

Again it's a real difficult situation cos it's all about trust again isn't it?

(Mental Health subject; DOMESTIC VIOLENCE scenario)

Subjects frequently reflected on the difficulty of the decision, and the dilemma faced by the doctor. Many subjects found it hard to commit to a particular course of action, often expressing ambivalence, uncertainty or in some cases outright contradiction within their views:

I mean I think it's a really difficult one and I think....it must happen such a lot ... I think it's really difficult. I keep saying that. ... And I think it raises really interesting questions about what makes people stay in violent relationships and (sighs). It's very complicated.

(Mental Health subject; DOMESTIC VIOLENCE scenario)

Yeh I can see both sides and I think it's incredibly difficult and I think it is inevitable that you're going to lose some people whichever way you go.

(Mental Health subject; DRIVING scenario)

Even where subjects had a clear view as to the right course of action, it was common for them to express some degree of discomfort or anxiety, and to recognise the potential negative consequences which gave rise to the dilemma:

It might be problematic but it's a question of.....it's just a safeguard for the neighbours and us.

(Mental Health subject; THREATS scenario)

Where subjects expressed a clear decision, and when the context of the interview permitted it, the interviewer was able to challenge the view expressed, or offer a counter-argument, to assess the firmness of the position adopted. Most subjects defended their initial decision despite the challenge:

(Interviewer; Do you think [maintaining confidentiality] could be okay or do you think the doctor's got to report it to somebody?)

No I think the doctor's got to, it's over his head so he's got to report it to somebody. Especially where children are concerned

(Mental Health subject; SEXUAL THOUGHTS scenario)

(Interviewer: Could that be a reason for keeping it confidential do you think, for the doctor not telling anybody?)

I think the doctor should tell somebody.

(Mental Health subject; DOMESTIC VIOLENCE scenario)

However in a smaller number of cases subjects did shift their position when challenged by the interviewer, suggesting that there was some remaining ambivalence or uncertainty in their views:

(Interviewer: Do you think there's any circumstances where the doctor might try and help him and keep it confidential. Do you think that could work?)

That could work that way yes as you say, and just see how it go from there.

(Epilepsy subject; THREATS scenario)

Overall there is convincing evidence that there was enough of a dilemma to raise significant ambivalence and uncertainty in all four scenarios, and that, even when they ultimately were able to express a clear preference for resolving that conflict, subjects were willing to consider alternative courses of action. The scenarios appear to have been sufficiently balanced and sufficiently open-ended to allow adequate consideration of risks and benefits and to engage some consideration of the utilitarian calculus.

5.4 COMMON THEMES AND DIFFERENCES

The nodes most commonly coded within each of the four scenarios are listed in Table 3. Figures in this table represent the number of interviews in which each node was identified, rather than the number of individual occurrences. **Support for reporting** is one of the two most frequently coded nodes in three of the scenarios, and is the fourth most common in the other. **Consequential deterrence** is also in the top two for three scenarios, and is fifth in the other, whereas **Anticipatory deterrence** is the most commonly coded in the SEXUAL THOUGHTS scenario, but rather less frequent in the others, and **Deterrence impairing treatment** is the only other node occurring commonly in all four scenarios. Other nodes show more variation between scenarios.

The possibility of deterrence is frequently raised in all scenarios, although rather less in the case of THREATS: conversely, **Deterrence unlikely** occurs less commonly, but was raised by 23 subjects in the THREATS scenario (where it was often associated with the view that an irrational patient would not have such a sophisticated understanding of the issues) and by 18 in the DRIVING scenario (associated with the view that a patient would need to continue with treatment, however unhappy with the doctor's decision). **Risk of alienation from doctor** occurs frequently in three of the scenarios, but considerably less (33rd – 7 references) in SEXUAL THOUGHTS, although why it should be less of an issue in that case is not clear.

Subjects' perception of risk varied between the scenarios. **Risk perception High** was the most commonly coded issue in the DRIVING scenario with 28 subjects raising this, but was considerably less frequent in the other scenarios (14th, 26th and 30th, averaging 11 references). **Importance of preventing harm** was similarly high in the DRIVING scenario, and also in THREATS, but featured less in the other two.

DOMESTIC VIOLENCE	n	DRIVING	n	THREATS	n	SEXUAL THOUGHTS	n
Reporting as way of accessing help or in patient's best interest	27	Consequential deterrence	28	Support for reporting	30	Anticipatory deterrence	28
Consequential deterrence	26	Support for reporting	28	Consequential deterrence	25	Support for reporting	24
Patient to have control over reporting decision	25	Risk Perception High	28	Reporting as way of accessing help or in patient's best interest	25	Reporting - negative consequences for patient	23
Support for reporting	23	Anticipatory deterrence	24	Lack of control of noncompliant patient	24	Actively seeking help	22
Anticipatory deterrence	23	Direct personal experience	22	Mental health is different; irrationality	24	Consequential deterrence	21
Different decisions in different situations	22	Importance of preventing harm	21	Importance of preventing harm	23	Treatment as primary concern	21
Treatment as primary concern	22	Patient censoring or choosing what to reveal	21	Deterrence unlikely	23	Deterrence impairing treatment	19
Crossing a line, threshold	21	Patient (should) take personal responsibility	20	Risk of alienation from doctor	22	Support for not reporting, maintain confidentiality	19
Risk of alienation from doctor	19	Deterrence increasing risk	19	Treatment reducing risk	20	General reluctance to talk to doctor about certain things	16
Deterrence impairing treatment	18	Dilemma, recognizing difficulty of decision	18	Anticipatory deterrence	19	Ambivalence or uncertainty about action	16
Report increasing risk	17	Deterrence unlikely	18	Patient reluctant to talk to doctor	19	Importance of preventing harm	14
Support for not reporting, maintain confidentiality	16	Risk of alienation from doctor	16	Risk management as alternative to reporting	19	Dilemma, recognizing difficulty of decision	14
Dilemma, recognizing difficulty of decision	16	Deterrence impairing treatment	16	Treatment as primary concern	19	Further clinical input before report	14
Ambivalence or uncertainty about action	15	Distancing self from risk behaviour	16	Risk Perception High	18	Not done anything yet	14
Needs doc to take control or make decision	15	Patients not following advice	16	Deterrence increasing risk	17	Risk of deterrence as reason for not reporting	13
Confidentiality valued or important	14	Self-disclosure	15	Deterrence impairing treatment	17	Children are different	13
Further clinical input before report	14	Patient at fault	15	Loss of control over process once reported	17		

Table 3: Most commonly coded nodes in each scenario

Several nodes relating to therapeutic input varied between the scenarios: **Reporting as a way of accessing help** was a very frequent node within the DOMESTIC VIOLENCE and THREATS scenarios (1st and 2nd respectively) but much less common in the other two. **Treatment as primary concern** was rarely coded within the DRIVING scenario but appeared frequently in the other three. The relationship is not a straightforward one: although there is high perceived risk and less concern for treatment in the DRIVING scenario, with the opposite true in DOMESTIC VIOLENCE, in both THREATS and SEXUAL THOUGHTS subjects frequently referred to both risk and treatment. Only in the THREATS scenario was there frequent reference to **Treatment reducing risk**, and only in this scenario were **Deterrence increasing risk** and **Deterrence impairing treatment** mentioned with equal frequency whereas in others deterrence was seen as impacting on treatment more than on risk. This suggests that subjects generally saw treatment and risk management as separate issues, and considered that deterrence would impair treatment but not increase risk, which would have implications for the weighting of factors in the utilitarian calculus.

While support for reporting is generally high, support for maintaining confidentiality is significantly lower: the surprising exception to this is in the SEXUAL THOUGHTS scenario, where **Support for not reporting** is mentioned almost as commonly as support for reporting. This seems to link to the patient's engagement with treatment, and a lack of immediate risk: both **Actively seeking help** and **Not done anything yet** are referenced much more commonly in this scenario than in any of the others.

Other variations may relate to specific features of the scenarios. For example **Reporting – negative consequences for patient** was a frequent issue in SEXUAL THOUGHTS (3rd most common), but unusual in any of the other three; **Mental health is different; irrationality** was specific to THREATS and **Patient to have control** was primarily raised in DOMESTIC VIOLENCE, although also occurring in DRIVING. **Patient should take personal responsibility** was commonly discussed in the DRIVING scenario; perhaps surprisingly it was not often coded in any of the others.

There are some general conclusions to draw from these patterns of responses. Risk was perceived as significant in all the scenarios, but rather less so in DOMESTIC VIOLENCE, where the reporting decision was also seen as more finely balanced (**Different decisions in**

different situations common here but not in other scenarios). Reporting was seen as potentially helpful to the patient in DOMESTIC VIOLENCE, and also in THREATS (where other therapeutic options such as compulsory admission were also discussed), was clearly harmful to the patient in SEXUAL THOUGHTS, and generally more neutral in DRIVING. Deterrence was widely recognised, as was the possibility of this impairing treatment, but this does not directly lead subjects to oppose reporting.

Attitudes to the patient varied between scenarios. Particularly in the DRIVING scenario the patient was often seen as irresponsible or at fault, and it may be significant that it was in this scenario that subjects most commonly anticipated the patient deliberately concealing information from the doctor. This was also the scenario in which *Distancing self from risk behaviour* most commonly occurred. The SEXUAL THOUGHTS patient was generally commended for his willingness to seek help (although for some subjects this was secondary to strong condemnation of sexual abusers), and this was a significant factor opposing reporting. The patient in the DOMESTIC VIOLENCE scenario was also a more sympathetic figure, although subjects were often critical of her perceived willingness to accept continuing violence. Finally, in the THREATS scenario the patient was not seen as culpable for his decisions, but his perceived irrationality appears to have had a similar effect on subjects' perception of risk as the deliberate actions of the patient in DRIVING.

5.5 SUPPORT FOR REPORTING

In each scenario the commonest position taken by subjects was to support reporting, rather than maintaining confidentiality. Approximately one third of all the nodes coded related to support for reporting. Further analysis was undertaken, reviewing both node descriptors and the actual comments coded at each, to identify thematic constructs that would better describe and explain subjects' reasons for supporting reporting. The resulting model is shown in Figure 8.

Six concepts were derived from this model, which appear to underlie the decision to support reporting⁵:

- Importance of preventing harm
- Lack of therapeutic or other options
- Patient at fault
- Obeying rules
- Reporting not harmful
- Minimising impact

They are not all of equal importance, and individual subjects relied on different combinations of these concepts, but taken together they provide an explanatory framework within which subjects reached that conclusion. This framework, and those developed in the rest of this Chapter, are summarised in Appendix 5.

⁵ The terms used to identify these concepts are those applied during the coding process. This illustrates how links were maintained between the data, the coding, and the developing theory, but at times the terminology adopted earlier in the process does not fully capture the final concept. For example in Section 5.6, "Patient to have control" might be better termed "Concern for autonomy", but the more atheoretical terminology has been retained.

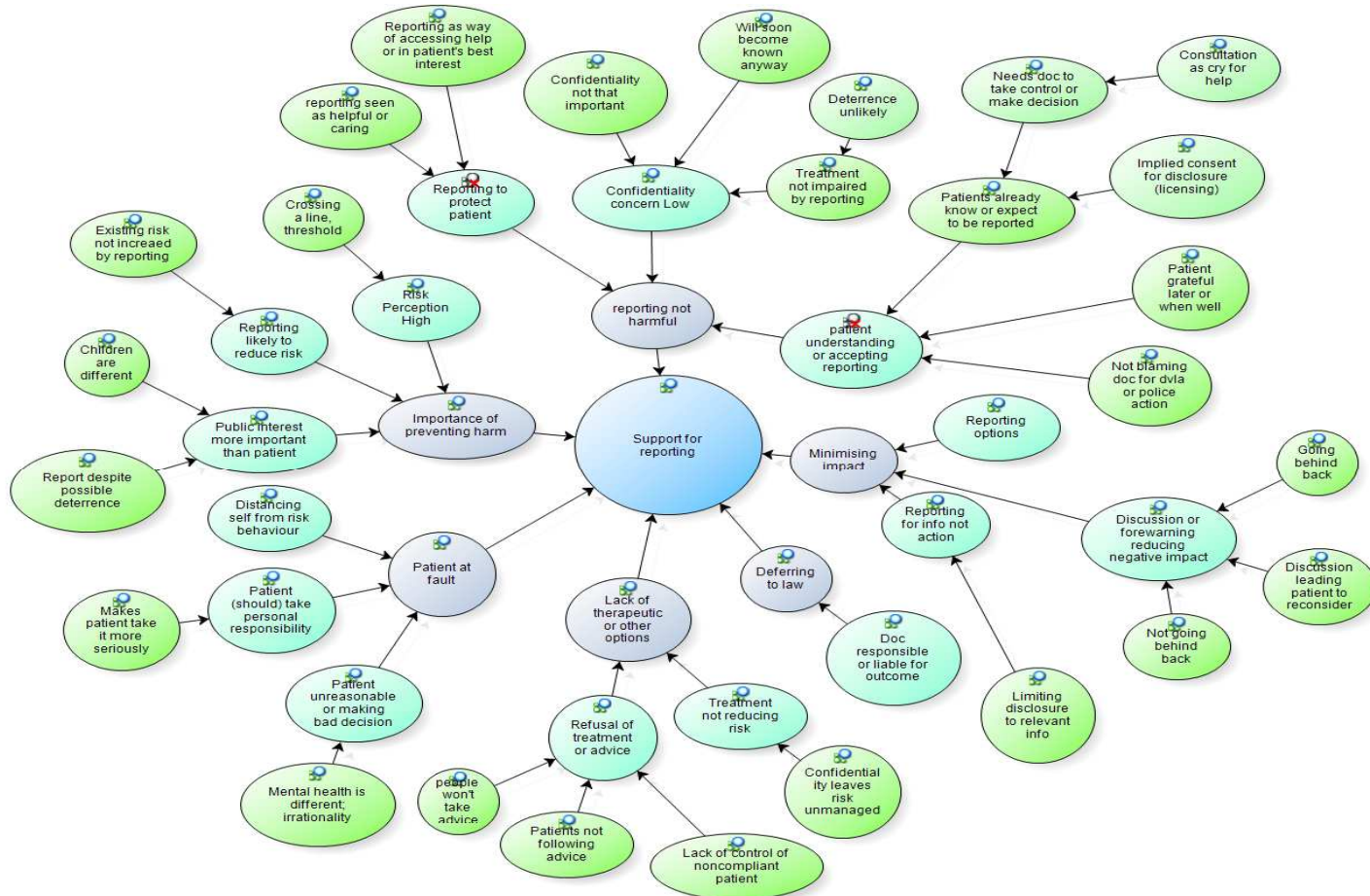


Figure 8: NVivo model for Reporting

There was clear support expressed for reporting in all four scenarios:

Clearly yes, the doctor should inform the DVLA. It's a simple right or wrong issue really

(Epilepsy subject; DRIVING scenario)

I think they should be reported definitely, definitely yes cos she's a danger to other people, danger on the roads cos the roads are bad enough as it is. Not being horrible to drivers but ... I think she'd be a danger. Very dangerous.

(Mental Health subject; DRIVING scenario)

5.5.1 IMPORTANCE OF PREVENTING HARM

Given the nature of the dilemmas presented it is not surprising that many subjects focussed on the need to prevent harm from occurring, and that this was a major factor leading them to support reporting. Within this concept, three sub-concepts were identified that contributed to this position: firstly a belief that the risk presented was high, in probability, magnitude of harm, or both; secondly a view that the safety of third parties should take precedence over the interests or wishes of the patient; and thirdly, a belief that reporting would be an effective way of reducing harm.

Nearly all subjects made references to the importance of preventing harm. One aspect clearly articulated was the view that doctors have a wider responsibility to society, not just to the individual patient:

It's not just causing that [risk] to her it could be causing that to all sorts of people. So yes in that instance I think he has a duty to do that. There's a wider issue there, you've got to think about other people.

(Epilepsy subject; DRIVING scenario)

I think on balance it's more important that um it's a corporate responsibility I think to protect everybody.

(Mental Health subject; THREATS scenario)

They've got to stand back and be professional haven't they really? Like my CPN says if I ever said I was going to kill somebody or attack somebody then she would have to go to the police.

(Mental Health subject; DRIVING scenario)

There were many examples of subjects emphasising the degree of risk that the patient represented, and this was usually cited as a significant reason for breaching confidentiality:

You see my opinion of it is, it's like walking round with a loaded shotgun, that's what a guy told me when he taught me to drive many years ago. He said you can do more damage with this than you can with a loaded shotgun and it's something I've never forgotten, I've seen it over the years the damage which has been done.

(Epilepsy subject; DRIVING scenario)

And if he's been going along for several years and he's made a complaint when he goes along that his neighbours are spying on him and poisoning his water and he's going to sort them out once and for all it certainly sounds like a risk to me especially with a history of violence.

(Epilepsy subject; THREATS scenario)

Risk perception was not an all-or-nothing thing, with some subjects being prepared to consider alternative courses of action depending on the perceived level of risk. This was most commonly expressed in the DOMESTIC VIOLENCE scenario, where reporting was often considered to depend on both the severity and duration of abuse, and was also raised in the SEXUAL THOUGHTS scenario, and the THREATS scenario (where degree of intention was seen as a variable). This issue was never raised in the DRIVING scenario, presumably reflecting the unintended and unpredictable nature of the risk being considered:

I don't want the breach of confidentiality unless it's some extreme, ... It's like with the driving, it's not too serious. With the domestic violence it's getting a bit more serious but she's got options to go upon and if something becomes more extreme then the doctor has got something to do, you know each one is getting more and more erm... then it can get worse and worse and when it comes to that breaking point where somebody could be badly hurt or sexually assaulted or something along those lines...that's where you cross the line.

(Epilepsy subject; Final reflections)

But I suppose the severity of the violence would be an obvious issue. I mean if he's been just sort of punching her around but if he then starts threatening her with sharp implements or something.

(Mental Health subject; DOMESTIC VIOLENCE scenario)

The balancing between the interests of the patient and those of other people is central to the utilitarian calculus explored in this study. A number of subjects expressed this explicitly,

allowing some insight into the way that balance was struck. In particular, when the risk justifies it, subjects were willing to support reporting even while recognising the risk of that impairing the patient's treatment:

I think for the greater good the police should actually come between the patient and the potential er potential, I don't want to use the term victim but.. ... It might be problematic but it's a question of.....it's just a safeguard for the neighbours and us.

(Mental Health subject; THREATS scenario)

The relationship with the doctor, yes maybe that could be damaged, but then.....mm....that's the, you know, at the expense of what? It is down to lives.

(Mental Health subject; DRIVING scenario)

One very specific concern, which subjects often seemed to raise as a way of explaining why third party interests should take precedence, was the view that protection of children was particularly important. For obvious reasons this was most commonly raised in the context of the SEXUAL THOUGHTS scenario, but several subjects also mentioned that there may be children at risk in the DOMESTIC VIOLENCE scenario and that, if there were, that would shift the balance to be struck in favour of reporting:

No I think the doctor's got to, it's over his head so he's got to report it to somebody. Especially where children are concerned

(Mental Health subject; SEXUAL THOUGHTS scenario)

Well I suppose he wouldn't be very pleased about it but the thing is that children come first don't they?

(Mental Health subject; SEXUAL THOUGHTS scenario)

Some subjects also focussed on the patient's wish to get pregnant in the DRIVING scenario, and the consequent risk to her unborn child if she were to be involved in an accident, but this was seen more as a possible way of motivating her to reconsider her intention to drive, rather than as a factor aggravating the risk:

she is trying to get pregnant so she has a personal objective in mind and presumably there is a connection there with her own desire for the welfare of her child should she succeed.

(Epilepsy subject; DRIVING scenario)

I suppose you'd think apart from anything the mother, potential mother, has got to think - if she has an accident, it's not just another person she could injure. There's herself and then there's also the unborn child. So that may make her think much more carefully about whether she thinks it's a wise thing to do or not.

(Epilepsy subject; DRIVING scenario)

Since the point of reporting is to reduce risk, a belief that it will be effective is important to the utilitarian calculus, and this was expressed by subjects:

He's going to think "oh if people know about this they're not going to like it" so he's not going to do nothing is he. If he thinks people know about it people will be watching him.

(Epilepsy subject; SEXUAL THOUGHTS scenario)

Well hopefully she'd get an official, I don't know how they deal with it, a warning or whatever, and it's a legal thing so hopefully it should work.

(Mental Health subject; DRIVING scenario)

5.5.2 LACK OF THERAPEUTIC OR OTHER OPTIONS

Although almost all subjects referred to the importance of preventing harm (even when ultimately coming down in favour of maintaining confidentiality in a particular scenario), it was widely recognised that breach of confidentiality was not the only way to achieve this, nor necessarily the most desirable way. A significant factor supporting reporting was therefore the perception that there was a lack of therapeutic or other options that might reduce risk. Two sub-themes were identified: the patient's refusal or non-cooperation with treatment or medical advice, and the possibility that treatment may not reduce risk, even if complied with:

the options are going to hospital, taking more medication or moving house maybe, or something like that. But he's wiped out all the other options and I think [reporting] will probably be the only option left

(Epilepsy subject; THREATS scenario)

Refusal or non-compliance with treatment was most explicit in the THREATS scenario, and this was frequently referred to as a reason for considering breach of confidentiality. This was less of an issue in the other scenarios: in DRIVING compliance with the medical advice (to stop medication) was the thing leading to the risk although the issue of non-compliance with the advice to stop driving remains an issue, in DOMESTIC VIOLENCE treatment had little role to play in mitigating risk, and in SEXUAL THOUGHTS the patient was actively seeking treatment to reduce risk. Non-compliance was also a significant factor in the perception of the patient as being at fault, which will be explored in Section 5.5.3:

But with them not, does it say they didn't want help? Yeh, that's why I think, that's a difficult one. I think that's the big difference I think that's the big difference that's why it's got to go further because I think the neighbours and that will be at risk on that one ... but if he's coming in and wanting help then I just think that's a different story.

(Epilepsy subject; THREATS scenario)

(Interviewer: What was the thing that decided you yes or no between the different situations?)

Well with the others it was the fact that the first three had bothered to go and ask for help.... and the fourth is where he is refusing any medication or becoming an inpatient in hospital.

(Epilepsy subject; Final reflections)

Even if treatment is complied with it may offer limited scope for reducing risk, and subjects were more willing to contemplate breach of confidentiality where there seemed to be less to lose in terms of risk management. For example in the SEXUAL THOUGHTS scenario, reporting would be more acceptable if treatment proved ineffective:

I suppose the thing is if he says it's getting worse and nothing's kind of working, I'm not sure what the benefit is because you're not sort of preventing him.... Erm I mean it's all very well to have someone to listen to you but...

(Epilepsy subject; SEXUAL THOUGHTS scenario)

I mean you could advertise that you won't breach confidentiality so you get people come to you but then you're not going to be able to do anything for them. You're just stuck with it

(Mental Health subject; DOMESTIC VIOLENCE scenario)

Whereas in the DRIVING scenario, the treatment offered little in the way of risk reduction:

(Interviewer: Why do you think that's different to say the first case?)

Because he's getting help [in the first scenario] ...Treatment that could help. She's not under any treatment. She'd stop the treatment anyway.

(Mental Health subject; DRIVING scenario)

5.5.3 PATIENT AT FAULT

The patient's failure to comply with medical advice is part of a wider concern that subjects express, that the patient is in various ways culpable or at fault. This led some subjects to a perception that, since the patient's behaviour is wrong, breach of confidentiality is to some extent justified or excused. This is at odds with a pure utilitarian calculus, since even the most wicked patient might be deterred from seeking medical care: instead it suggests that to some extent subjects see confidentiality as a privilege that can be forfeited, or at least modified, in some circumstances:

She, you know, it's different if the doctor hadn't pointed it out and she didn't realize, that she shouldn't be doing it but if she knows and she makes that decision to go ahead anyway she is culpable.

(Mental Health subject; DRIVING scenario)

Three subthemes were identified within the overall theme of "patient at fault". In line with the above discussion the most frequent concern was the refusal to follow medical advice or to accept treatment: as well as providing justification for reporting because this prevents therapeutic risk management, it is also seen by some subjects as disqualifying the patient from the full protection of ethical codes:

Well if he drops out of treatment voluntarily then I would, it's a bit difficult, I mean if he says that he's going to stop taking his medication, he doesn't believe what the psychologist is saying or telling him or curing him or helping him then he does become a menace to society. And the Child Protection Team I would presume would have to have his name

(Epilepsy subject; SEXUAL THOUGHTS scenario)

if she was going to carry on driving she won't talk to the doctor about it, she's already said that to him and if he then said to her well I'm going to inform the DVLA if you are going to keep driving cos I have to do that, then she'd say well I'm not going to then he wouldn't inform the DVLA and she'd probably still drive anyway. She'd be breaking the law and everything would be her own fault.

(Epilepsy subject; DRIVING scenario)

A subset of this issue, specifically within the THREATS scenario, is the irrationality demonstrated by the patient. While not expressed in terms of fault, there was a strong feeling that an irrational patient did not deserve the same level of consideration as others, either because they would not appreciate the value of it, or in a more consequentialist way, because they would not respond rationally, and therefore the normal utilitarian calculus would not apply to them. A few subjects recognised that a paranoid patient might be more, rather than less, sensitive to a breach of confidentiality, but this did not seem to change the view that confidentiality was less important with such patients:

Would he be worried about it though? Would he know what is going on because obviously he thinks the neighbours are poisoning his water. He thinks everything's going AWOL. He thinks everything's sort of going against him anyway so the police coming in is not going to be any different is it?

(Epilepsy subject; THREATS scenario)

I don't know how much aware he'd be in that case.

(Mental Health subject; THREATS scenario)

The other two subthemes were often linked: a few subjects expressed disapproval of the patients' behaviour, and said that they should be taking responsibility for the risks they caused. For some subjects breach of confidentiality was potentially a way of encouraging patients to reconsider and to take more responsibility:

Well if you've got a conscience, if you've got a conscience you should do it [report to DVLA] yourself.

(Epilepsy subject; DRIVING scenario)

People can't just go wandering around doing they want.

(Mental Health subject; DRIVING scenario)

Finally, many of the subjects were keen to distance themselves from what was perceived as irresponsible behaviour by the patients in the scenarios:

Well I informed the DVLA about myself cos I didn't want to drive if I weren't really allowed to do so and I informed the DVLA about twenty odd years ago.

(Mental Health subject; DRIVING scenario)

5.5.4 OBEYING RULES

Some subjects avoided trying to resolve the dilemmas presented by appealing to external authority, and particularly legal rules. Various subjects gave responses that indicated that doctors should follow whatever rules were in place, although understanding about what those were was variable. Some subjects strongly felt that confidentiality should only be breached where there was a clear legal mandate, and valued the certainty that that would provide. This worked both ways; some subjects relied on a legal rule to justify reporting, but others felt a report should not be made unless a legal rule required it:

Well personally I think it would be what the law says really, wouldn't it?

(Epilepsy subject; DRIVING scenario)

But I don't think they should just inform if they feel like they should I think there should, there should be a cut and dry law.

(Epilepsy subject; DRIVING scenario)

In addition to the certainty that following a clear rule would provide, subjects also spoke of the position that the doctor was placed in by the patient's disclosure. Reporting was seen not only as a way of reducing risk but as a means for the doctor to discharge legal responsibilities, and to avoid being held liable for harm subsequently caused by the patient:

I really think it's up to the patient I suppose to decide what they want to do. But then I suppose they can see the other end of the spectrum where if something happened and they had an accident and it was just to the doctors, I suppose [the doctor]'d get into trouble as well. It's a difficult one.

(Epilepsy subject; DRIVING scenario)

Well exactly so, she could do that, yes she could do that. So I think doctors are obliged to tell the DVLA. Because if someone hit me when I was driving and they'd had a fit and the doctor hadn't reported it then I think I'd sue the doctor. I wouldn't be very happy would I?

(Mental Health subject; DRIVING scenario)

Subjects also sympathised with the anxiety such decision might cause doctors, and saw compliance with legal rules as a way of reducing that:

Just imagine the guilt the doctor might feel if something did happen, other people were involved, and he or she got to hear about that. You know, what's going to go through his mind.

(Epilepsy subject; DRIVING scenario)

Again I think it depends, in some ways it is best to report it I suppose cos again the doctor would be the one standing there saying well he came to me and I didn't take any notice of it, he'd be the one that would have to actually stand up and say well you know I knew this was happening or I knew it was going to happen or.....so it's the GPs job on the line as well really. Like that Baby P just recently. That lady's now lost her job because of it ... you have got to protect yourself haven't you?

(Mental Health subject; SEXUAL THOUGHTS scenario)

5.5.5 REPORTING NOT HARMFUL

Although many subjects were willing to justify reporting, and to accept the consequent harm to the doctor-patient relationship and to the patient's interests, for some subjects support for reporting was based on a perception that it was not particularly harmful anyway. For these subjects the utilitarian calculus was different, because if there are no significant costs to reporting, then any potential benefits are unchallenged.

Three major subthemes emerged from this group of subjects. Some couched the decision to breach confidentiality primarily or substantially in terms of the patient's own best interests. Secondly, some subjects generally felt that confidentiality was of limited importance or relevance, and thirdly some subjects argued that patients would accept or understand the rationale for reporting, either at the time or at some future point.

For the first group reporting was seen as a caring or supportive action, or as a way of accessing help and support, and almost all subjects made some reference to this. In the DRIVING scenario it was seen as a way of protecting the patient from accidents that might result from her lack of foresight: in the THREATS scenario it was seen as a way of accessing help (often including compulsory admission or treatment, as well as or instead of police involvement). In the DOMESTIC VIOLENCE scenario this was associated with the view that the doctor should act to protect the patient, and that she may be disempowered from protecting herself by the experience of abuse, and also with a concern that her husband needed help for his alcohol abuse. Finally in the SEXUAL THOUGHTS scenario this attitude reflected a wish to protect the patient from the negative consequences of a physical act of abuse:

But I think the psychiatrist, if he's worried, it's not the fact that the neighbours are at risk from the man, it's the fact that the patient needs help. He's ill and he requires treatment and when he's coming out with things like that I think the psychiatrist has every right to actually admit the patient.

(Epilepsy subject; THREATS scenario)

they might be able to get some help outside somewhere else mightn't they? With the doctor reporting it they might be able to get some help with someone.

(Mental Health subject; DOMESTIC VIOLENCE scenario)

Particularly in the THREATS scenario, this view was often linked with an explicit perception of police involvement as something supportive rather than punitive, something that seems to have been more commonly expressed by Mental Health subjects:

I had the community police involved and the police are very, very good now. Well, they were good with me. So you know the police doesn't necessarily mean bad or you know, we're going to keep an eye on him just in case he stabs somebody, but the community police can be involved and just keep an eye, maybe, but it would have to be in agreement with him you know. ... I'm just saying that's been my experience. I have met some pretty horrible policemen actually but for every one there's another ten who've been really helpful.

(Mental Health subject; THREATS scenario)

Well I think it would have to be handled delicately um by the police involved. Um I don't really know if they have a department that deals, because I know that the police if they feel that somebody's in need of psychiatric care then they'll under section whatever it is they'll bring them into....So I don't know if they've got a section for that but it would have to be done very delicately but you can't have him sort of getting violent with other people.

(Mental Health subject; THREATS scenario)

The second group considered that confidentiality generally was not that important, and that breach would not cause significant problems:

a lot of people would just ignore it [a breach of confidentiality]. The majority would you know even with a police warning.

(Epilepsy subject; THREATS scenario)

(Interviewer: how important do you think it is for doctors to keep things confidential?)

No not really, it don't bother me that much no, not particularly no. ... I suppose that depend on the patient. I don't mind it but I think they'd be some who do, but as far as I'm concerned that wouldn't bother me too much in that respect no.

(Epilepsy subject; Final reflections)

A subgrouping here was of subjects who, even if they valued confidentiality in the abstract, considered that in the circumstances of the scenarios information would soon become known anyway, so that breach by the doctor would be of little practical effect:

But in the very end if it goes that way, he stops going to the doctors, he stops getting his medication, it's a guarantee he's going to get involved with the police very, very shortly.

(Epilepsy subject; THREATS scenario)

Well if she does have a fit and um she has an accident then (laughs) everyone's going to know anyway. Do you see what I'm saying?

(Mental Health subject; DRIVING scenario)

Congruent with the view that confidentiality is of limited importance, some subjects clearly felt that breach of confidentiality would not have any significant detrimental effect on treatment:

I think they'd lie anyway whether you were going to say it or not. I don't think it would make a lot of difference what they actually say to you.

(Epilepsy subject; DRIVING scenario)

I think most people probably would go and see the doctor yeh.

(Interviewer: you don't think they'd be put off?)

Well I wouldn't be anyway. No. No.

(Mental Health subject; DOMESTIC VIOLENCE scenario)

Subjects' perception of deterrence will be analysed separately (Section 5.8), but some subjects expressed the view that patients would be unlikely to be deterred from seeking medical treatment by breach of confidence, and this was a factor supporting the view that treatment would not be impaired, and therefore supporting the decision to report:

It might make her a bit more sceptical of him, a little bit, but I think she'll understand the reason why he did that and hopefully she'll forgive him for doing that. ...I think it will take a little while for her to trust him again, but I think eventually she will trust him again.

(Mental Health subject; DOMESTIC VIOLENCE scenario)

I suppose it would alienate some people but other people it wouldn't affect so it depends on their attitude. I would imagine it's only a few people really because most people I've seen throughout the years of me coming here seem to sort of, should be at ease with the situation, the medication and everything, you know.

(Mental Health subject; DRIVING scenario)

Subjects who felt that patients would understand or accept breach of confidentiality fell into two groups. The first was those who believed the patient would already understand the consequences of disclosing to the doctor, or might even want the doctor to take such control, which was particularly associated with the DOMESTIC VIOLENCE scenario:

I think really everybody knows exactly what happens.... and that's probably why people don't have as much trust because they all know exactly what happens. I mean even when I was talking to them about it at work and things like that, different scenarios, they all know exactly what happens and they all know as soon as it get to the doctor, that's it.

(Epilepsy subject; DRIVING scenario)

She could lie about the bruises, she chose not to. She didn't have to say when the bruises became obvious, that her husband has a drink problem. And she didn't have to say when he's drunk he hits her. These are stages of revealing things that she didn't initially go to see the doctor about. So these are all choices on her behalf.

(Epilepsy subject; DOMESTIC VIOLENCE scenario)

An important point raised by only a couple of subjects in relation to driver licensing was that drivers have explicitly consented to medical information sharing as a condition of holding a driving licence, and have no reason to object if doctors act on that, although whether a patient affected by this scenario would have such a dispassionate response is perhaps doubtful:

I suppose the fact that the DVLA get in touch with the doctors beforehand just to confirm the patient has been seizure-free for a period of time in order to get a licence gives the doctor the right to respond without the patient's say so, they ask for the patient's permission to contact the doctor and the patient's obviously given that for the licence application to go ahead

(Epilepsy subject; DRIVING scenario)

No I think the doctor should inform the DVLA if he thinks she's still driving because the conditions of holding a licence you should tell them if you're banned anyway. So she's breaking her contract as such if that's the word, with the DVLA and she should tell them.

(Mental Health subject; DRIVING scenario)

Conversely, some subjects accepted that patients would be angry about disclosure initially, but felt that they would come to understand and accept the decision in the future, either with the passage of time or, in the THREATS scenario, once the paranoid symptoms had resolved. Some subjects saw this outcome as strengthening the doctor-patient relationship in the longer term:

I felt a bit betrayed I think in a way cos you know this counsellor's had me sectioned...I look back now and know that he probably save my life. He either saved me from killing somebody or killing myself but at the time I felt a bit angry

(Mental Health subject; THREATS scenario)

If it's a GP then she's probably going to be wary of trusting her again, the same with the specialist as well, but if she sits down and thinks about it she's going to realise it was done for the right reasons.

(Mental Health subject; DRIVING scenario)

Some subjects took the view that, although the patient might be angry about the outcome, they would not necessarily blame the doctor for actions taken by, for example, the police or the DVLA. This may seem unrealistic, but had some links to the view that, if the doctor was seen to be following explicit rules, the patient would not blame the doctor for negative outcomes:

I think she'd be annoyed more with the DVLA than the doctor. I don't think it would register so much that the doctor has informed the DVLA.

(Mental Health subject; DRIVING scenario)

You put the blame on the police rather than on the nursing staff and doctors.

(Mental Health subject; DRIVING scenario)

5.5.6 MINIMISING IMPACT

Although not directly a justification for breaching confidentiality, some subjects who supported reporting also explored ways in which the negative impact of it might be reduced. Three approaches emerged, discussing the breach with the patient beforehand, and explaining the rationale for it, limiting the amount of information disclosed, and selecting an

appropriate recipient for the information, all of which are prominent features of professional guidelines.

The importance of telling the patient that the doctor would report concerns – and the reasons for it - was stressed by many subjects:

if you discussed it with the patient about the fact that you might have to bring these other people in so that this didn't happen. So that if he understood what was going on, so that you understood you weren't just doing it for his benefit but you were doing it for everybody else's as well then he might feel a bit safer. He might not feel as angry and resentful at accepting any further treatment from you

(Epilepsy subject; THREATS scenario)

I mean if you, whichever way you go you've got to tell the bloke that you're going to report it...I do not think that you should do it without telling the chap because that would immediately destroy any confidence that he had in the doctor at all

(Epilepsy subject; SEXUAL THOUGHTS scenario)

Informing the patient was seen as a way of minimising the negative impact, and of preserving a degree of trust between patient and doctor. For some subjects it was also a further opportunity to encourage the patient to reconsider, and so possibly to avoid the need to report:

Well I don't say "this is what I'm going to do", I would say "this is what could be done". So then the person has the choice of whether they want to do it or ask the doctor to do it for them or whatever the case may be. "This will be" is different, very different from "this could be". You know the patient still has a choice ... It's up to them whether they want to choose it but at least they're now made aware of the different pathways that they could take.

(Epilepsy subject; THREATS scenario)

Well yes it's cover for the GP and it's also I suppose a psychological probe for the woman herself. He's serious, he's given the advice which I'm not taking, am I happy with it? And then she thinks twice about whether she's happy with it or not.

(Epilepsy subject; DOMESTIC VIOLENCE scenario)

Subjects generally were opposed to any suggestion that the doctor might report concerns without the patient being aware of this. However some subjects took a different view in the

THREATS scenario: this seems to have been a response to the perceived irrationality or unpredictability of a mental health patient:

Where I guess I'd be a little at sea is having said in previous cases that the patient must know as he leaves the room what's going to happen, but I can see there may be difficulties in delivering that situation: "you know what I've got to do now" is quite a difficult thing for the psychiatrist to say.

(Epilepsy subject; THREATS scenario)

They're not informed when this sort of thing happens. The doctor doesn't say "I've told the police" to the patient necessarily does he?

(Mental Health subject; THREATS scenario)

The wording of the vignettes suggested an appropriate reporting option, but some subjects did raise alternatives that might be seen to make reporting more acceptable to the patient:

I can understand him telling the patient's next of kin that they should stop driving so they've got encouragement from both sides from the medical and the personal side. I would agree with that disclosure but not to go to the DVLA or the police.

(Epilepsy subject; DRIVING scenario)

Maybe the way to go here is not for the GP to report it directly but to offer the lady some kind of counselling or go and see a domestic violence unit at the police.

(Epilepsy subject; DOMESTIC VIOLENCE scenario)

I don't think I'd call the police because I think that would make matters worse in a way. I'd probably have a word with the neighbours and explain that he hasn't been well or whatever and that he hasn't perhaps been taking his medication.

(Mental Health subject; THREATS scenario)

Another strategy for minimising the negative impact of reporting, though one discussed by fewer subjects, was limiting the amount of information disclosed, and being clear that it was specifically relevant:

The police will only get involved if they need to and the doctors don't have to tell the police everything, do they?

(Epilepsy subject; THREATS scenario)

I still think overall the police, albeit limited by relevant stuff, ought to be aware of what they're doing

(Mental Health subject; THREATS scenario)

One option, suggested by a number of subjects, was that reporting might not lead to immediate action, but might be useful information for the police or other agencies to have if problems arose in future. The rationale for this was unclear, since it seems to accept breach of confidentiality, with possible negative consequences, without any steps being taken to reduce risk. In one extreme case a subject felt this would allow the police to arrest a perpetrator after a murder had been committed! On the other hand, subjects may have viewed this as offering some potential future protective effect with less detriment to the patient:

if she doesn't want action to be taken then there should be some way of putting it down in case anything happens in the future and that could be their first port of call if she's found beaten to death somewhere or stabbed or something then quite likely it would be him so at least go to him first wouldn't you?

(Epilepsy subject; DOMESTIC VIOLENCE scenario)

I suppose tell the police just to keep an eye on him just to see that his neighbours are not in risk. But then he should get the help for his treatment that he needs. To help him and be safe for others around him. Especially with his neighbours.

(Epilepsy subject; THREATS scenario)

Although most discussion of reporting focussed on the intended consequences, some subjects recognised that once information had been shared, there would be no guarantee that it would be used only for that purpose, and that it might subsequently be disseminated more widely in unpredictable ways:

I think it should be kept. I don't think that's right serious enough. Cos you don't know what's going to happen do you if you inform the police.

(Epilepsy subject: THREATS scenario)

you're dropping a small pebble in the pond but it's big ripples and it carries on, like with this scenario, that scenario erm, I think all of these, it might be good in the short term but is it good in the long term? It depends how much you want to wreck that person's life.

(Epilepsy subject; Final reflections)

I think so but then again there needs to be the rules set in place. Because if the GP reports just to be aware just in case but we're referring him to a psychologist, and then the child protection team take it upon themselves to go "well that's not good enough we're suspending him and we're doing this" then he's asked for help and then he's lost his job for the time being he's signed off and his name's on local news and everything and his life's ruined and so no. There needs to be rules in place.

(Epilepsy subject; SEXUAL THOUGHTS scenario)

5.5.7 SUMMARY OF REPORTING MODEL.

Reporting was widely endorsed by subjects and it is clear that this was predominantly motivated by the perception that the risks involved were high, particularly when the patient was considered to be responsible for that, or not taking reasonable steps to reduce the risk. It is less clear whether the views expressed that breach of confidentiality would not be too damaging were factors that supported subjects in coming to a decision, or were rationalisations that they expressed after deciding that reporting was necessary. In the latter case, this would suggest that even where reporting is supported on grounds of risk, a substantial proportion of subjects recognise the possible harm to the doctor-patient relationship and are keen to find ways to minimise it. This issue is explored further in Section 5.11.3.

5.5.8 DUTY OR DISCRETION

One further issue that was not directly raised in the scenarios, and was not generally explored in detail by subjects is whether, if reporting is supported, it should be a mandatory duty. Subjects who supported reporting may still be willing to leave some discretion to doctors, or they may see it is a requirement, so that doctors might be held liable for non-compliance. Most subjects expressed their views in less than mandatory terms:

then the doctor has to decide, you can't really write those sort of things down on paper, the doctor has to decide when confidentially should be breached.

(Epilepsy subject; Final reflections)

No I suppose what I'm saying consistently is that each case needs to be looked at separately....And the doctor's got to be able and skilled enough I suppose to make an initial risk assessment and act on that.

(Mental health subject; Final reflections)

Many subjects struggled with the dilemma, which probably weighed against them imposing a clear and categorical duty. Where factors both for and against reporting were identified, subjects were more likely to conclude that judgement would have to be exercised in individual cases, without a hard and fast rule

Some subjects recognised that doctors might reach different decisions, in terms that implied they were willing to leave at least some discretion to the doctor:

I think the onus has got to be on the patient but if they aren't forthcoming and there are definite risks then I think the doctor should have the option to pass the information across himself

(Epilepsy subject; DRIVING scenario)

I would say from the doctor's aspect if they've all got the right attitude towards it and have their patients' best wishes at heart then they would know what needs to be shared and what doesn't

(Epilepsy subject; Final reflections)

At the end of the day you see all GPs are different aren't they? Someone might say one thing and another one's going to say complete opposite.

(Mental Health subject; DOMESTIC VIOLENCE scenario)

Other subjects took the view that doctors should defer to whatever legal rule is in place. This does not necessarily imply mandatory reporting: a legal rule might allow discretionary reporting with no sanction for a reasonable decision not to report, or may be mandatory. Similarly a legal rule could impose an absolute requirement of confidentiality:

It depends on how the law stands on it whether the law says that don't count as confidential

(Epilepsy subject; DOMESTIC VIOLENCE scenario)

It would have to become part of the law rather than "Well, I think I better tell the DVLA".

(Epilepsy subject; DRIVING scenario)

Although the issue was not raised directly, several subjects used mandatory forms of wording when discussing their expectation that a doctor would report:

if it's getting further then you've got to report it.

(Epilepsy subject; SEXUAL THOUGHTS scenario)

It's a simple right or wrong issue really. He's really not, it's not a question of the doctor having to decide anything

(Epilepsy subject; DRIVING scenario)

One related theme, discussed in more detail under "Forewarning", was that several subjects felt that there needed to be clear rules known in advance. This might imply some form of mandatory reporting (or of absolute confidentiality), since if the doctor retains discretion to report or not in a particular situation, the patient cannot know in advance the consequences of any disclosure. However it is not inconsistent to take the view that patients should know of the *possibility* of reporting in advance, without being sure how a doctor will actually decide to act, and by permitting further negotiation and discussion this would seem to be more in line with the concerns for patient autonomy being expressed by these subjects.

5.6 SUPPORT FOR CONFIDENTIALITY

While the commonest response across all scenarios was for subjects to support breach of confidentiality, most subjects also supported maintaining confidentiality in at least some of the scenarios, or under some circumstances. Even those subjects who ultimately endorsed a breach of confidentiality usually did so only after considering alternatives or, if they supported breach from the outset, were willing to contemplate other possible actions. A similar analysis and modelling exercise was carried out on topics relating to maintaining confidentiality, and a model derived which is shown in Figure 9.

From this model seven explanatory themes emerged, several of which paralleled the themes identified in the Reporting model (Appendix 5). The seven themes were

- Risk Perception Low
- Treatment as primary concern
- Harm caused by reporting
- Confidentiality concern High
- Patient to have control
- Reporting not making a difference
- Patient not at fault

I wouldn't say that the doctor should tell the DVLA because I think medical stuff should stay with the medical profession.

(Epilepsy subject; DRIVING scenario)

Really he should keep it confidential if she doesn't want anything done about it. But, 'cos you have to keep patients' confidentiality don't you?

(Mental Health subject; DOMESTIC VIOLENCE scenario)

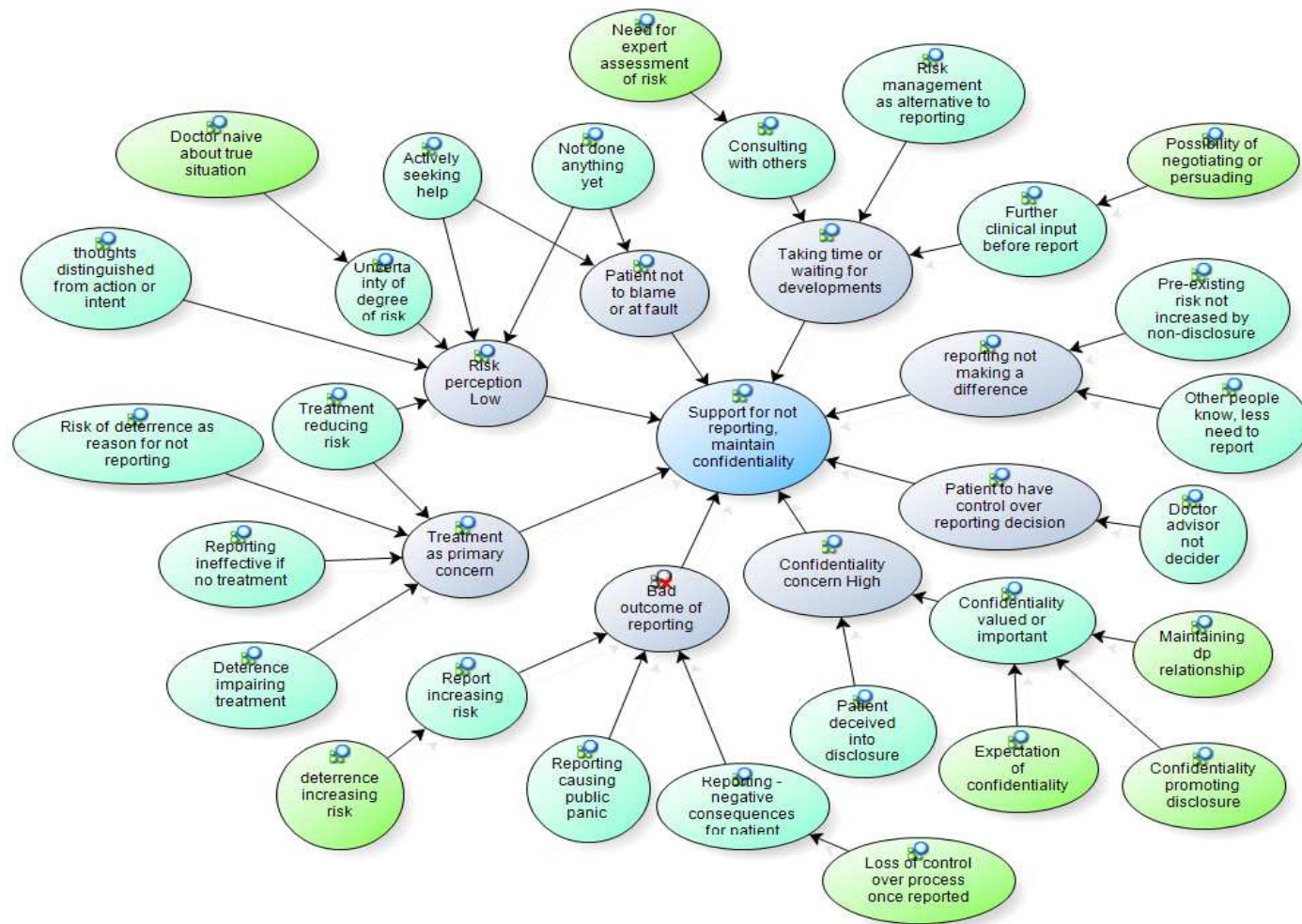


Figure 9: NVivo model for Confidentiality

5.6.1 RISK PERCEPTION LOW

In contrast to subjects who supported reporting, it is not surprisingly that those who supported maintaining confidentiality were more likely to assess the risks in the scenario as low or acceptable. Several subthemes could be identified within this concept: subjects often perceived the risk as uncertain or hypothetical, distinguished between thoughts/threats and actual harm, or referred to the fact that no harm had actually been caused so far. The patient's cooperation with treatment (particularly in the SEXUAL THOUGHTS scenario) was also important.

Several subjects commented on the uncertainty of the risk, feeling that there was insufficient evidence to justify breach of confidentiality. One aspect of this was also the perception that the doctor may have incomplete information, and not be in a good position to judge the situation:

I think with the other one I think the risk was immediate and clear. If she stops taking her medication and drives that could you know that's going to happen - fairly immediately. Whereas with this I think on balance, by the sound of this particular case, you've got more than five minutes as it were.
(Mental Health subject; SEXUAL THOUGHTS scenario)

So he doesn't actually know, the doctor doesn't actually know what the patient's doing anyway so it's sort of guesswork.
(Epilepsy subject; DRIVING scenario)

Many subjects referred to the fact that the patient had not caused any harm so far, and this was used to justify non-reporting in two distinct ways; either because it meant reporting would be disproportionate to the risks, or because, in the absence of actual conduct no action would result from reporting (in particular, that the police could do nothing until an offence was committed):

I think it should be kept [confidential]. I don't think that's right serious enough. Cos you don't know what's going to happen do you ...not certain enough to actually report it to the police. When they "said" it, in this world everything is said isn't it? I mean everybody says something jokingly don't they?

(Epilepsy subject; THREATS scenario)

You see she could report him but in the end the police isn't going to come knocking on his door until he actually do something. They can't just knock on the door can they? He hasn't done nothing has he?

(Epilepsy subject; SEXUAL THOUGHTS scenario)

Cooperation with treatment was a significant consideration, and one which clearly contrasted to settings in which subjects supported reporting, where non-cooperation was often a key factor. Although this arose particularly in the SEXUAL THOUGHTS scenario, where the patient was actively seeking treatment, it was mentioned in the context of all four scenarios, with subjects seeing some reason to hope that the patient would continue to engage with treatment:

The chap recognises a problem and that's half the battle and I think he should go along with it to see how things pan out because if the chap recognises that he's got a problem well. So I would say in the first instance no. Go along with what the chap is suggesting.

(Epilepsy subject; SEXUAL THOUGHTS scenario)

I think he's taking responsibility by seeking help....So I think he's demonstrating, certainly at the moment, that he's trustworthy. So no I don't think in this case the GP should report him. ...I think he should be praised for taking that responsibility and for going to see the GP and you know I think he should be treated positively for...you know not sort of judgmentally or punitively at this stage.

(Mental health subject; SEXUAL THOUGHTS scenario)

5.6.2 TREATMENT AS PRIMARY CONCERN

When supporting reporting subjects tended to see prevention of harm as the most important issue: in contrast, when subjects (often the same subjects) supported maintaining confidentiality, they spoke in terms of providing effective treatment as the primary concern:

*And that GP, it's not his duty to report it. His duty is for patient care
(Epilepsy subject; SEXUAL THOUGHTS scenario)*

I think you should treat him in a psychiatric ward. I think he should be sectioned and think he would get into hospital. [Keep it] Within the health service and not tell the police.

(Mental Health subject; THREATS scenario)

He's gone to his doctor for help. He hasn't gone to the Child Protection Team or the police for help. He's gone for medical help and that means he hasn't gone for legal help he's gone for medical help and it's the GP's duty to give him that medical help and get him the treatment in the specialist area. It's not his job to change a medical problem to a legal problem

(Epilepsy subject; SEXUAL THOUGHTS scenario)

Although these subjects seem to prioritise patient care over public safety, there were also comments emphasising the role of treatment as a way of reducing risk. These subjects still supported maintaining confidentiality, but as much for its wider protective effect as for the benefit of the patient:

And of course the patient actually being violent with the man, with the neighbours, is a problem of the patient. If the patient is violent that's a patient problem isn't it? It's not a legal problem.

(Epilepsy subject; THREATS scenario)

He's not a threat if he's under medication and in the right place. As long as he goes into hospital and takes his medication he's not a threat.

(Mental Health subject; THREATS scenario)

Other subjects expressed similar concerns but from a different perspective: that reporting may be of limited value if it is not combined with effective treatment. These subjects also prioritised effective treatment over reporting:

And what's [reporting him] actually going to resolve? Still nothing's happened preventing it from happening.

(Epilepsy subject; SEXUAL THOUGHTS scenario)

if he was referred to a psychologist then that's hopefully going to help, but then if the GP reports this man to the child protection team I can't see how that would help

(Mental Health subject; SEXUAL THOUGHTS scenario)

It was widely recognised that if breach of confidentiality were to result in deterrence, this would impair future treatment, and that this might be a reason not to report, a view that was expressed independently of any consequential effect on risk:

If it goes to child protection straightaway it may hinder the treatment of the problem in future because somebody wouldn't dare admit, even to the GP, that they've got a problem with it because they know that it will go straight to child protection and they will lose their job and everything else.
(Epilepsy subject; SEXUAL THOUGHTS scenario)

I don't think he really should report this because they'll completely lose trust with the GP. So I think he should probably keep it to himself and probably just advise her.
(Epilepsy subject; DOMESTIC VIOLENCE scenario)

5.6.3 HARM CAUSED BY REPORTING

Subjects also explored the possible negative consequences of reporting, both in terms of increased risk and also the negative outcomes for the patient. There were also concerns in the SEXUAL THOUGHTS and THREATS scenarios that reporting, particularly if it led to no specific intervention, might increase public anxiety for no real benefit.

Negative consequences in terms of increasing risk were raised in all scenarios:

Again because [confidential help] would keep the person talking about it where they might hide it and then do something.
(Mental Health subject; SEXUAL THOUGHTS scenario)

if you involve social services, the police and all that, once he has been messed up and resettled somewhere else there's more chance he will go ahead and do it anyway and think "what have I got to lose now".
(Epilepsy subject; SEXUAL THOUGHTS scenario)

I think you possibly lose the persuadability option which is what I started with as what I would expect People not declaring things of that nature just in case the doctor was going to have to lift the phone or write the letter. That would be my view and in terms of personal situations cases may not progress as well because doctors would actually know less about the circumstances with which they were dealing.
(Epilepsy subject; DRIVING scenario)

The potential negative consequences for the patient varied widely between the scenarios: subjects commented on the problems resulting from loss of a driving licence, police involvement in the THREATS and SEXUAL THOUGHTS scenarios, possible damage to the marital relationship in the DOMESTIC VIOLENCE scenario. Concerns were most marked in the SEXUAL THOUGHTS scenario, where it was recognised that career and family were at risk, as well as possible criminal prosecution and public stigma:

if it is reported his life's gone, straight away. Job, family, it's home, it's area where he lived because anybody around, it gets out it mushrooms.

(Epilepsy subject; SEXUAL THOUGHTS scenario)

Well [she is] frightened of her husband and I suppose frightened about what could happen. Like she doesn't want him to be sent to prison which could mean that the family, if she's got children or whatever, they could be dragged into it if he got sent to prison. It could break the family unit up.

(Mental Health subject; DOMESTIC VIOLENCE scenario)

5.6.4 CONFIDENTIALITY CONCERN HIGH

Those subjects who opposed reporting typically viewed confidentiality as an important component of the doctor-patient relationship, and had high levels of concern about breaches:

I mean there is an overall business about giving personal information to any areas which seems to be more prevalent these days and I'm totally agin that.

(Mental Health subject; DOMESTIC VIOLENCE scenario)

you trust them [doctors] for knowing your inner secrets that you most probably wouldn't normally talk about to anybody else.

(Mental Health subject; Final reflections)

Subjects generally saw confidentiality as central to the doctor-patient relationship – even when ultimately supporting reporting subjects were often uncomfortable with the implications of that. Several spoke about the expectation or tradition of confidentiality:

I'm still rooted in a childhood expectation rightly or wrongly of going to the doctor and saying how I feel and expecting the doctor to say well I think we should do this, and I think the worry that the doctor might react in a particular way might condition how the public at large saw doctors - as an agent of the state for example.

(Epilepsy subject; DOMESTIC VIOLENCE scenario)

At the moment you trust the doctor and what you say to the doctor won't go any further. So you sit there and tell the doctor and believe it will go no further, it might be written down but it won't go no further.

(Epilepsy subject; DRIVING scenario)

I think most people assume that there is this confidentiality and that anything they say with their doctor or consultant is completely private, and yeh I think in a way that probably needs to remain that way

(Epilepsy subject; Final reflections)

Confidentiality was valued not just as an abstract concept, but as a way of promoting open communication and trust between the patient and the doctor. Many subjects commented that lack of confidentiality would inhibit full and frank disclosure:

I think if he knows that that's going to be reported that might not make him ask in the first place and ...if they know that it's going to be reported straight away and they're going to get that bad reputation then people aren't going to trust doctors to be able to say 'I would like to seek further help'. I don't think as many people would ask for help and at the end of the day I think patients have got to feel that's what doctors are for

(Epilepsy subject; SEXUAL THOUGHTS scenario)

if she doesn't have that trust I doubt she'd even go and see the GP again. She'd either change surgeries or something along those lines. I'm a firm believer in trust that what I say, apart from like what we're doing now, that it's not going to be transmitted everywhere

(Epilepsy subject; DOMESTIC VIOLENCE scenario)

5.6.5 PATIENT TO HAVE CONTROL

Although the intention in this study was to explore the utilitarian grounds for confidentiality, subjects did refer to other justifications. In particular a number of subjects expressed the view that it should be for the patient to have control of the reporting decisions, and the use to which their information was put. This was particularly prevalent in

the DOMESTIC VIOLENCE scenario, where the fact that it was the patient herself at risk seemed to weigh heavily with subjects, but interestingly was also commonly expressed in the DRIVING scenario, often linked to a clear statement that it is the patient who has the legal duty to report medical impairments:

Well I believe in giving options to the person that they can take. It's not for you to choose which way they go. .. you're taking control of a person's life, a person should be allowed to live their own life not be told by someone else. I know we have laws and things along those lines but I think sometimes it can be taken too far.

(Epilepsy subject; DOMESTIC VIOLENCE scenario)

I think he should really keep it to himself and advise, but I really think it's up to the patient I suppose to decide what they want to do.

(Epilepsy subject; DRIVING scenario)

No that's it. And if she's told the doctor "I'm not driving" and she is well that is her problem isn't it. I mean if she wants to cause an accident and kill herself that's up to her.

(Epilepsy subject; DRIVING scenario)

Expanding on this, a number of subjects clearly articulated the view that the doctor's role in a consultation is as an adviser rather than the final decision-maker, and that making decisions on behalf of the patient would go beyond that professional remit:

Well he's done what he can, hasn't he. He's told her that she may have to stop driving and if she is going to try and have a baby she may have to stop taking her medication. So he's done everything he can, he's told her all her situations and like there's not really much more he can do. He's there for her isn't he?

(Epilepsy subject; DRIVING scenario)

I have always assumed that I was speaking to a doctor on the basis of privilege and rather like the monarch the doctor is there to "persuade and advise" rather than to actually intervene and govern the situation.

(Epilepsy subject; DRIVING scenario)

5.6.6 REPORTING NOT MAKING A DIFFERENCE

Just as subjects who supported breach of confidentiality expressed a belief that it would effectively reduce risk, subjects who opposed breach were more likely to consider that reporting would not make a significant difference:

If she doesn't want to report it you can give your opinion to the police if you feel it's necessary but unless she wants to report it they can't take it any further. If she's not going to cooperate or take it any further then they're not going to have a case to work on so there's actually no point.

(Epilepsy subject; DOMESTIC VIOLENCE scenario)

My question is what are the Child Protection Team going to do? Because they can't put him on a risk register or the Sex Offender's Register or anything like that because he's not done anything and there's nothing to say that he will

(Epilepsy subject; SEXUAL THOUGHTS scenario)

5.6.7 PATIENT NOT AT FAULT

Another theme which had a counterpart in the Reporting model was that of reporting being unjustified because the patient was not at fault. As with "Patient at fault" in the reporting model, this had links to issues of treatment acceptance/compliance, and in line with that was a view most commonly expressed in the SEXUAL THOUGHTS scenario:

I don't think he should tell the police cos I don't think they can help it. Some patients maybe but he might not be able to help it. Cos I had the same problem a few years back but I'm fine now.

(Mental Health subject; THREATS scenario)

he's actually seeking assistance. Yeh [reporting] wouldn't be fair, in this instance, I don't think it would be fair to report him straightaway. I think you've got to at least let him see if he can sort himself out.

(Mental Health subject; SEXUAL THOUGHTS scenario)

There was also a view expressed that to report the patient in the SEXUAL THOUGHTS scenario would be to "punish him for seeking help" – something that seemed to appeal to a sense of justice rather than to the consequences of reporting or not reporting. This echoed

other comments relating to unfairness, that patients were encouraged to rely on confidentiality, so it would be unfair to exploit that by then reporting them:

Definitely [keep it confidential] because otherwise really he would be punished for asking for help and having feelings.

(Epilepsy subject; SEXUAL THOUGHTS scenario)

the doctor should have pre-empted her answer by giving her the right question and not forcing her in a sense to give an answer which he was then bound by his profession, I suppose or position, where he was bound to then tell the DVLA. In a sense it's a bit of a trick, because he's not giving her the chance to make the decision first.

(Epilepsy subject; DRIVING scenario)

5.6.8 DELAYING DECISION

The above concepts relate to the view that the doctor should not breach confidentiality to report the patient in the scenario. Some subjects did not go that far, but argued in favour of delaying the decision, or waiting for further developments. Although they did not rule out reporting at a later stage, their views seem to have more in common with subjects supporting confidentiality, so will be discussed here:

I think it would be very important to go through again the people like the psychiatrist or support groups. Because they might be able to calm the situation before the police were involved. I'd quite like that situation to be a last resort... 'cos also I think that would keep the trust

(Mental Health subject; THREATS scenario)

But she might lose her trust with the GP if he reacted to it straightaway. I think there's a little bit more to be done before he reports it to the authorities.

(Mental Health subject; DOMESTIC VIOLENCE scenario)

Some subjects adopted a non-committal position because of ambiguity or lack of detail in the scenarios. More generally however three different views seemed to underlie deferring a final decision.

The first group of subjects felt that further risk assessment was needed. This was partly related to the lack of detail provided in the vignettes, but also to the view that the doctor,

particularly the GP in the SEXUAL THOUGHTS scenario, should not make the decision alone. Many subjects felt that the decision should be referred to “the psychologist”, and a few subjects who identified the doctor in the DRIVING scenario as a GP also felt that specialist advice was needed. Particularly in the SEXUAL THOUGHTS scenario it was instructive that many subjects felt that once the patient was referred to a psychologist the GP had discharged any responsibility to address the risks, and should defer totally to the “expert” view, although this is something that professional and legal guidelines would not support:

And I was thinking in a way that if he was referred, which one would hope he was, that I mean in a way the onus is then transferred to whoever he's been referred to.

(Epilepsy subject; SEXUAL THOUGHTS scenario)

It would be interesting to know how he feels about his risk and another thing is he would have had a risk assessment done as a continuum, a regular risk assessment, so this needs to be part of the whole process that's what risk assessments are for.

(Mental Health subject; THREATS scenario)

Secondly, there was a group of subjects who felt that time should be taken before making a decision, either to wait for further developments or information, or to take time to try to persuade the patient to agree to reporting:

Well this is why I say you need to give her some time but if she doesn't do it in that time you need to say to her that you've given her X amount of time to do it but you have to as the law says, if she doesn't, you have to.

(Epilepsy subject; DRIVING scenario)

Through a series of appointments the GP can do two things, return to the issue and secondly see what's happening to the woman's health in those circumstances and if it's stable ...But it's a discussion that's probably not finished is what I'm saying

(Epilepsy subject; DOMESTIC VIOLENCE scenario)

Finally, other subjects contemplated deferring any report indefinitely, in the hope that treatment would offer effective risk management. They were basically opposed to reporting, but not prepared to rule out reporting at a future point if clinical management proved ineffective:

If there was some form of treatment that you knew might be able to work and you thought that would be able to work first. Try that for a couple of months, see if that worked. If that works, fine then keep that going and you know just keep that between the two of you and that's that.

(Epilepsy subject; SEXUAL THOUGHTS scenario)

I would say to him as the GP, see, monitor it very closely. If the thoughts get stronger and then fade away and then come back and then fade away and you begin to see a pattern. This just suggests you are coping with it in some sort of manageable way. It could be that it will fade away altogether. If it starts to become unmanageable after you've established some sort of idea about the pattern of it, perhaps "we" the doctor says to the man should report it to the child protection team.

(Epilepsy subject; SEXUAL THOUGHTS scenario)

5.6.9 SUMMARY OF NOT REPORTING MODEL

Overall maintaining confidentiality was less widely supported than breach, but there is still considerable evidence of the value subjects attach to confidentiality, both in principle, and as a practical way of promoting trust in the medical profession. There is a clear engagement with utilitarian concepts, with less support for reporting if it does not result in reduced risk, and support for confidentiality where treatment has risk management benefits. Deterrence is clearly recognised by many subjects, and often given as one factor weighing against reporting, but not generally the decisive one.

Deontological concerns included patient autonomy, as expected, but there were also concerns for the lack of fairness involved in reporting a patient for potential future conduct, particularly when that appeared uncertain, and (particularly in the SEXUAL THOUGHTS scenario) some subjects referred to reporting as "punishing him for seeking help" – something that was seen not only as counterproductive in terms of deterrence and impaired treatment, but also as unfair.

5.7 RELATIONSHIP WITH DOCTOR

One topic that emerged frequently, and seems to play a role in all of the other topics identified, was the issue of the patient's relationship with the doctor, and the role of the doctor. Because this could not be related to one specific topic, such as deterrence or reporting, the nodes relating to this were collected and analysed in a separate model (Figure 10).

Within this topic five themes were identified (Appendix 5):

- Value of doctor-patient relationship
- Trust in doctor
- Trust already reduced
- Stressful for doctor
- Role of doctor

And also it's nice to have a regular doctor. I mean for example with my doctors, because they're often busy or off or they're running two hours late you never get to see your regular doctor which I think – and that's got worse over the years I think. Which does definitely affect the confidentiality.

(Epilepsy subject; DOMESTIC VIOLENCE scenario)

You should be able to talk to your doctor about anything shouldn't you?

(Epilepsy subject; DRIVING scenario)

I think if the trust was lost you could lose a lot of patient benefits.

(Mental Health subject; THREATS scenario)

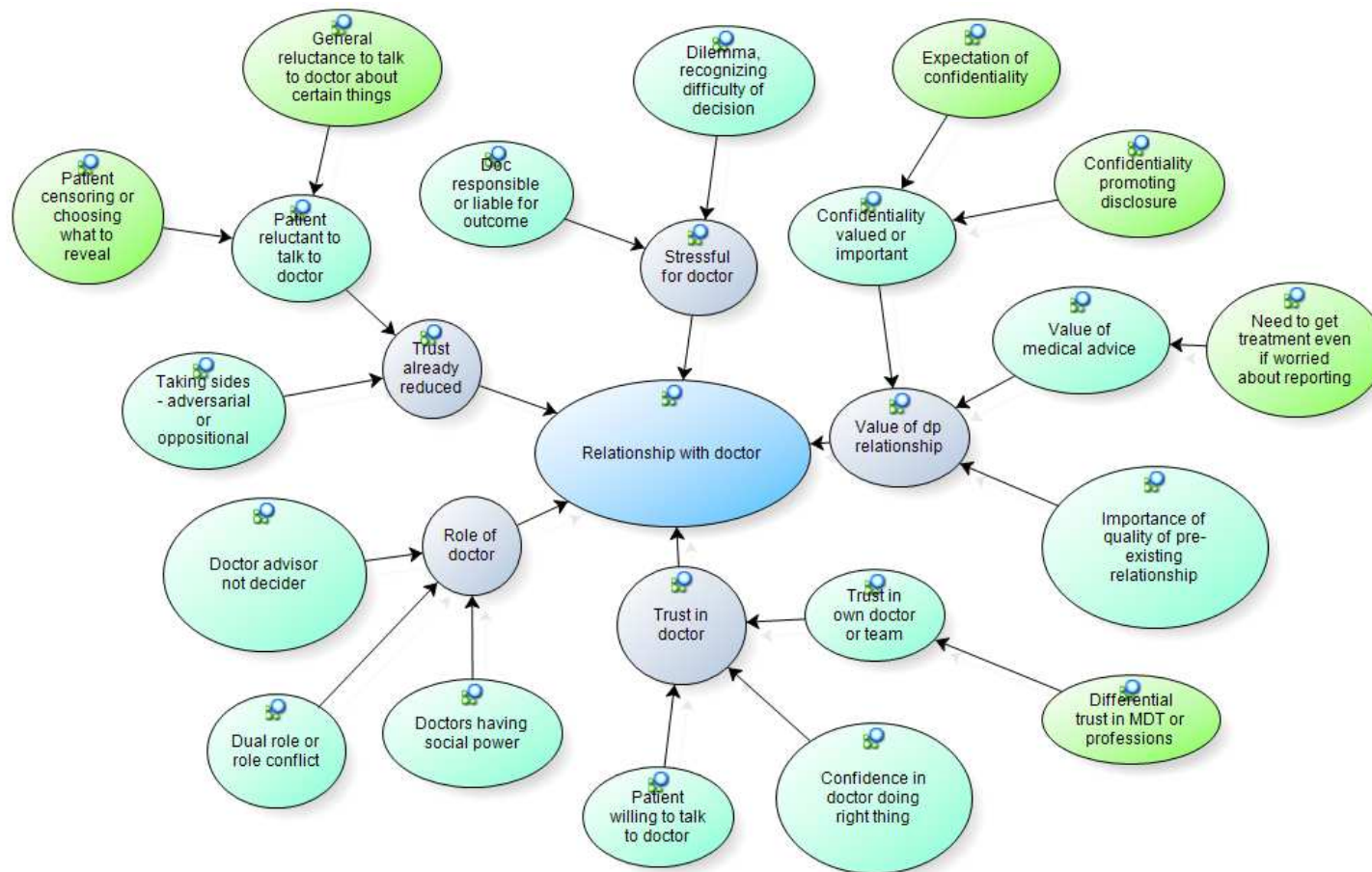


Figure 10: NVivo model for Relationship with doctor

5.7.1 VALUE OF DOCTOR-PATIENT RELATIONSHIP

The importance of the doctor-patient relationship was a very common theme explored by almost all subjects, with various components emerging. On a very practical level, subjects spoke of the importance of being able to access medical advice. Since reporting was generally seen as something that would damage the doctor-patient relationship this was seen by many as a factor that would count against breaching confidentiality. Conversely, for some the imperative to access treatment implied that, even if trust was lost, patients would not be deterred from seeking treatment, and this could be seen as an argument for permitting reporting:

*I don't think as many people would ask for help [if confidentiality was breached] and at the end of the day I think patients have got to feel that's what doctors are for, asking for extra help and being given it really.
(Epilepsy subject; SEXUAL THOUGHTS scenario)*

*Well personally there again it wouldn't put me off because I'd have to go and get a certain thing like that sorted out anyway.
(Epilepsy subject; Final reflections)*

*I think people'd still come to the doctors. I think you've still got to go to your GP, you've got to have your GP.
(Epilepsy subject; Final reflections)*

Another issue discussed was the importance of the quality of the pre-existing relationship between doctor and patient for determining the consequences of any reporting. Where that relationship was already strong, subjects felt that patients would be more likely to accept the doctor's decision to report, and quicker to re-establish a therapeutic relationship. Conversely, if the pre-existing relationship was poor, subjects felt that a negative reaction would be more likely:

*as regards how he might think about his doctor...that depends on like what he thinks of the doctor, whether he looks at his doctor and he knows that the doctor is helping him by the medication he is giving him,
(Epilepsy subject; THREATS scenario)*

I think it depends if they've got a relationship with their doctor in the first place or not. You know if they feel comfortable and okay with the GP to start with then that's a good starting place, but if it's turning up cold I think that could be very difficult

(Mental Health subject; SEXUAL THOUGHTS scenario)

Thirdly, subjects who valued the doctor-patient relationship were also more likely to express a belief in the value or importance of confidentiality, either specifically with the aim of promoting frank disclosure and effective treatment, or more generally as a good thing in itself:

I think it changes the terms of the relationship in terms of trust ... because if it became known that your GP had a duty to look out for X, Y and Z and then take action on it then I think your own preparation for going to a GP or the circumstances under which you were prepared to go to a GP would be modified

(Epilepsy subject; DOMESTIC VIOLENCE scenario)

I want to have the freedom to have a full discussion so that I am able to give as much information as I think is relevant or appropriate and I leave with as much information as is relevant or appropriate

(Epilepsy subject; Final reflections)

5.7.2 TRUST IN DOCTOR

Some subjects expressed a general trust in doctors, and usually felt that other patients would feel the same:

I think at the moment you trust the doctor, they could say anything.

(Epilepsy subject; DRIVING scenario)

I'm still rooted in a childhood expectation rightly or wrongly of going to the doctor and saying how I feel and expecting the doctor to say well I think we should do this, and I think the worry that the doctor might react in a particular way might condition how the public at large saw doctors as an agent of the state for example.

(Epilepsy subject; DOMESTIC VIOLENCE scenario)

Other subjects, often while expressing some general lack of trust in the profession, were keen to stress that, nonetheless, they had trust in their own doctor:

I mean if I'm ever worried about anything myself I always go straight to my doctor.

(Epilepsy subject; DRIVING scenario)

I have good CPNs and any problems between the three-week visits I see her I just ring her up and she tries to sort the problem out there and then on the phone so it's like I've got good communication with her and I've found out with the psychiatrist I've got good communication with them. I haven't had any experience yet where I haven't trusted a psychiatrist so I've been quite lucky.

(Mental Health subject; THREATS scenario)

Less commonly explored, perhaps because it was not addressed in the scenarios, was whether subjects had greater or lesser trust in other professions. Particularly for Mental Health subjects discussing the THREATS scenario, there was a feeling that nursing staff could be more trusted with information, possibly because patients felt they had a closer relationship with their community nurses, but also apparently because doctors were more closely identified with negative consequences, particularly detention under the Mental Health Act:

I tell my nurses yeh, but I don't tell Hellesdon Hospital no.

(Mental Health subject; THREATS scenario)

Trust was not only viewed as doctors maintaining confidentiality; some subjects expressed confidence in doctors making the decision that the subject felt would be right, and this applied to subjects who supported reporting as well as those who supported confidentiality:

I'm sure the police will make the right decisions and doctors will all make the right decisions.

(Epilepsy subject; THREATS scenario)

I would hope [it would be reported] yes. I feel quite confident that my GPs would.

(Mental Health subject; DRIVING scenario)

Well hopefully they [maintain confidentiality], they should do, it's part of the hospital's erm part of the way they work isn't it?
(Mental Health subject; THREATS scenario)

There were fewer comments to the effect that doctors might not act in the way the subject thought best, but some did raise this possibility, particularly subjects who did not support reporting, but were concerned that doctors may breach confidentiality:

So in my view the doctor should [report] ...Whether he would or not that's another matter.
(Epilepsy subject; DRIVING scenario)

It depends on the GP I suppose or the doctor. Everybody's different aren't they? Even though you're a doctor you've got your own personality linked in with that and I suppose it just depends on how you feel about these sort of things. How you feel about different things.
(Mental Health subject; SEXUAL THOUGHTS scenario)

5.7.3 TRUST ALREADY REDUCED

For subjects who felt that trust was already reduced, this was often seen as a symptom of a wider breakdown of trust within society, or a growing reluctance to accept that professionals or experts know best. This was not always an entirely negative view, with some subjects seeing this as supporting independence or autonomy for patients:

The trouble is whether people really trust doctors anyway. It's not whether they might lose the trust in doctors it's whether they really trust doctors now.
(Epilepsy subject; THREATS scenario)

Well I don't think people trust doctors as much as they used to. But then I don't think the trust that people had for doctors at one time was really genuine.
(Epilepsy subject; Final reflections)

Reduced trust was seen as reducing patients' willingness to disclose to doctors, and linked to the issue of anticipatory deterrence discussed in Section 5.8.1. One specific consequence

of reducing trust was that subjects saw the doctor-patient relationship, particularly in the sorts of dilemmas envisaged in the scenarios presented, as becoming more adversarial: the perception that doctors might be acting in the interest of others, rather than of the patient, was strongly linked to a consequential reduction in trust within the relationship:

You'd think "the doctor is on [the neighbour's] side", wouldn't you in that situation?

(Epilepsy subject; THREATS scenario)

Well he already thinks that somebody's trying to poison him so what he's going to think about anyone else, you know, do you see what I mean. He might sort of feel, if he's sort of paranoid about it he might sort of think that the police are in league with the people who are trying to poison him.

(Mental Health subject; THREATS scenario)

Conversely, a doctor who was clearly putting the patient's interests first was perceived as being more caring and trustworthy:

He did ask me did I need to drive for my work and he seemed to be sort of suggesting that if ... I mean nothing was actually said but I got the distinct impression that if I really needed to drive for my livelihood that he may not report it. It felt like he was treating me as an individual

(Epilepsy subject; DRIVING scenario)

5.7.4 STRESSFUL FOR DOCTOR

While most subjects considered the scenarios predominantly or exclusively from the patient's point of view (as was intended), a few also discussed the doctor's situation. Most commonly this was to sympathise with the doctor's dilemma, with what was frequently perceived as a difficult balancing act to achieve:

Just imagine the guilt the doctor might feel if something did happen, other people were involved, and he or she got to hear about that. You know, what's going to go through his mind?

(Epilepsy subject; DRIVING scenario)

I don't know. I don't think I'd want to be a doctor (laughs) to make all these decisions. You're making the decisions for people aren't you really?

(Mental Health subject; DRIVING scenario)

For some subjects this was also a factor to take into account in determining a decision: the doctor was seen by them as having a legitimate interest in selecting a course of action based in part on minimising the doctor's own anxiety, or limiting exposure to future liability:

That's a good question really because the doctor's under pressure if she does have a fit. That's the main thing in a way. It would be his fault if she had a crash and got killed through an epilepsy fit or something. The doctor's in a bit of a situation there in a way.

(Mental Health subject; DRIVING scenario)

5.7.5 ROLE OF DOCTOR

Finally in this theme are grouped some comments subjects made about the role of the doctor either within the consultation or more generally in society.

Within the clinical encounter a small number of subjects felt strongly that the doctor's role should be to advise the patient, rather than to make decisions for the patient, and this was associated with strongly held views that confidentiality should not be breached, and that the patient should retain that control. This was exclusively discussed by Epilepsy subjects: the reasons for this are unclear but it may suggest that mental health patients have a different experience or perception of the balance of power in the doctor-patient relationship, and see themselves as having less right to assert their own autonomy:

But I think with that one the GP, I think all he can do is advise the woman, but I don't think he can take it any further. I don't think he really should report this because, especially with there being thousands of people that are in that situation I think they'll completely lose trust with the GP.

(Epilepsy subject; DOMESTIC VIOLENCE scenario)

And if she's told the doctor "I'm not driving" and she is well that is her problem isn't it. I mean if she wants to cause an accident and kill herself that's up to her. (Epilepsy subject; DRIVING scenario)

More widely, some subjects described doctors as having considerable power within the relationship and within society more generally. This was often a factor which intensified the dilemma, because having such power increased the potential consequences, for good or bad, of the decision. It was seen as something which could be intimidating, and could

exacerbate the deterrent effect of reporting, but subjects also saw that power as something which could achieve positive benefits, both in terms of public protection and also for the patients themselves:

I think perhaps people in this situation aren't quite fully aware that doctors actually are quite a powerful person in society
(Epilepsy subject; DOMESTIC VIOLENCE scenario)

On the other hand I would say that she's made the decision because the nature of doctors' position in society is not well enough understood. They're not just a friend or a confidante. They've got power which this woman clearly hasn't really taken on board, because she's gone further than she wanted to go really
(Epilepsy subject; DOMESTIC VIOLENCE scenario)

Finally a few subjects reflected explicitly on the conflicting expectations of doctors in the scenarios, and the dual roles, of therapist and public protector, that doctors could be expected to fulfil. This was usually discussed sympathetically, linking to recognition of the stressful nature of the scenarios for the doctor, and the difficulty of resolving the role conflict in order to reach a satisfactory conclusion:

Which is very difficult for people to suddenly realise that the doctor isn't only the kind, sympathetic, fatherly or motherly figure, that they actually have a hidden layer underneath.
(Epilepsy subject; DOMESTIC VIOLENCE scenario)

I mean if that policeman-behind-the doctor role is going to stay in place, as it should really because obviously he is party to many things that other people don't see
(Epilepsy subject; DOMESTIC VIOLENCE scenario)

5.8 DETERRENCE

Central to this thesis is the concept of deterrence. Do subjects see it as a possibility? Do they incorporate it into the utilitarian calculus, and if so how? Does it influence their perception of whether it is right to breach or maintain confidentiality? And is it something that subjects recognise as occurring to others, or is it only the patients who experience it directly who give it significant weight?

As in the previous sections, NVivo nodes relating to deterrence were identified, and a conceptual model developed (Figure 11).

Five themes were identified relating to deterrence (Appendix 5):

- Anticipatory deterrence
- Consequential deterrence
- Calculus of risk and benefits
- Deterrence unlikely
- Mitigating the effects

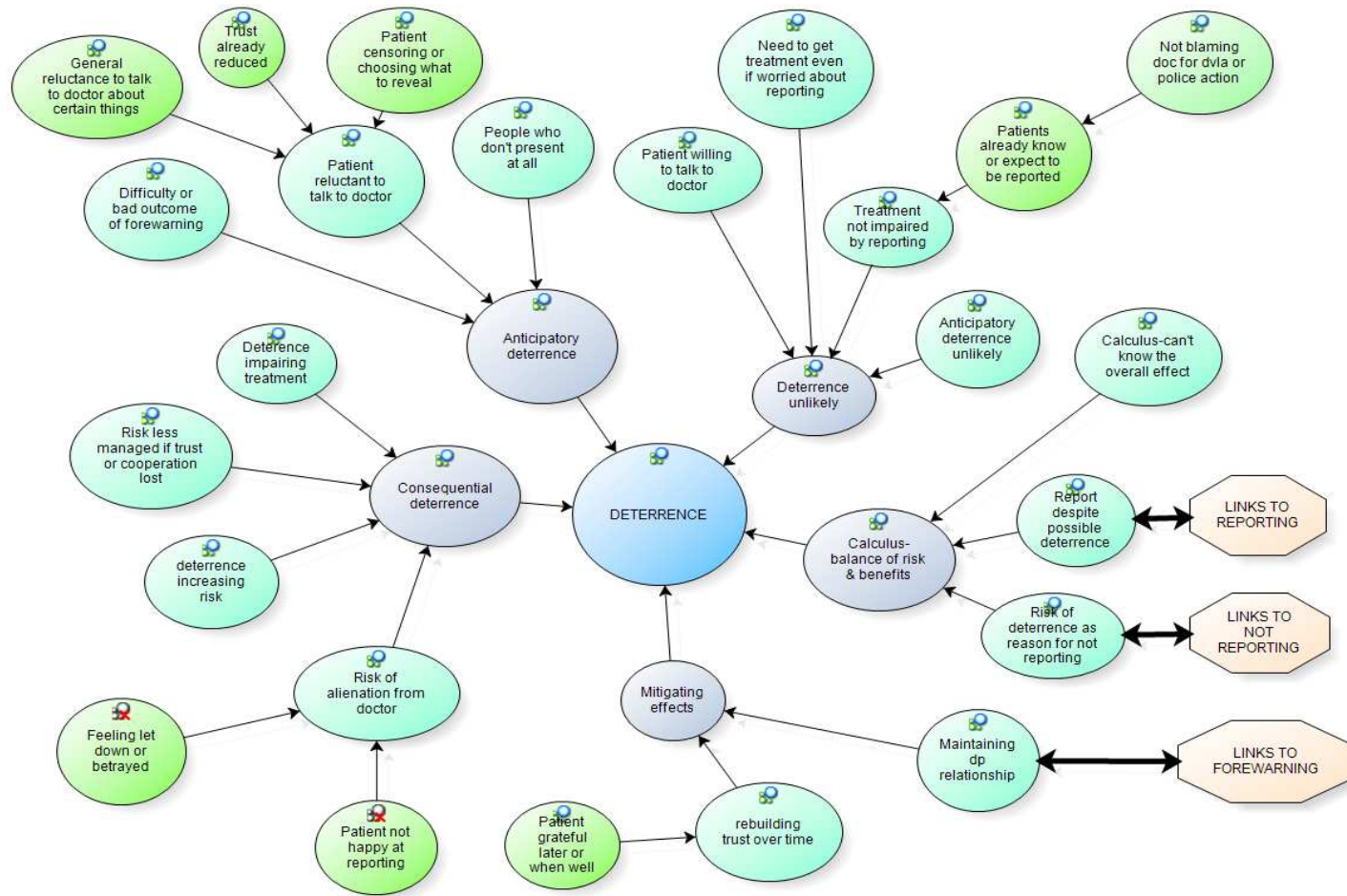


Figure 11: NVivo model for Deterrence.

Deterrence was very widely recognised, with all subjects making some reference to one or more aspects. It was explored most commonly as a relatively abstract concept:

Well it means that the patient's not going to trust the doctor any more. ... if your confidence gets broken once then you're never going to trust someone again. It's like telling a secret. If you tell a secret then the person tells other people then what's the point of the secret and you're never going to tell them again.

(Epilepsy subject; DRIVING scenario)

they would probably stop seeing the psychiatrist and he would stop being supervised and that could really cause a lot of problems, that's a real, real problem.

(Mental Health subject; THREATS scenario)

I think especially with like epilepsy and things, you feel it's quite a personal thing so when it comes to them passing it on I can understand people not having that much trust in doctors from then onwards.

(Epilepsy subject; DRIVING scenario)

In a number of these instances, the conversation would never happen in the first place if the black and white rule existed and people were aware of that black and white rule

(Epilepsy subject; Final reflections)

A smaller number of subjects were also able to relate the concept to their own history directly, and were willing to disclose these experiences. Previous work has suggested that between 20% and 40% of patients have already experienced some degree of deterrence, and findings in this study are broadly in line with that, with 16% (6/38) saying that they had already been deterred to some extent:

When I got my licence back I did have another seizure which I didn't tell anybody about ... and I think that's why some people would lie.

(Epilepsy subject; DRIVING scenario)

*the reason I don't phone em [when] I haven't been very well, [is that] every time I do now, the first thing they say is "M*** we're having you sectioned".*

(Mental Health subject; THREATS scenario)

he had to go through social services or something because I was ill at the time so again like with the trust thing, I didn't trust him for oh I think it was about a couple of months I didn't trust him, I was going ill and I was ill with my asthma and I wanted inhalers but I wouldn't go and get my inhalers from the doctors. It took me a couple of months to trust him again.

(Mental Health subject; DRIVING scenario)

Other subjects, who had not experienced deterrence themselves, or were not willing to share that experience, were nevertheless able to recognise the possibility that they would be deterred, if they found themselves in the sort of situation where it would arise:

[It's a] hard one. You go to the doctor ...I'd err on the side of caution probably and not tell the doctor everything. ...I wouldn't bring it up.

(Mental Health subject; DRIVING scenario)

Well I'd still go and see him I just wouldn't trust him with information sort of like saying about that you've got ill again I wouldn't show it. You hide that you're feeling ill but in fact you tell the psychiatrist that you feel fine and everything's okay. You'd lie to the psychiatrist.

(Mental Health subject; THREATS scenario)

Finally, and importantly for the central questions of this study, subjects were able to recognise the possibility of others being deterred, even when they did not experience this directly themselves, although as discussed above, this was often in the context of the subject distancing themselves from the possibility of irresponsible behaviour. This suggests both that the scenarios presented and the questions posed were credible and recognisable to subjects, even when they were not directly related to their own experience, and also that the issue of deterrence is not so abstract or divorced from people's experience as to be recognised only by those who are personally affected:

they ain't going to tell 'em and they're going to start withholding information back in case that doctor go and do the same thing. ...I think it is a bad thing for her if she goes and gets a new doctor and doesn't disclose a lot of it, it's going to affect her health isn't it?

(Epilepsy subject; DRIVING scenario)

because say she was having another baby and the same scenario comes around, she's going to say something along the lines yes I'll stop taking the drugs and not tell

(Epilepsy subject; DRIVING scenario)

What would that woman feel? Probably never ever go back to the GPs for anything. It destroys everything...She'd never trust a GP again for a long, long time.

(Mental Health subject; DOMESTIC VIOLENCE scenario)

5.8.1 ANTICIPATORY DETERRENCE

Most subjects were able to identify the possibility of consequential deterrence with little or no prompting, but anticipatory deterrence generally arose only in response to directed questions. It is a rather more remote concept, and does not arise from the details provided in any of the vignettes, so it is perhaps not surprising that subjects did not raise this spontaneously. To what extent was this concept recognised by subjects, and to what extent was it imposed on them by the questioning? A number of comments suggest that, when it was put to them, subjects did recognise the concept:

I think it changes the terms of the relationship in terms of trust ... I think the a general effect might be to make it much more of a client/provider relationship because if it became known that your GP had a duty to look out for X, Y and Z and then take action on it then I think your own preparation for going to a GP or the circumstances under which you were prepared to go to a GP would be modified

(Epilepsy subject; DOMESTIC VIOLENCE scenario)

But I definitely think that if there was a suspicion that the DVLA were going to be informed then there's a good chance that they wouldn't actually reveal what their intentions were.

(Epilepsy subject; DRIVING scenario)

I don't think he can take it any further otherwise like the other situation the rumours could get out and other people hear and they're desperate for help and desperate for someone to talk to like a doctor but they know that they're going to take it further...I definitely think that would put people off.

(Epilepsy subject; DOMESTIC VIOLENCE scenario)

Conversely, a few subjects were clear in their rejection of the possibility of deterrence – it does not seem that either group were being unduly led by the questions posed:

it would get to the point where you know you hear your grandparents talk about "well it didn't used to be like that in my day" and it didn't and we'd end up saying that as well. It's probably more my parent's generation that would be saying that about the doctors "well I can't believe they can tell everybody that" and we'd be a little bit like it and then the next would be okay cos they wouldn't know any different.

(Epilepsy subject; Final reflections)

I suppose they'd be angry, I wouldn't say they wouldn't trust them cos they're only doing their job like you know thinking of everyone's safety.

(Epilepsy subject; Final reflections)

For some people, reporting would make little difference, because they perceived patients as already having lost a degree of trust:

I think they'd lie anyway whether you were going to say it or not. I don't think it would make a lot of difference what they actually say to you. You see there's an awful lot of people think they're telling you something and you'll believe them but..

(Epilepsy subject; DRIVING scenario)

When one says, and I don't know, when one always says they understand about how many units of alcohol they drink or how many cigarettes they smoke that they always kind of massage the truth a bit anyhow.

(Epilepsy subject; DRIVING scenario)

One aspect of anticipatory deterrence was raised spontaneously by a number of subjects; the possibility that the patient in the scenario may already be reluctant to disclose sensitive information because of confidentiality concerns:

that's probably why people don't have as much trust because they all know exactly what happens. I mean even when I was talking to them about it at work and things like that, different scenarios, they all know exactly what happens and they all know as soon as it get to the doctor, that's it.

(Epilepsy subject; DRIVING scenario)

You've got to be careful what you say though haven't you? Got to be careful what you say because as I say you could end up in a hell of a lot of trouble.

(Mental Health subject; SEXUAL THOUGHTS scenario)

Well already they're not honest with the doctors, they're not and they're not honest with the DVLA.

(Mental Health subject; DRIVING scenario)

Subjects also recognised that deterrence could lead to patients censoring the information they give to doctors, and possibly to complete non-presentation:

People are going to lie. If they know it's going to be reported they won't tell the exact truth. It's my opinion and how I hear people speak. What I've learned over a period of time with people.

(Epilepsy subject; DOMESTIC VIOLENCE scenario)

If I suspected, if I were in her position and I suspected that the doctors were going to talk to the DVLA then I definitely would, I think, I would imagine that the person and possibly myself, if it was essential that I drove for my livelihood then I might well withhold that information. One does. One maybe shouldn't that's probably what I'd do but if it were essential to carry on then you know if your job was therefore important to you.

(Epilepsy subject; DRIVING scenario)

5.8.2 CONSEQUENTIAL DETERRENCE

Consequential deterrence was a more straightforward concept, directly related to the facts of the scenarios, and most subjects recognised the possibility. Some subjects spoke of this primarily in terms of the patient becoming alienated from the doctor, and losing trust. Some subjects saw this as affecting only the particular doctor involved, while others thought the patient would lose trust in the medical profession more widely:

But she might lose her trust with the GP if he reacted it straightaway. I think there's a little bit more to be done before he reports it to the authorities.

(Mental Health subject; DOMESTIC VIOLENCE scenario)

Lack of confidence, I wouldn't believe in him and stuff like that. I wouldn't trust him. ... I'd still go and see him I just wouldn't trust him with information sort of like saying about that you've got ill again I wouldn't show it.

(Mental Health subject; THREATS scenario)

It is very much about trust. I think it could damage the relationship between the doctor and the patient. ...if the doctor reported it.
(Mental Health subject; DRIVING scenario)

For other subjects the more significant aspect was the impairment to treatment that might result from consequential deterrence, and subjects spoke both about the effect on health and the possible unintended increase in risk that might result if trust in the doctor was lost:

If they lose [the trust] I think there could be a lot of trouble. Some people won't bother going to the doctor even if there is something wrong. They won't go and face the doctor will they? Some of them won't bother getting a new one so their health will just go down.
(Epilepsy subject; THREATS scenario)

Once they've had that experience they'll want to move away from that doctor if they'd done something like that. See they've learnt something with that doctor the next doctor ain't going to do it because they ain't going to tell 'em and they're going to start withholding information back in case that doctor go and do the same thing. ...I think it is a bad thing it's going to affect her health isn't it?
(Epilepsy subject; DRIVING scenario)

5.8.3 CALCULUS OF RISK AND BENEFITS

Some subjects spoke very clearly about the need to balance risks and benefits, and to reach a decision based on the predicted consequences of various actions, whereas for others this was more implicit, but appeared to underlie the decisions subjects were making:

Yeh, I think so, yeh. And I guess some relationships are going to break down and then you've got to decide on balance... (sighs) that's why you've got to somehow do some sort of impossible risk assessment haven't you? ... and (sighs) it's very hard to know whether you can actually come up with a formula that's going to fit everybody because it would seem that every case is going to be individual.
(Mental Health subject; THREATS scenario)

somehow striking the balance between guaranteeing as far as possible that that space is confidential and wanting to encourage the patient to feel free to um be honest um but you know the bottom line is, if lives are at risk, something needs to be done and then the doctor's own discretion's got to come in as to whether the first thing that he's done is that the discussion takes place between them and the patient

(Mental Health subject; Final reflections)

There are certain cases, extreme cases, where I do think, and I think most people would agree, that if a person is in a dangerous state in some way or another or is threatening the lives of other people, and all the other possibilities, then the doctor has to decide, you can't really write those sort of things down on paper, the doctor has to decide when confidentially should be breached. Up to that point I think there is a need for a bit more confidentiality.

(Epilepsy subject; Final reflections)

Only one subject appeared to take a significantly different view, arguing that it was not possible or appropriate to consider the effects of a decision on patients as a whole, but that rather a decision should be made specifically on the immediate situation:

It's difficult isn't it? If you want to base everything on statistics then maybe the answer would be yes, but when you come down to how it impacts on individual lives..... Well I think it's the one person in front of you (laughs) because human beings are infinitely unique and you can't tar everybody with the same brush. Even though it might look nice and neat on paper.

(Mental Health subject; DRIVING scenario)

Another doubted the utilitarian approach in the DOMESTIC VIOLENCE scenario, relying more on a principle of autonomy or self-determination:

it's prejudicing the relationship with the GP which in itself is the wrong thing to do but it sets up the GP as an arbiter of what's right and what's wrong. I guess I still feel quite strongly that the cards should be on the table and the patient should know what is to be done on his or her behalf. They are after all supposed to be adults.

(Epilepsy subject; DOMESTIC VIOLENCE scenario)

Although subjects generally adopted a utilitarian view, several recognised the difficulty in implementing that in practice, and the inherent problems in assessing the outcomes of

complex interactions with many uncertainties. For some this appeared to render the exercise futile, and a few subjects seemed to abandon the utilitarian calculus because of these difficulties:

Yeh I can see both sides and I think it's incredibly difficult and I think it is inevitable that you're going to lose some people whichever way you go. It's very difficult to make a scientific general decision that's going to, you can't protect everybody. Whatever decision you make somebody is going to fall through the net, whichever way you do it, I think.

(Mental Health subject; DOMESTIC VIOLENCE scenario)

As subjects struggled to achieve the balance between risks and benefits, there were examples both of subjects who came down on the side of reporting, despite recognising the potential costs associated with deterrence, and of those who concluded that those costs tipped the balance, and that confidentiality should be maintained. Those views have been analysed in more detail in Sections 5.5 and 5.6.

5.8.4 DETERRENCE UNLIKELY

Although most subjects recognised the possibility of deterrence, a few rejected it, and others considered it to be unlikely, or affecting only a few patients. This reflected the perception that patients would strike a balance between concern for confidentiality and need for treatment: subjects who felt that confidentiality concerns would be low, and those who felt that whatever the degree of concern, need for treatment would override it, both saw deterrence as being unlikely:

It wouldn't put me off because I'd have to go and get a certain thing like that sorted out anyway.

(Epilepsy subject; Final reflections)

But as I say as I said to you, when sometimes I'm not very well but I don't tell people how bad I am. Actually I do tell Danielle, my nurse yeh, I tell her everything because at the end of the day she's the only person I've got.

(Mental Health subject; SEXUAL THOUGHTS scenario)

Subjects who saw deterrence as unlikely also expressed the view that breach of confidentiality was not likely to impair ongoing treatment. Associated with this was the view that, whether they like it or not, patients generally understand that some things will be reported, and are therefore not likely to change their behaviour in response to a breach:

That's probably why people don't have as much trust because they all know exactly what happens. I mean even when I was talking to them about it at work and things like that, different scenarios, they all know exactly what happens and they all know as soon as it get to the doctor, that's it.

(Epilepsy subject; DRIVING scenario)

I think people should feel that it's reasonable. I think it's an incredibly difficult sort of ethical question. Um but if it is explained at the outset then you know you can refer back to it and remind people

(Mental Health subject; THREATS scenario)

One aspect of this that will be discussed in more detail in Section 5.9 is the role of forewarning, or establishing clear limits to confidentiality, as a way of reducing the negative impact of a breach of confidentiality. Another was that if doctors are perceived to be following external rules, they may not be blamed for the negative consequences. Conversely, while this may help to preserve some relationship with the doctor, if those consequences are in fact negative, patients may be deterred from seeking help, even from a doctor who remains trusted:

I think she'd be annoyed more with the DVLA than the doctor.

(Mental Health subject; DRIVING scenario)

I don't think she'd necessarily blame the doctor for telling them. As a patient you don't realise how much the doctors and nurses, or I don't, get in touch with the police and inform them. You may be annoyed with the police when they pick you up for running away or whatever but you don't blame the nurses and doctors for that. You put the blame on the police rather than on the nursing staff and doctors.

(Mental Health subject; DRIVING scenario)

5.8.5 PROTECTING THE DOCTOR-PATIENT RELATIONSHIP⁶

Although many subjects were willing to accept some deterrent effect as a consequence of reporting, there was still concern to mitigate the negative effects of this as far as possible. Chiefly subjects relied on some form of discussion with the patient or at least informing of them of the decision to report, and this will be discussed in more detail in Section 5.9. Two other themes emerged in this discussion; the value of the doctor-patient relationship, and the possibility that trust, if lost or impaired, could be rebuilt over time. There was very strong support for the value of the doctor patient relationship and the need for that to be protected:

*You should be able to talk to your doctor about anything shouldn't you?
(Epilepsy subject; DRIVING scenario)*

*I want to have the freedom to have a full discussion so that I am able to give as much information as I think is relevant or appropriate and I leave with as much information as is relevant or appropriate.
(Epilepsy subject; Final reflections)*

Maintaining that relationship was therefore seen as an important reason for maintaining confidentiality:

*I mean if as a result of that comment, that was put into practice and doctors suddenly became less approachable, less friendly, less confidential I suppose, it would be a sad day for society because I think a lot of people look to doctors for a relationship or an area in their life that is missing in other places
(Epilepsy subject; DOMESTIC VIOLENCE scenario)*

*I'd be quite worried generally that people were out there that perhaps were ill and hadn't got the help because they're frightened to go and talk to someone initially.
(Mental Health subject; Final reflections)*

⁶ Data in this section can be traced to nodes in the coding framework and models labelled as "Mitigating the effects": a different title has been given to reflect more accurately the issues arising here.

Many subjects referred to the possibility of rebuilding trust over time. Subjects varied over how long this might take – with references to “a couple of months” as well as “many years”, but few subjects saw the breakdown as being a once and for all thing:

*I think that would take many years for some people to get the trust back
(Epilepsy subject; Final reflections)*

*I think it will take a little while for her to trust him again, but I think eventually she will trust him again. It will get there. It will just take a little time to trust him again but yeh I think she'll trust him again.
(Mental Health subject; DOMESTIC VIOLENCE scenario)*

Generally the rebuilding of trust was seen as something in which doctor and patient had to collaborate, but there was also a view that, over time, the patient would come to understand the doctor's actions and would change their view of the breach of confidentiality. This was particularly true in the THREATS scenario, where subjects anticipated the patient's mental state improving with treatment, and the patient then understanding the decision that had been made, but in other scenarios subjects also expected patients to change their minds over time:

*I look back now and know that he probably saved my life. He either saved me from killing somebody or killing myself but at the time I felt a bit angry
(Mental Health subject; THREATS scenario)*

*She'd be annoyed quite a bit but I think in the long run in time she'd realise that if she did get pregnant and have the baby then the decision was made for her own interests in the long run.
(Mental Health subject; DRIVING scenario)*

5.8.6 FREQUENCY OF DETERRENCE

It is difficult, in advance of any breach of confidentiality, to make a reliable estimation of the consequences that would enable a balance of risks and benefits to be made. However there are some preliminary indications of the possible frequency of deterrence that might serve as a starting point for the calculus.

Firstly, even although they were not directly asked about their own experience, and the subject group was not chosen to sample patients who had experienced deterrence, 6 out of the 38 subjects (16%) described having avoided health care or concealed information because of confidentiality concerns, a proportion consistent with previous findings in this area. It was more commonly reported by Mental Health subjects, and this sometimes related to the experience of having been detained under the Mental Health Act, suggesting that it is not just release of confidential information to outside agencies that can damage trust. However this remains relevant to the study question, since detention would be one possible outcome of breach of confidentiality in the THREATS scenario:

When I was initially diagnosed with epilepsy and I got told I had to stop driving I did and I absolutely hated it, but then when I got my licence back I did have another seizure which I didn't tell anybody about

(Epilepsy subject; DRIVING scenario)

*I haven't been very well and I would normally call the Crisis Team for help and the reason I don't phone em cos I haven't been very well, every time I do now the first thing they say is "M**** we're having you sectioned" ... when sometimes I'm not very well, I don't tell people how bad I am*

(Mental Health subject; THREATS scenario)

he had to go through social services or something because I was ill at the time so again like with the trust thing, I didn't trust him for oh I think it was about a couple of months I didn't trust him, I was going ill and I was ill with my asthma and I wanted inhalers but I wouldn't go and get my inhalers from the doctors.

(Mental Health subject; DRIVING scenario)

Secondly subjects often gave their own estimate of the frequency of deterrence. While there is no way of knowing whether they are reliable judges of the responses of other people, their views offer an interesting perspective on the question. Also, the public perception of the likelihood of deterrence is a significant factor in determining the sort of confidentiality policies that would be acceptable to public opinion. In three of the four scenarios the commonest view was that deterrence would affect only a minority of patients:

you get the odd person like you say wouldn't take no advice from anyone they'd just do it automatically themselves.

(Epilepsy subject; DRIVING scenario)

It might worry one or two people yeh. I think it depends on the individual actually how they'd react.

(Mental Health subject; THREATS scenario)

I think possibly yeh. Some people but the minority of them yeh.

(Mental Health subject; DRIVING scenario)

However views were generally different in the SEXUAL THOUGHTS scenario. In that case most subjects who considered the question seemed to feel that lack of confidentiality would be a major barrier to most people seeking medical help. This difference appeared to arise primarily from subjects' perception of the negative consequences of reporting for the patient in that scenario, but a few subjects seemed to see deterrence as more likely because of the nature of the problem. In comparison to, say, epilepsy, where there was a view that a patient would need to seek treatment even at the cost of privacy, the patient in the SEXUAL THOUGHTS scenario was perceived as having more choice about seeking or avoiding treatment:

They wouldn't say anything. Well some would but the majority wouldn't. Because there's too much for them to lose just by saying one thing.

(Epilepsy subject; SEXUAL THOUGHTS scenario)

certainly if it were known that any sort of discussion of this sort were going to be reported to the Child Protection Team then the conversation would never take place in my view.

(Epilepsy subject; SEXUAL THOUGHTS scenario)

I think that then the confidentiality would have to be anonymous I think otherwise you wouldn't get people going.

(Mental Health subject; SEXUAL THOUGHTS scenario)

5.9 FOREWARNING

A number of issues relating to forewarning arose during the interviews, and a model was created within NVivo (Figure 12) that collected together various nodes relating to this concept.

Three themes were identified, although compared to the other models produced these are more akin to a classification than to distinct concepts (Appendix 5):

- Informing pre-disclosure
- Informing after disclosure
- Going behind back

The first two themes relate to the timing of forewarning. The third theme, “Going behind back” gathers together comments from subjects who opposed the idea of forewarning, or discussed situations in which doctors might make reports without informing the patient at all.

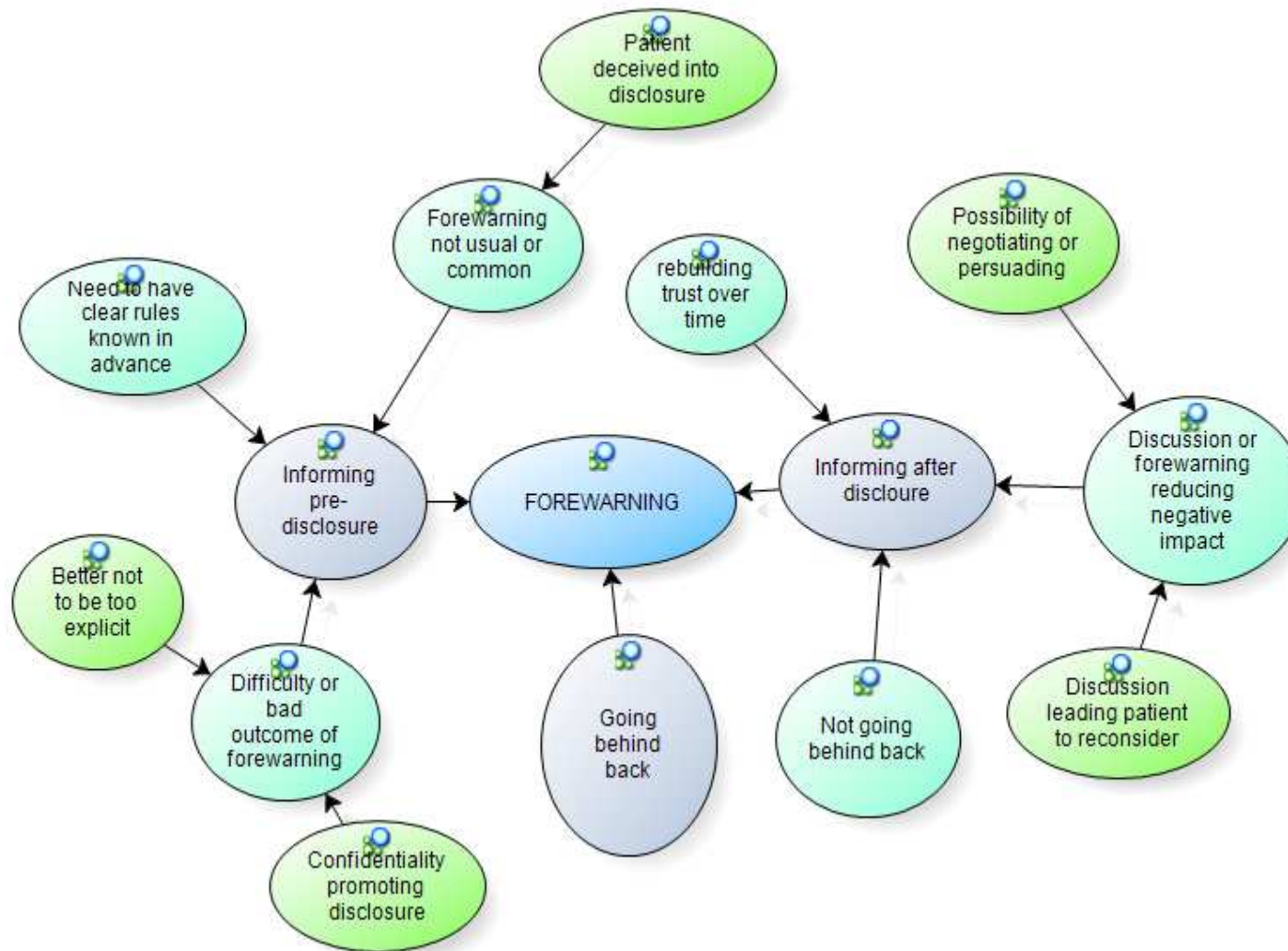


Figure 12: NVivo model for Forewarning

5.9.1 INFORMING PRE-DISCLOSURE

Within this theme subjects spoke about the possibility of patients being advised of the limits to confidentiality in advance. Most subjects were in favour of some sort of disclosure, and often saw this as promoting a positive relationship and dialogue between doctor and patient:

He could at that point, I suppose, in his role as the doctor say “you are under no obligation to answer the questions” in which case she would never have been put in the position of having confessed something that the doctor then has to carry on the process and tell the DVLA ... the doctor could have said to her “there is an issue concerning epilepsy, concerning the lack of medication and epilepsy and driving. There is an issue. We need to discuss this but some of your answers, I may have to relay some of your answers to the DVLA if you consent to discuss it with me”.

(Epilepsy subject; DRIVING scenario)

A common theme was subjects explicitly emphasising the importance of clear and explicit rules that were known and understood in advance. As well as empowering patients to take control of their situation this was also seen by some subjects as a safeguard against capricious or inconsistent reporting, or against unfairly punitive responses:

It would have to be known that he would have to tell her that he has to inform the DVLA. It would have to become part of the law rather than “Well, I think I better tell the DVLA”. She would have to know that’s what they were going to do.

(Epilepsy subject; DRIVING scenario)

I think it would be good for boundaries of the relationship to be described from the outset.

(Mental Health subject; THREATS scenario)

However this was not a universal view. Some subjects recognised difficulties that might arise from forewarning, particularly if this was too vivid or explicit. Subjects saw this as undermining trust in the doctor, and as deterring frank disclosure. For them, the patient’s autonomy was less important than the effectiveness of the medical care that could be provided:

*Well I think it would sort of weaken the relationship really.
(Epilepsy subject; THREATS scenario)*

*if as a result of that comment, that was put into practice and doctors suddenly became less approachable, less friendly, less confidential I suppose, it would be a sad day for society
(Epilepsy subject; DOMESTIC VIOLENCE scenario)*

Some subjects therefore concluded that explicit details about the limits to confidentiality might be harmful, and that it might be better for some of these details to remain concealed or unspoken:

*I don't think that would help in a way having things up [front]. If anything that probably makes it feel a bit worse because people know and then they've got it right in front of them in print. It makes it a bit scary.
(Epilepsy subject; DRIVING scenario)*

*If the rule was too black and white I don't think as many people would ask for help and at the end of the day I think patients have got to feel that's what doctors are for, asking for extra help and being given it really.
(Epilepsy subject; SEXUAL THOUGHTS scenario)*

Finally, whether supporting or doubting its value, some subjects commented on the lack of forewarning that they had experienced in practice. There was a common perception that these issues were not generally discussed with patients, and that many patients were unaware of the potential consequences of disclosing information to their doctors until after the event:

*(Interviewer: Do you think doctors [explain those limits] very often?)
Not in my experience no.
(Epilepsy subject; DRIVING scenario)*

Within this topic, some subjects explicitly commented that when forewarning did not take place, patients were effectively deceived into making disclosures that might then be used in ways contrary to their interest or intention. Subjects raising this generally saw this as dishonest and unethical; the contrary view, that such deception might serve a greater good in terms of risk management was not voiced:

the doctor should have pre-empted her answer by giving her the right question and not forcing her in a sense to give an answer which he was then bound to then tell the DVLA. In a sense it's a bit of a trick, because he's not giving her the chance to make the decision first.

(Epilepsy subject; DRIVING scenario)

what the GP didn't do I suppose, is like what happens when you are arrested on the street by a policeman. "Anything you say may be taken down in evidence against you". Because obviously the GP-patient relationship is about healing I suppose. ...Which is very difficult for people to suddenly realise that the doctor isn't only the kind, sympathetic, fatherly or motherly figure, that they actually have a hidden layer underneath.

(Epilepsy subject; DOMESTIC VIOLENCE scenario)

5.9.2 INFORMING AFTER DISCLOSURE

The possibility of informing the patient of the likelihood of reporting *after* some disclosure had been made was explored by most subjects, and generally this was seen in a positive way. Three sub-themes were identified: "not going behind back", being honest with the patient which was seen as ethical and as good practice, "rebuilding trust", where openness about reporting was seen as the first step in a process of rebuilding a positive relationship with the patient, and "reducing negative impact", where it was seen as a way of encouraging the patient to accept or understand the decision.

Being honest about the decision to report was generally supported, and was seen as something intrinsically desirable, distinct from any beneficial effect on the ongoing relationship:

they have to be honest with you so if they're going to inform DVLA, if they're going to inform police when you've asked them not to you have to know that they're going to do it

(Epilepsy subject; DOMESTIC VIOLENCE scenario)

Many subjects believed that informing the patient of the decision would help to reduce the negative impact, generally by helping the patient to understand the reason for it:

That would make it better if that was discussed with the doctor yes. ... At least he knows she's going to tell the police so he knows there could be a policeman. So that way he knows what's going to happen.

(Epilepsy subject; THREATS scenario)

I mean if you, whichever way you go you've got to tell the bloke that you're going to report it...I do not think that you should do it without telling the chap because that would immediately destroy any confidence that he had in the doctor at all.

(Epilepsy subject; SEXUAL THOUGHTS scenario)

For other subjects this was a way of raising the concerns with the patient, and leading them to reconsider or to persuade them to consent to reporting:

You know the patient still has a choice of - the doctor has shown them the different routes that they could take instead of saying, well no you're going to do that. It's up to them whether they want to choose it but at least they're now made aware of the different pathways that they could take.

(Epilepsy subject; THREATS scenario)

It might work to say "look you really need to try and get this under control because otherwise the police may have to get involved and so on". I don't know. It may sort of kind of get him sort of calmer if he realises the possible ramifications of it.

(Epilepsy subject; THREATS scenario)

Finally, some subjects accepted that patients would be unhappy with the decision to report, but felt that while discussion might not change that initially, it could be the first stage in a longer-term rebuilding of trust with the doctor:

if he understood what was going on, so that you understood you weren't just doing it for his benefit but you were doing it for everybody else's as well then he might feel a bit safer. He might not feel as angry and resentful at accepting any further treatment from you

(Epilepsy subject; THREATS scenario)

I would say the majority of people want to know, they want to know things and the worst thing about communication is when people don't tell the truth or they tell half the truth but to be honest and upfront, the majority of people, vast majority of people will go with that. It's like a two-way thing, so in a therapeutic relationship, that would have been built up anyway, hopefully.

(Mental Health subject; THREATS scenario)

5.9.3 GOING BEHIND BACK

Most subjects were clear in the view that the patient should at least be aware that the doctor would make a report, but not everyone was confident that this would always be the case. A few considered that this might be difficult to do, or exacerbate tensions between doctor and patient. Particularly in the THREATS scenario there was also a concern that his might increase the risk of violence from the patient. These subjects accepted that there may be situations in which a report might be made without the patient's knowledge, though they were not always comfortable or in agreement with this:

[I] said in previous cases that the patient must know as he leaves the room what's going to happen, but I can see there may be difficulties in delivering that situation: "you know what I've got to do now" is quite a difficult thing for the psychiatrist to say.

(Epilepsy subject; THREATS scenario)

What I'm not clear about is if the doctor were to do that whether he would say that he were going to do it. Whether it's something that he can just do without actually informing the patient. I certainly wouldn't be happy with it if it were done without my knowledge.

(Epilepsy subject; DRIVING scenario)

5.10 GROUP DIFFERENCES

5.10.1 SUBJECT GROUPS

Although the utilitarian argument for confidentiality assumes that an objective assessment of the calculus is possible, it is likely that individuals' views of the risks and benefits involved will be different when they perceive themselves as directly involved in the situation. This study deliberately presented subjects with dilemmas relevant to their own health problems, with the intention of exploring whether the two groups reached different conclusions.

Table 4 presents the proportion of subjects in each group (Mental Health and Epilepsy) who made statements coded at some of the most important nodes while discussing each of the four scenarios. Because of the small sample size and the qualitative study design no claims are made for the statistical significance of any differences, but those cases in which the larger proportion is more than twice the smaller are highlighted. Because of the risk of finding chance differences resulting from multiple comparisons, it is also suggested that these differences should be given more weight if they appear to form part of a coherent pattern, and less weight if they are isolated or contradictory findings.

Considering the responses to all four scenarios combined there were few differences between the Epilepsy subjects and the Mental Health subjects in the proportion of subjects making reference to central concepts such as support for reporting or confidentiality, recognition of deterrence, or confidentiality concern (see Table 4). Epilepsy subjects made comments suggesting a low level of perceived risk almost twice as often as the Mental Health subjects, although comments indicating high risk were recorded at very similar levels in the two groups.

	ALL		DOMESTIC VIOLENCE		DRIVING		THREATS		SEXUAL THOUGHTS	
SUBJECTS	Mental Health (n=21)	Epilepsy (n=17)	Mental Health	Epilepsy	Mental Health	Epilepsy	Mental Health	Epilepsy	Mental Health	Epilepsy
Confidentiality valued or important	81	82	29	47	5	35	29	18	24	24
Confidentiality not that important	19	29	0	0	0	6	5	12	0	0
Support for reporting	100	94	67	53	81	65	71	88	62	65
Support for not reporting	81	82	29	59	5	47	43	18	52	47
Deterrence unlikely	86	76	38	29	52	41	71	47	24	24
Anticipatory deterrence	86	100	62	59	43	88	71	24	67	82
Consequential deterrence	95	100	86	47	71	76	81	47	62	47
Confidentiality concern High	67	53	5	29	0	29	29	12	14	18
Confidentiality concern Low	33	41	5	0	5	6	14	18	10	0
Risk Perception High	95	88	19	29	76	12	38	59	24	18
Risk perception Low	24	47	0	12	19	12	0	0	14	35

Table 4: Subjects (%) in each group coding at specific nodes

Within individual scenarios, most of the cases in which they two groups differed were in the two “relevant” scenarios. Within the two “neutral” scenarios, Epilepsy subjects more frequently expressed higher levels of concern about confidentiality and support for not reporting than Mental Health subjects in the DOMESTIC VIOLENCE scenario, and more commonly perceived risks to be low in the SEXUAL THOUGHTS scenario.

The picture is different in the “relevant” scenarios. Within the DRIVING scenario Epilepsy subjects were more frequently recorded at nodes reflecting concern for confidentiality, valuing confidentiality, recognition of anticipatory deterrence, and support for maintaining confidentiality, and were less frequently coded as perceiving the risk to be high. These differences consistently suggest that Epilepsy subjects had more concern for confidentiality, and lower perception of risk in this scenario.

Conversely, in the THREATS scenario, Mental Health subjects expressed more concern for confidentiality, were more likely to recognise anticipatory deterrence, and were more likely to support maintaining confidentiality. Epilepsy subjects were more likely to consider confidentiality relatively unimportant, though support for this view was generally low in both groups.

Taken together, the results for the two “relevant” scenarios support the prediction that subjects are more concerned about confidentiality in a scenario relevant to their own situation, and this conclusion is more convincing because of the lack of evidence of systematic differences between the two groups overall, or in the two neutral scenarios.

Group differences with respect to deterrence are complex. In the “neutral” scenarios both groups raised issues of anticipatory deterrence and of consequential deterrence at about the same frequency. In both of the “relevant” scenarios, the subjects directly affected were more likely to recognise anticipatory deterrence than non-affected subjects were, but both groups recognised consequential deterrence at similar frequencies.

5.10.2 AGE GROUPS

No clear differences were found in the patterns of coding between the different age groups. Table 5 shows the percentage of subjects within each age group with any content coding for the same nodes reviewed above. Because of the small numbers in some groups figures for individual scenarios are not given.

AGE GROUP	18-30 (n=6)	31-45 (n=11)	46-60 (n=17)	>60 (n=4)
Confidentiality valued or important	83	82	76	75
Confidentiality not that important	17	18	29	0
Support for reporting	100	100	88	100
Support for not reporting, maintain confidentiality	83	91	76	50
Deterrence unlikely	83	64	82	100
Anticipatory deterrence	83	91	94	75
Consequential deterrence	100	100	88	100
Confidentiality concern High	50	64	53	100
Confidentiality concern Low	50	27	35	25
Risk Perception High	83	91	94	75
Risk perception Low	33	27	29	50

Table 5: Subjects (%) in each age group coding at specific nodes

5.10.3 GENDER DIFFERENCES

Previous studies have not explored gender differences in attitudes to confidentiality. Table 6 shows the coding pattern divided by gender: few large discrepancies are seen, and there is

no strong pattern to those that are. One potentially interesting difference is that female subjects were more likely to support maintaining confidentiality in the DOMESTIC VIOLENCE scenario, and it is possible that this reflects either the experience of some female subjects as victims of domestic violence, or a greater propensity to identify with the patient in the scenario and to see themselves as potential victims. If so, this would be congruent with previous findings that victims of domestic violence are less likely to support mandatory reporting than non-victims. However the evidence here is weak: corresponding differences in other related nodes are not seen, and no data was collected on how many, if any, female subjects had experienced domestic violence. It is also recognised that men are victims of domestic violence, so gender may be only weakly related to such experience.

SCENARIO	ALL		DV		EP		MH		SX	
	M (n=23)	F (n=15)	M	F	M	F	M	F	M	F
Confidentiality valued or important	78	87	35	40	17	20	17	33	26	20
Confidentiality not that important	22	27	0	0	4	0	13	0	0	0
Support for reporting	96	100	57	67	70	80	74	87	57	73
Support for not reporting, maintain confidentiality	83	80	30	60	22	27	30	33	61	33
Deterrence unlikely	78	87	35	33	39	60	48	80	17	33
Anticipatory deterrence	87	100	57	67	61	67	39	67	74	73
Consequential deterrence	100	93	65	73	74	73	65	67	70	33
Confidentiality concern High	70	47	13	20	17	7	26	13	22	7
Confidentiality concern Low	39	33	4	0	9	0	26	0	0	13
Risk Perception High	87	100	26	20	65	87	35	67	17	27
Risk perception Low	39	27	9	0	17	13	0	0	26	20

Highlighted cells indicate difference >2x

Table 6: Subjects (%) by gender coding at specific nodes

5.10.4 CONFIDENTIALITY AND MENTAL HEALTH

Mechanic (2000) found that mental health patients had higher levels of concern for confidentiality than patients with long-term physical health conditions, and many authors have taken the view that confidentiality is particularly important in mental health practice: as Beigler (1984) expressed it, *“as asepsis is to surgery, so confidentiality is to psychiatry”*.

Results from this study do not confirm that view. In overall support for reporting, described in Section 5.2, Mental Health subjects were more likely to support reporting than Epilepsy subjects across all four scenarios. The data in Table 7 do not show any consistent differences between the two groups. Where differences do occur in the “neutral” scenarios” it is the Epilepsy subjects with greater concern for confidentiality and less concern for risk. Mental Health subjects did express more concern for confidentiality than Epilepsy subjects in the THREATS scenario, but they were still more likely to support reporting (71%:63% - see Table 2). This does not exclude the possibility that some subgroup of mental health patients might have greater concerns, perhaps among patients who were not accessed by this study, and further work may reconcile previous findings with the apparently contradictory results here.

5.11 ADDRESSING THE STUDY QUESTIONS

The results above describe some of the central issues raised by subjects in response to the scenarios, and represent a first step towards identifying the underlying concerns that may shape those responses. How do they relate to the Research Questions posed in Section 3.2?

5.11.1 VALUE OF CONFIDENTIALITY

Data from this study supports the pre-existing view that patients value medical confidentiality. **Confidentiality valued or important** was coded 82 times, reflecting comments by 31 of the 38 subjects. **Confidentiality promoting disclosure** was also frequently coded (17 subjects), and many subjects articulated very strong endorsement of confidentiality. Conversely, **Confidentiality not that important** was reflected in only 9 of the interviews. Whereas **Confidentiality valued or important** was often mentioned repeatedly (82 references by the 31 subjects who raised this), **Confidentiality not that important** tended to be mentioned in isolation, with only 11 references to it coming from the 9 subjects who mentioned it all. 7 of those 9 also made comments supporting the value of confidentiality, so that clear and unambiguous rejection of confidentiality was very unusual.

Previous findings that mental health patients are more concerned about confidentiality than others were not replicated in this study. 14 out of 17 Epilepsy subjects (82%) and 17 out of 21 Mental Health subjects (81%) made comments reflecting **Confidentiality valued or important**, and subjects from both groups expressed this view strongly. The strength of feeling varied between subjects, but there was no evidence of a systematic difference between the two groups.

5.11.2 RECOGNITION OF DETERRENCE

Eight nodes directly related to subjects' recognition of deterrence and its consequences. The two central concepts, **Anticipatory Deterrence** and **Consequential Deterrence** occurred in 35 and 37 of the 38 interviews respectively, with 168 and 211 individual references. Other related nodes also occurred frequently: **Deterrence impairing treatment**, **Risk of alienation from doctor** and **Deterrence increasing risk** all occurred in more than 30 interviews, **Risk less managed if trust lost** in 23 and **Risk of deterrence as reason for not reporting** in 19. Seven subjects gave a **Direct example of real-life deterrence**, even though these were not directly sought. In total 795 references to nodes related to deterrence were recorded, and every subject made some reference to the concept.

Comments rejecting the possibility of deterrence were correspondingly uncommon. Although **Deterrence unlikely** was a commonly referenced node (112 references from 31 subjects), this typically related to subjects who recognised the possibility of deterrence but felt it would occur in only a minority of cases, rather than to comments doubting the existence of deterrence at all. Similarly, references to **Anticipatory deterrence unlikely** (31 references from 18 subjects) were more likely to be expressed in terms of many patients not considering the possibility of confidentiality being breached, and therefore not being deterred from treatment until after the fact, rather than a view that patients would tolerate breach.

Few subjects saw breach of confidentiality in a positive light. Four subjects (seven references) suggested that patients would not hold the doctor responsible for actions taken by other agencies such as the Police or DVLA, and seven (10 references) described the act of reporting as being helpful or caring towards the patient. More commonly subjects believed that patients would come to accept the situation in the future (19 subjects, 38 references), particularly in the THREATS scenario if the patient's mental state improved, or saw trust as something that could be re-established over time (6 subjects, 10 references).

5.11.3 BALANCING CONFLICTS OF INTEREST

The scenarios were used as starting points from which the dilemmas could be explored. It was not always possible to determine how subjects approached this: some subjects focussed on the specific details in a vignette, and were reluctant to explore hypothetical variations; others immediately expressed such a firm opinion about the correct response that the process leading to a decision remained hidden. However many factors taken into account by subjects did emerge during the discussion.

The difficulty of the decision was frequently referred to. 31 subjects (77 references) discussed this directly, 29 (64 references) expressed ambivalence or uncertainty about the best course of action and 24 subjects (62 references) recognised that the correct decision would vary, contingent upon details of an individual case. Even where subjects expressed a clear view about the correct decision, few took the view that this was inevitable with no room for debate.

A small number of subjects made reference to the utilitarian balancing of costs and benefits, but for most this was implicit rather than explicit. Even so most subjects did seem to reach a decision based on some form of utilitarian calculus. Two exceptions to this were noted: subjects for whom patient autonomy was a major concern took a more deontological approach, seeing confidentiality as a right rather than as a strategy to promote good outcomes, and some subjects considered it better to defer to legal or other rules of conduct rather than to attempt to solve the dilemma themselves.

Two subjects rejected the idea of an objective utilitarian calculus, seeing the decision as a subjective one based in a specific set of circumstances, from which attempts to generalise would be unhelpful, and four subjects, while accepting the idea of a calculus in principle, felt that the consequences of any course of action were too hard in practice to predict (particularly in relation to longer-term anticipatory deterrence), and fell back on a narrower consideration of the immediate situation. However, most subjects accepted that longer-term consequences were a valid part of the decision-making process.

5.11.4 FEATURES DETERMINING DECISION

Although every subject's decision-making process was different, a small number of common factors appeared repeatedly throughout the interviews. As intended, the most significant factor considered was the risk to others: the **importance of preventing harm** was the most common justification for reporting (35 subjects and 127 references), and several other frequently coded nodes related to this. Risk could also be seen as a reason for maintaining confidentiality: **Report increasing risk** (26 subjects, 48 references) and **Treatment reducing risk** (24 subjects, 36 references) were frequently coded justifications for not reporting. A common view was that degree of risk (a combination of both severity and likelihood of harm) was a determining feature, often expressed in terms of "crossing a line" or the decision depending on some form of risk assessment.

Although subjects often addressed the issue of engagement with treatment (for example, the patient's active request for treatment in the SEXUAL THOUGHTS scenario, compared with the rejection of treatment in the THREATS scenario), this was generally presented as something which modified the risk rather than as a reason for or against reporting in itself.

Another commonly raised issue was the patient's right to confidentiality, generally expressed in terms of autonomy or the patient having control over the decision. This was most commonly raised in the DOMESTIC VIOLENCE scenario, reflecting the fact that the patient herself was primarily at risk, but it was also raised in the DRIVING scenario and, less frequently, in the other two.

Two patient characteristics emerged as important to the decision-making process. A perception that the patient was at fault, either deliberately or recklessly, led subjects to consider that their right to confidentiality was reduced accordingly, and in the THREATS scenario a view that the patient was irrational also encouraged subjects to support breach of confidentiality. This was not just a judgement of the patient's entitlement: an irrational patient or one rejecting medical advice was seen as representing a risk that could not be mitigated by treatment, thus undermining the utilitarian benefit of the doctor-patient relationship.

5.11.5 ROLE OF DETERRENCE IN DECISION-MAKING

Although, as discussed below, subjects recognised the possibility of deterrence, it was not generally something which they described as a major factor in determining whether or not to support reporting. Subjects (the majority) who recognised deterrence but also supported reporting tended to see any resulting impairment to treatment as unfortunate, but not as changing the decision primarily based on perceived level of risk. Even where subjects accepted that deterrence might increase risk, either immediately or in the long term, this did not appear to be a major consideration that would support maintaining confidentiality, and where support was expressed for maintaining confidentiality, deterrence was not commonly mentioned as a reason for this.

5.11.6 LIKELIHOOD OF DETERRENCE

Finally, but crucially for the utilitarian calculus, do the results allow any estimation to be made of the frequency with which deterrence might occur? There are some conflicting data to be considered.

Most importantly, 6 out of the 38% subjects reported that they had already concealed information from doctors because of concerns about confidentiality, a figure broadly in line with other studies. This is likely to underestimate the true rate of existing deterrence for several reasons: subjects were not directly asked about their own history, and were discouraged from volunteering such information; some patients would be reluctant to admit non-compliant behaviour in the research interview (similarly to the various “distancing” statements described above), and patients most deterred from treatment would be underrepresented in the study population. It seems credible that some instances of deterrence would be unreported, but not that such an account would have been fabricated, so the reported frequency must be considered to be a lower bound on any estimation of past deterrence.

Almost all subjects recognised the possibility that some patients would be deterred from treatment by breach of confidentiality: 35 subjects referred to the possibility of anticipatory deterrence, and 37 to that of consequential deterrence. Generally deterrence was seen as something that would apply to only a small number of patients, and although subjects were not asked to quantify this (and there is anyway no convincing reason to believe that subjects' predictions of the behaviour of others would be particularly accurate), the impression was that this was seen as exceptional rather than common, and would probably be less than the 1 in 6 figure obtained above. The main exception to this was in the SEXUAL THOUGHTS scenario, where subjects were more likely to see deterrence, particularly anticipatory deterrence, as a probable consequence of reduced confidentiality. In other scenarios the patient described was perceived as being unusual, or the need to obtain medical care was seen as likely to override any concerns that a patient may have so that, even if they were unhappy about a breach of confidentiality, treatment would be likely to continue.

6 DISCUSSION

6.1 NEGOTIATING CONFIDENTIALTY

It is clear from this study that confidentiality will remain a vital component of interactions between doctors and patients. It is also clear that neither complete and unconditional confidentiality, nor unfettered sharing of medical information, would be accepted by patients or the public. There is therefore a need to discuss, negotiate, and agree rules that are acceptable. While deontological considerations will play a part, utilitarian considerations will remain central in doing so.

Such discussions will take place partly at the level of public policy, and subjects have acknowledged the role played by legal and professional rules, and recognised their validity. However, much will remain to be negotiated between individual clinicians and patients, and subjects also accepted the need for individual discretion and judgement. Even where explicit rules are followed without discretion, many of the consequences of maintaining or, more importantly, of breaching confidentiality will depend on the interpersonal dynamics between the individuals concerned. There is consistent evidence from this study that both the quality of the pre-existing doctor-patient relationship and the way in which breaches of confidentiality are handled will be important determinants of the outcome.

We can identify four phases in the negotiation of confidentiality: setting explicit rules in advance, responding to a specific disclosure, the process of breaching confidentiality, and subsequently rebuilding trust. In each of these phases wider aspects of the doctor-patient relationship will modify the processes, which will, for example, be very different for a family GP with years of familiarity with a patient and a junior doctor in Casualty having a first encounter with a patient. Similarly, the negotiation of confidentiality will be only one component contributing to the continuing development of that relationship, but in at least some cases it will be a vital determinant of gaining, keeping, or losing the trust of the patient.

6.1.1 RULES IN ADVANCE

As described in Section 5.9.1 subjects generally supported the idea of explicit limits to confidentiality being known in advance. The main concern was that breach of confidentiality should not come as a surprise: many subjects saw unexpected breaches as unfair, and some went further, seeing it as dishonest or deceitful, a view also expressed by writers in the field (Herbert, 2002):

To allow [patients] to continue believing their information is secret when it is not is shortsighted and paternalistic. (Jenkins et al., 2005)

To use a promise of confidentiality to secure otherwise inaccessible information when it is known that such a promise may never be kept, is manifestly contrary to notions of fairness. (Lee, 1994)

While there were concerns that emphasising limits might weaken the relationship, others thought that openness about limits that were known to exist could actually increase trust. However there was recognition that if warnings were too explicit or detailed the negative effects may outweigh the positive; some subjects specifically felt that written information would be more intimidating than a discussion, and one subject commented that there is less value if the process is too automatic with little explanation:

*'Cos they make you sign all this Data Protection Act and I'm still not exactly sure who they can tell and who they can't.
(Mental Health subject: Final reflections)*

We might conclude that forewarning about limits to confidentiality would generally be welcomed, but that it should be part of the ongoing development of the therapeutic relationship, rather than something separate. It should be explained in terms emphasising the continuing commitment to patient interests as well as public safety, rather than seeing disclosure as a separate, non-clinical, policing role, and made explicit that any decision to disclose will take into account the patient's interest as well as those of others. It is still likely that some patients will be deterred from disclosing some information, but the overall effect is probably small. Patients who are seriously concerned about this issue are likely already to

be aware of the possibility of reporting so an explicit warning may have little effect on their behaviour.

Some authors have suggested that a legal-style caution should be given, along the lines of “anything you say will be taken down and may be used in evidence against you” (Fleming & Maximov, 1974). While that seems extreme in a clinical context, arguably more subtle wording may convey a less accurate message. Given the strong cultural belief in “absolute” medical confidentiality, a warning which stresses the confidentiality of the relationship, and the rarity of breach, though more reassuring, may be misperceived by some patients as promising greater confidentiality than can actually be offered. Such warnings may enhance the doctor-patient relationship in the short term, but lead to a greater sense of betrayal, and greater damage to the relationship, if confidentiality is breached (Smith-Bell & Winslade, 1995).

Given the long-term nature of many doctor-patient relationships another question arises: how should a doctor respond if a patient begins to disclose risk-related information, given that limits to confidentiality may have been discussed months or years before? If it is right to give warnings at all, whether for deontological or utilitarian reasons, it must surely be right to remind the patient at the point that it becomes relevant, or else the risk of the doctor being seen as deceptive would be unavoidable. While there is clearly a risk of deterrence at this point, it also gives the possibility of exploring the risk issues, and of encouraging the patient to reconsider:

So then the person has the choice of whether they want to do it or ask the doctor to do it for them or whatever the case may be. You know the patient still has a choice ... It's up to them whether they want to choose it but at least they're now made aware of the different pathways that they could take.

(Epilepsy subject; THREATS scenario)

Boundary setting during an ongoing clinical relationship poses particular problems. Doctors are in the position of trying to anticipate when a damaging disclosure is approaching, and may give warnings when no disclosure would have taken place, or miss the signs and find an unanticipated disclosure has already occurred. Timing is difficult to judge: too soon may appear inappropriate or intrusive, too late may be ineffective. However a timely and well

judged warning may limit deterrence, by clearly identifying the issue that may give rise to reporting, and by demonstrating the doctor's trustworthiness and concern for the patient's interests.

Effective forewarning, while good for patient autonomy, may discourage patients from disclosing, and indeed may be seen as having that intention. It is therefore potentially very bad for risk management, promoting a "Don't ask, Don't tell" culture in which patients are actively discouraged from divulging information relating to risk. This point underlies many of the concerns expressed by Bollas & Sundelson (1995) and by Kipnis (2006), who argued that reporting without consent is likely to result in vital information being concealed.

6.1.2 RESPONDING TO DISCLOSURE

Once a disclosure has been made, the way in which this is handled by the doctor becomes crucially important. Subjects seem clear on three issues. Firstly, there are strong feelings that any decision about reporting should be discussed with the patient, and opposition to any suggestion of "going behind the patient's back" – something which is specifically encouraged in some official guidance (Home Office, 2004). The only exceptions to this arose in the THREATS scenario where reluctance to propose such a discussion related to fears of an irrational or unpredictable response from the patient, rather than to any suggestion that discussion was wrong in principle. Secondly, subjects were opposed to mandatory reporting, and supported the concept of doctors, in discussion with patients, undertaking a utilitarian calculus of risks and benefits and reaching a decision based on the specific facts of the case. In neither the DRIVING nor SEXUAL THOUGHTS scenarios would the wording of current guidance (Department for Children Schools and Families, 2010; Drivers Medical Group, 2010) be supported. Indeed, the SEXUAL THOUGHTS scenario was the one in which subjects were least likely to support reporting. Thirdly, there was clear recognition that reporting was only justified if it would lead to a reduction in risk, and the need to judge the potential benefits is one reason why automatic reporting was often rejected.

There was a common view that discussion of the issues might lead a patient to reconsider their position, perhaps by reducing the risk, or alternatively by agreeing to reporting of information. Subjects were more likely to see this as a process rather than a one-off event, possibly happening over a number of consultations and an extended period of time, which also supports the view that reporting should not be automatic.

6.1.3 BREACHING CONFIDENTIALITY

If a decision is made to breach confidentiality there are still decisions to be made, and to be negotiated, about how it is done. The options available, and the pros and cons of each, are likely to vary considerably. Subjects in this study had divergent views, so this is an area in which individual discussion will be vital. Issues to be considered include the difference between informal reporting (for example to family members) and to official agencies, reporting which is seen as helpful compared to that perceived as punitive or controlling, and the potential consequences of breach for the patient.

It is important to recognise that patients are willing to disclose information to doctors that they would not disclose to other agencies (police, social services), and to understand why this is. Evidence from this study suggests two reasons: subjects believed that doctors would maintain concern for patients' interests, even while undertaking a wider utilitarian calculus, and also trusted doctors to use discretion and judgement wisely (see Section 5.7.2). While subjects will tolerate breach of confidentiality, if this is not done in ways that justify their trust then deterrence becomes more likely:

clients come to counselors for help with troubling issues, not to be turned over to health officials. When considering breaching a client's confidentiality, counselors should consider why they are privileged to hear the information in the first place. (Kain, 1988)

A few subjects recognised that once a report had been made, the doctor would not be in control of the subsequent response (see Section 5.5.6), but others felt it important that doctors obtained some form of undertaking about how the information might be used. While this may be naïve, it emphasises that even if an unwanted breach of confidentiality is

made, one reason patients are willing to disclose to doctors rather than to other people is that they expect doctors, more than other agencies, to be mindful of their interests:

I mean they go to see doctors for many reasons and I think one of the reasons is because they are one of the few people in society that hopefully one can think of positively in a reassuring way.

(Epilepsy subject; THREATS scenario)

if they've all got the right attitude towards it and have their patients' best wishes at heart then they would know what needs to be shared and what doesn't in a medical aspect from the file. And then patients in that situation won't mind things being shared with the right people if it's going to benefit them in the long run.

(Epilepsy subject; Final reflections)

One concern discussed in guidelines and the literature is the further dissemination of information once a report is made (Department of Health, 1996, 2003). Although assurances may be obtained about the way in which information is handled, the doctor has no direct control over this (Eastman, 1987). In this study many subjects seem to accept reporting, but still expect doctors to safeguard patients' interest, suggesting that they would expect doctors to have ongoing concern for the handling of information. If doctors are able to satisfy these expectations this may be a powerful way of maintaining trust following a breach of confidence: conversely, if doctors are not able to do this (as seems likely), patients may see this as a further betrayal that might damage trust more than the original disclosure did.

One issue often raised in professional guidelines and ethical discussions, but rarely mentioned by subjects in this study, is the importance of limiting any disclosure to information which is necessary to achieve the utilitarian goals which justify the breach (Department of Health, 1996; Confidentiality and Security Advisory Group for Scotland, 2002; Department of Health, 2003; Fleetwood, 2006). This may be because in the vignettes presented to subjects there was specific information that was the subject of the decision to report or not, and it may have been implicitly understood that other information would not be shared. Intuitively it seems that patients would object more to release of large amounts of information, irrelevant to the aims of reporting, than to more limited reporting, but this may not be so. If the doctor decides to reveal the critical information, detrimental to the

patient's interests, it may be little or no consolation that other, less sensitive, information remains confidential.

6.1.4 REBUILDING TRUST

Subjects clearly recognised that a breach of confidentiality might change the dynamics of the relationship between doctor and patient, but would be unlikely to terminate it completely. The ongoing management of that relationship is therefore important to both parties. The perception of subjects in this study was that regaining trust would take from “a little time”, “a couple of months” to “many years”, but that “in the end”, “eventually” or “after a while” the relationship could be rebuilt: however there were few indications as to how that would best be facilitated.

As described in Section 5.5.5, some subjects took the view that a breach of confidentiality would not necessarily damage the relationship. These comments seem to support the findings of Mechanic & Meyer (2000), that trust in doctors is a wider concept than confidentiality, and that if patients have that trust, they may be willing for rules to be relaxed:

Mm I would say from the doctor's aspect if they've all got the right attitude towards it and have their patients' best wishes at heart then they would know what needs to be shared and what doesn't in a medical aspect from the file.

(Epilepsy subject; Final reflections)

I mean if the doctor was open with him from the start and saying that certain information might need to be shared, not in the public arena but with professionals, the patient is already trusting the doctor that they're going to make the right call on them so just widening it out a bit to whether they share it with other people or not for their benefit I'm sure would be quite positive.

(Epilepsy subject; THREATS scenario)

6.2 TOWARDS AN INTEGRATED MODEL

Decisions about maintaining or breaching confidentiality are complex. Not only are there conflicting considerations to be balanced, and uncertainties in both the current situation and the future consequences to be estimated, but there remain fundamental questions on which, even given complete information, people would in good faith fundamentally disagree. This ultimately is the weakness of the utilitarian calculus: even if all of the competing interests could be precisely and accurately measured and balanced each against the other, different individuals would ascribe different values and different weights to the outcomes, and so reach different conclusions.

We can however look for more general agreement in two domains. Firstly, it seems likely that most people, possibly everyone, could agree on the issues or factors that need to be taken into account, even while disagreeing profoundly on how those variables should be combined to reach a decision. Secondly, we may be able to determine the dimensions along which individuals vary in their approach to these issues, in order to understand why such different conclusions are reached. While it would be naïve to assume that such understanding could lead to a resolution of the differences, it may at least be possible to construct the terms of the debate such that useful discussion can take place. More optimistically, it may be possible to construct a broader integrated model which would allow conflicting positions to be reconciled.

In order to decide whether a doctor should breach confidentiality in a given situation or not, we have to balance two aims: the wish to protect the public from harm, and the wish to protect confidentiality. The relative weight given to these two aims will determine the decision reached.

6.2.1 PROTECTING THE PUBLIC

The dominating factor in most subjects' deliberations appears to be the degree of risk. Different subjects have different perceptions of the degree of risk in a given scenario, but all

seem to accept that, if the risks are high, breaching confidentiality is justified. Although the way in which they estimate risk is likely to vary, once that assessment has been made there is general agreement that high levels of risk can justify breach of confidentiality.

The weight given to public protection will be increased if the level of risk is perceived to be high, and if reporting is considered to be effective in reducing risk. The underlying perception of risk is determined by many factors, but one particularly relevant to this discussion is whether or not continuing with (confidential) treatment is seen as a way of reducing risk: if it is, then this will count against reporting. A patient's cooperation with treatment and the availability of therapeutic options are factors which increases the perception of treatment as effective.

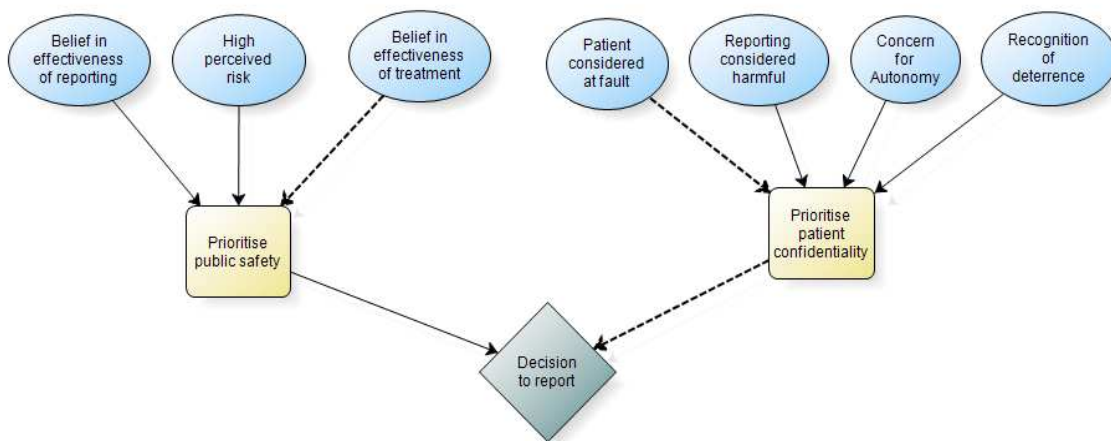
6.2.2 CONFIDENTIALITY

The second major issue determining choice of action is the perceived value, or lack of it, of confidentiality. Confidentiality will be valued where it is seen as necessary to providing effective treatment, and by those who value patient autonomy. It will also be considered more important in circumstances where the patient is likely to suffer harm as a consequence of breach, and correspondingly less important if steps can be taken to minimise such harm. Subjects in this study gave less weight to confidentiality in circumstances where the patient was considered culpable or at fault, for example by refusing to cooperate or comply with advice. If deterrence is perceived is a real possibility, this is also a reason for giving more weight to the importance of maintaining confidentiality.

6.2.3 A POSSIBLE MODEL

The factors outlined have been combined into a possible model (Figure 13). The two major variables, concern for public protection and concern for confidentiality are determined, in this model, by a person's perception of seven other factors:

- The level of risk
- The effectiveness of reporting
- The effectiveness of treatment
- The patient’s culpability for the risk
- The harm to the patient resulting from breach
- The importance of autonomy
- The likelihood of deterrence



Solid line: increases or makes more likely
 Broken line: reduces or makes less likely

Figure 13: Summary model

6.3 ARCHETYPAL POSITIONS AND APPROACHES

Based on the factors proposed above, we might tentatively identify discrete approaches to the sort of confidentiality dilemmas explored in this thesis. These may reflect the cultural cognitions discussed in Section 2.7.2, for example, a strongly hierarchical individual may be more concerned about risks posed by a patient who rejects medical advice; a strongly communitarian person will be concerned about actions which are seen as selfish; a strongly individualistic person will prioritise autonomy over other considerations. Even where people with different cultural positions reach the same conclusion, they will justify this in different ways, congruent with their underlying positions.

We would expect that those positions will be consistent between scenarios for a given subject, even where different decisions are reached – in other words the reasoning underlying decisions will be consistent, even though the facts of a scenario may lead to different conclusions, and this seems to be the case for many subjects in this study.

Whether or not these factors map neatly onto Cultural Cognition groupings (which is a possible avenue for future investigation), this suggests that there are certain positions which people might take on these issues, which are internally consistent, but which will lead them to different conclusions from the utilitarian calculus. Examples of these positions can be seen within the subjects of this study.

6.3.1 RISK AVERSE

Subjects varied in their sensitivity to risk. Some subjects perceived the risks in all scenarios to be high, and 9 of the 38 subjects supported reporting in all four scenarios. These subjects were typically highly concerned about risk, and believed that reporting was an effective way of reducing risk. Patient interests were a secondary consideration, and the benefits of reporting were seen as outweighing any positive negative effects:

it's not just an issue for her, you know it's other people's safety, so I completely agree that he should do the right thing and pass it all on and everything.

(Epilepsy subject; DRIVING scenario)

He's working with people's children and I think he should be reported yeh....Because he could do anything at any time couldn't he?

(Epilepsy subject; SEXUAL THOUGHTS scenario)

If these subjects considered deterrence, it was discounted either as being unlikely or remote, or as applying only to irresponsible people who were less deserving of confidentiality anyway. The potential harm caused to the patient by breach was minimised, or considered less important than the risk to others, and autonomy valued only to the extent it does not compromise the rights of others. This group appears close to Kahan's description of Communitarians, prioritising public welfare over individual interests.

6.3.2 TRUST THE EXPERT

Another common response was for subjects to defer to authority, often in the form of trusting the doctor to make the best decision in any given case, but also evidenced by subjects who would rely on external expertise:

Yeh I'm sure the police will make the right decisions and doctors will all make the right decisions...They'll all be fair on his well-being like I said. The police will only get involved if they need to and the doctors don't have to tell the police everything, do they?

(Epilepsy subject; THREATS scenario)

I would say from the doctor's aspect if they've all got the right attitude towards it and have their patients' best wishes at heart then they would know what needs to be shared and what doesn't.

(Epilepsy subject; Final reflections)

Importantly, this includes views expressed both by subjects who supported breach of confidentiality and by others who supported maintaining confidentiality. The key similarity is that they were willing to defer to an "expert" decision-maker. There were also subjects who wanted clear-cut rules to be in place and to be followed, to reduce variability between

individual doctors, but who still trusted in an authority (Parliament, the GMC, the courts) to decide appropriate rules.

These subjects tended to have lower perception of risk, and would be willing to see confidentiality maintained if that was the expert view. They had positive expectations of the effectiveness of both treatment and of reporting, in appropriate circumstances, congruent with their view that established structures are trustworthy. Issues of autonomy and culpability are less crucial for this group, and they may have less perception of deterrence, because they consider that patients should be willing to follow whatever rules are in place. Subjects in this group have much in common with Hierarchists within Kahan's model, deferring to social norms and trusting authority to be benign and competent.

6.3.3 PATIENT CENTRED

A smaller group of subjects argued for greater respect for confidentiality based on patient autonomy:

*But she should inform the DVLA, not the doctor, that's up to the patient...
The doctor's told her or advised her ...The doctor can only strongly advise
(Epilepsy subject; DRIVING scenario)*

*I have always assumed that I was speaking to a doctor on the basis of
privilege and rather like the monarch the doctor is there to "persuade and
advise" rather than to actually intervene and govern the situation ... one
needs confidence in confidentiality if you like in that situation.
(Epilepsy subject; DRIVING scenario)*

For this group autonomy was key, and they had higher concerns than others about the negative effects of breach for the patient. They were likely to see continuing treatment as more effective than reporting in reducing risk, and be concerned about the consequences of deterrence. They were also likely to perceive risk as lower than other subjects, and to pay less attention to information suggesting the patient is at fault, although for some giving the patient the right to decide also entails holding them responsible for subsequent harm. This

group looks much like Kahan's Individualists, and provides perhaps the best fit to cultural cognition theory.

6.3.4 A THEORY OF CONFIDENTIALITY DECISIONS

Combining the characteristic positions described above with the factors proposed in Section 6.2.3 leads to a tentative theory of confidentiality decision-making. It should be clear that the positions described are extreme or paradigmatic examples of approaches which vary continuously, so that we would expect to find some examples of individuals closely matching the descriptions, but most people would occupy some intermediate position. It is not clear at this point whether people would be evenly spread across the range of possible views, or whether they would cluster into discrete positions, with broadly homogenous views within clusters, and clear separation between them. The latter is, perhaps, intuitively more likely, and is the pattern strongly predicted for the group/grid typology by Thompson *et al.* (1990) but would require further investigations to demonstrate or disprove. With this in mind we can summarise the proposed positions in Table 7.

In addition to the features incorporated in the model proposed in Section 6.2.3 (Figure 13), "complying with rules" is an important issue for many subjects. It was not included in the initial model because, without knowing the content of the rule, it cannot be said to predict reporting/not reporting, but it has a place in the developing theory. However the concept of rule-following has different meanings for different groups of subjects.

SUBJECT GROUP	PATIENT CENTRED	TRUST THE EXPERT	RISK AVERSE
Perception of risk	Low	Intermediate	High
Confidence in efficacy of reporting	Low	High	High
Confidence in efficacy of treatment	High	High	Low
Relevance of patient culpability	Intermediate	Low	Intermediate
Perception of harm caused by reporting	High	Low	Low
Concern for autonomy	High	Low	Low
Impact of deterrence	High	Low	Low
Complying with rules	Intermediate	High	Intermediate
Importance of public safety	Low	Low	High
Function of rule-following	Protecting patient from idiosyncratic decisions	Incorporating good professional standards	Protecting public from dangerous patients
Most likely to say	Patient gets to decide	Doctor knows best	Safety is paramount
Primary concern	Autonomy	Expertise	Risk

Table 7: Summary of proposed theory

Cultural cognition theory predicts that subjects would minimise their direct exposure to the dilemma by selectively attending to features that confirm a pre-existing cultural position. So a subject strongly influenced by individualistic concerns for patient autonomy would be predisposed to see treatment as effective, deterrence as real and harmful, and risk as uncertain, whereas given the same facts a communitarian would tend to estimate treatment as ineffective, deterrence as hypothetical, and risk as immediate. Neither would perceive the situation as difficult to resolve, although they would reach opposite conclusions.

There is some evidence of this phenomenon: subjects do take very different views of the risks and benefits, despite being presented with the same information, and the views taken are generally congruent with the decision reached. A straightforward reading of this would be that subjects reach a decision based on the facts as they perceive them, whereas cultural

cognition theory would suggest that the decision is based on pre-existing opinions, and the “facts” are interpreted to fit this. It is not easy to distinguish between these two potential mechanisms, but some observations can be made, which may go some way towards doing so.

Supporting the cultural cognition model, many subjects expressed an immediate view about breaching or maintaining confidentiality, and although they went on to explain that choice and to explore aspects of the dilemma, there was a strong implication that the decision preceded the detailed analysis of the scenario. As described in Section 5.10.1, almost half of the subjects supported either confidentiality or reporting across all four scenarios, and only 5 subjects supported confidentiality in two scenarios and reporting in the other two. This suggests that subjects have a degree of consistency in their views independent of the details of the scenarios, and consistent with a pre-existing cultural orientation.

Conversely, more detailed analysis of the interview data demonstrates that subjects often experienced considerable ambivalence and uncertainty about the decision. There were many references to the difficulty of the dilemma, and some examples of subjects reaching a decision based on specific features of the situation, or indicating that their decision would be altered by such details. This does not disprove the cultural cognition model, but suggests that individuals from a particular cultural position, though inclined to a particular decision, still pay attention to specific details of a scenario, particularly those that resonate with their fundamental concerns. This demonstrates the value of the qualitative methods employed, providing an understanding of the process by which subjects make decisions, not just the choice that they make.

A cultural cognition model may therefore help to explain the issues within a scenario to which individual subjects will attend, and the framework within which they will undertake a utilitarian calculus, but the precise outcome will still depend on the detail of a particular situation.

6.4 IMPLICATIONS FOR POLICY AND PRACTICE

Many authors assume that lack of confidentiality would have a profound deterrent effect, to the point of rendering medical practice impossible. For example Leeman *et al.* (2001) asserted that:

if psychiatrists in comparable situations were to report their patients, we could expect substance-abusing drivers to do their best to avoid all contact with psychiatrists

Data from this study does not support such an extreme view of deterrence. While subjects clearly recognised the possibility of deterrence it was seen as something that would affect a minority of patients (for some, an irresponsible minority who would pose a risk to others even within a confidential setting), that would lead to censoring of some sensitive information rather than complete withdrawal from treatment, and which would be redeemable over some variable time period. In this respect it is important that subjects not only recognised the clinical dilemmas presented in the scenarios, but described having been deterred themselves in similar situations. This was not a population of over-compliant patients for whom the possibility of being reported was remote, but one of individuals directly familiar with the dilemma, and with direct personal experience of deterrence. That experience was of a limited form of deterrence that did not prevent continuing engagement with medical care.

A good example of this came from the Mental Health subject who described reluctance to report symptoms to a psychiatrist, because of fear of being “sectioned”, but who remained willing to report similar things to a community nurse, despite realising that this would be shared within the clinical team. Allowing the potentially damaging information to be filtered through a more trusted intermediate has parallels with situations where a patient discloses to a doctor information that may later be communicated to another agency. Subjects who suggested that the doctor may not be blamed for actions taken by the DVLA, or the Police, were also recognising this possibility. Mechanic and Meyer’s (2000) observation that confidentiality is only one component of a trusting relationship is important here: particularly if the doctor continues to be seen as having the patient’s interests in mind,

breach of confidentiality may not be fatal to the relationship, and can be a constructive part of the ongoing dialogue within that relationship.

6.4.1 POLICY

While subjects did not expect or support unconditional confidentiality, many did see decisions as finely balanced, and contingent on details of the situation. This broadly supports the utilitarian approach, and has some important consequences for mandatory reporting regimes. Subjects in this study do not support automatic reporting in most situations. The SEXUAL THOUGHTS scenario in this study is one in which doctors would often be considered to have an automatic duty to disclose, but subjects did not support this. In fact support for reporting at all in this scenario was relatively low, primarily because it was felt that the immediate risk was low. The perceived likelihood of deterrence was also greater in this scenario than in the others. A number of subjects carried out a more or less explicit balancing, concluding that reporting would have little protective effect and that promoting therapeutic options was likely to have a better outcome. Even in the case of potential child abuse, subjects supported a utilitarian approach, with support for reporting only where benefits outweighed the costs, rather than mandatory reporting.

Policymakers should therefore be cautious about introducing or extending mandatory reporting regimes. Patients in general expect doctors to exercise a degree of discretion, and have confidence in them doing so, even to the extent of tolerating some bad outcomes:

You've also got to understand that you're not going to be right ten times out of ten and there are going to be a few that will backfire, but overall whether it would make that much difference as regards the statistics as they like to say, only time will tell if they change the law for the confidentiality, you know.

(Epilepsy subject; Final reflections)

You know I think people forget that really, that there's a lot of sacrifice and good heart in the choice to be a doctor. So if they fall short a bit sometimes, well you know people expect [doctors] to be something to be more than human, they're not, everybody's got their fallibilities.

(Epilepsy subject; Final reflections)

Trust in doctors is able to withstand limits to confidentiality, but is threatened by doctors acting automatically or mindlessly in situations where patients trust them to exercise judgement. Patients understand that doctors will sometimes balance their interest against those of others, and trust them to do so in ways that remain respectful and mindful of the patient's interests: they may be less tolerant of doctors who act as agents of a public safety agenda from which the patient's interests are excluded.

Policymakers should also be reluctant to extend the uses of "medical" information beyond the clinical setting, following Francis's (1982) categorisation of "divergent" and "convergent" breach. Patients retain a strong sense that doctors have their interests at heart, even while acknowledging that sometimes other interests will intrude into that relationship. It is important for patient confidence that such circumstances remain exceptional, and using doctors as a source of information for non-medical purposes is likely to undermine the trust that is necessary for such information to be disclosed in the first place.

Policymakers must also be sensitive to the different views expressed by patients who are directly affected by confidentiality dilemmas. It is clear from this study that support for breach of confidentiality is higher amongst patients who are not directly affected. It is entirely possible that a majority of the public, and even of patients, would support a reduced level of confidentiality which would be opposed by those to whom it would apply. Popular policies are not always right, and as O'Neill expresses it:

There is no necessary link between democratically legitimated policies and ethical requirements (O'Neill, 2002a, p 170)

There are both principled and practical reasons why the view of the majority should not simply override the minority, even within a democratic process. Firstly minorities with specific interests deserve protection from exploitation by others who are not directly

affected. Secondly policy makers should recognise that the utilitarian value of confidentiality is lost if the individuals directly affected do not have confidence in the rules, and are deterred from treatment.

6.4.2 CLINICAL IMPLICATIONS

One very encouraging finding from this study is that most subjects recognised the issues involved in negotiating confidentiality, and with minimal prompting were able to engage with the complex balancing of risks and benefits. They also readily understood and accepted that doctors do have wider responsibilities than those to an individual patient, and although they had divergent views about the best course of action in specific situations, there was no reluctance to accept that some form of utilitarian balancing would be necessary. Given the necessity of a constructive dialogue between doctor and patient on this sensitive issue, it is encouraging that patients already seem well-equipped to confront the issues involved.

There is also evidence from this study that patients will recognise the difficulty of the dilemma faced by clinicians, and that they have a significant degree of confidence in the medical profession in general to reach appropriate decisions. Although individual patients may have different perceptions, doctors should not in general be reluctant to initiate such discussions; indeed there is good reason to believe that patients will welcome such openness, and that explicitly addressing the issue is more likely to increase than to reduce trust.

Despite this generally sophisticated engagement with the issues, the variation in interview length, density of coding, and coverage of interview content by relevant coding is congruent with literature suggesting that levels of health literacy (in part, the ability to understand and process complex health-related information) vary both between populations (mental health patients tending to have lower health literacy) (Wolf *et al.*, 2005) and with socio-demographic factors (Department of Education, 2006). Future work could usefully examine the effect of this on attitudes to confidentiality, and also use techniques derived from health literacy research to make the dilemma more accessible and understandable to those subjects who find it difficult.

Individuals will have different concerns and priorities when addressing confidentiality dilemmas, and for such discussions to be as productive as possible, and to maximise the positive benefit for the doctor-patient relationship, doctors need to address the issues in a way that addresses the patient’s specific concerns. An understanding of the positions proposed in Section 6.3.5 may enable the doctor to speak more directly to issues relevant to an individual patient.

For example, a patient with a patient-centred stance will require reassurance that reporting requirements will not fatally undermine their autonomy. They are more likely to accept and understand a rationale for reporting if it is framed in terms of holding an individual responsible for their own actions, rather than in terms of the good of the general community. Conversely, a risk-averse patient will need little persuading of the justification for reporting, but will be more willing to accept a balancing need for confidentiality in terms of the general good of promoting health care, and the risk-reducing value of treatment, rather than in terms of individual rights. In general, and recognising that all patients will present a different combination of opinions and concerns, a doctor might approach the issues of maintaining and breaching confidentiality in the following terms (Table 8):

POSITION	IN FAVOUR OF CONFIDENTIALITY	IN FAVOUR OF BREACH
Patient-centred	Autonomy	Personal responsibility for choices
Risk averse	Treatment reducing risk	Public safety
Trust the expert	Trusting doctor	Following social rules

Table 8: Addressing individuals’ concerns

This can never provide a complete resolution to confidentiality dilemmas, which will continue to raise complex issues, in which one party’s interests will ultimately be subordinated to another’s, with benefits and, in particular, costs on both sides that can be balanced, but never eliminated completely. What it may provide, however, is a framework of shared understanding within which individuals of very different views can strike a mutually acceptable balance.

6.4.3 CURRENT APPROACHES

A number of subjects expressed confidence in the current rules regarding medical confidentiality, but it is less clear that the actual rules are congruent with subjects' expectations.

As described in Chapter 2, GMC guidelines adopt the principles laid down in the *Egdell* judgement, that there is a strong public interest in confidentiality, as well as the patient's private interest, that breach of confidentiality should be exceptional, and should be based on a utilitarian balancing of risks and benefits. All of these are broadly consistent with the views expressed by subjects in this study. GMC rules also contain strong statements about the importance of confidentiality in non-exceptional circumstances, something with which subjects would also agree.

GMC guidelines also explicitly refer to the need for confidentiality if patients are to trust doctors with personal information, and by implication the risk of deterring patients from treatment if confidentiality is not assured. Subjects here seem less certain: as discussed above, while recognising the risk of deterrence in theory, many subjects saw its impact in practice as being quite limited.

Although they would support the general principles, subjects are less happy about the detail of current regulations. Firstly, although guidelines refer to breach of confidentiality as exceptional, it is increasingly seen as expected in many routine situations. Subjects in this study generally support breach of confidentiality when there is a significant risk which is likely to be reduced by reporting, but they do not, for example, endorse automatic breach of confidentiality for child protection purposes.

A second issue is that of mandatory reporting. The *Egdell* judgement was clearly permissive rather than mandatory in nature, but GMC guidelines repeatedly use mandatory-sounding language to imply that reporting is expected – discussed in Section 2.3.2. Once again, subjects in this study seem to be closer to Lord Bingham's views than to those of the GMC, generally expecting doctors to exercise judgement and discretion over whether, and what, to report, rather than being bound by mandatory reporting regimes.

Because of the range of opinions expressed, and the lack of clarity in the guidelines, it would perhaps go too far to say that the public, or patients, would not support the GMC position, but it does seem that the erosion of protection for confidentiality over the last two decades is towards one extreme end of the range of positions that the subjects in this study would expect, and that further weakening of the position would go further than the majority of subjects would feel comfortable with.

Given subjects' expressed trust in the medical profession there is scope for the articulation of professional standards that oppose political pressure for reducing confidentiality. Subjects are happier, at an individual level, for such decisions to rest ultimately with doctors than with legislators, and it is likely that this will be replicated at a policy level. There seem to be contradictions here with increasing calls for external regulation of professions such as medicine, which have not been resolved in this study, although O'Neill's distinction between the reduction of trust in institutions and the preservation of trust in individuals (discussed in section 2.4) is relevant here.

7 CONCLUSIONS

7.1 VALUE OF CONFIDENTIALITY

In keeping with previous findings, and with the opinions of the great majority of authors, a large majority of subjects in this study valued confidentiality and expected that it would be provided by health professionals. Even where subjects expressed themselves as less concerned about their own personal information they generally recognised the value of confidentiality for others, and the need for it to be protected.

Various reasons emerged justifying the need for confidentiality. One was the need for privacy, the desire for certain information not to become widely known: details of sexual behaviour was given as an example. Another was support for autonomy – the patient to have control over the reporting decision, and to be able to seek health care without unwanted consequences. Issues of fidelity were also raised, with some subjects being particularly concerned that patients should not be misled, and should be aware of all the potential consequences when deciding what information to disclose.

Confidentiality is an important component of the wider trust that patients have in doctors, but it is only one component, and other issues are also important, in particular the perception that the doctor has a fundamental concern for the patient's interests. All subjects accepted that there are circumstances in which a doctor should consider the wider interests of society, and that while patient interests must not be ignored, in some situations they take second place to issues of public safety.

Subjects also clearly recognised and understood the concept of deterrence, both for themselves and for others. It was generally accepted as one significant factor to be taken into account, but often given less weight than other issues such as public protection and patient autonomy, and deterrence on its own was not a sufficient reason for most subjects to oppose reporting.

The negative impact of a breach of confidentiality is likely to be minimised by the existence of a positive and trusting relationship prior to any breach, explicit concern for the patient's

interests within any utilitarian calculus that is undertaken, and keeping the patient informed about any action to be taken, and the rationale for it. Forewarning about the limits to confidentiality has a role to play in establishing a good relationship and reducing the surprise factor of a subsequent breach, but, as previous studies have shown (Nowell & Spruill, 1993; Kremer & Gesten, 1998; Sokol, 2008b), forewarning that is too explicit may be counterproductive, not only deterring disclosure but also decreasing the quality of the relationship, because of the implication that the doctor is less focussed on patient interests than on wider concerns.

What does this mean for the place of confidentiality in medical practice? It can be summarised as follows:

- **Keeping trust is more important than keeping secrets**
- **The two are not the same, so it is possible to keep a patient's trust even while breaching confidentiality**
- **This can be achieved by being demonstrably and explicitly concerned for patient's interests, even if they must be overridden, and by recognising and engaging with an individual patient's specific concerns .**

7.2 SCALE OF DETERRENCE

A predominantly qualitative study will always encounter difficulties in providing the quantitative data on which the utilitarian calculus will ultimately depend. However this study can go some way estimating the scale of deterrence from three separate perspectives: the beliefs of patients about the actions of others; patients' own personal experience of deterrence; and patients' opinions of the probable consequences of deterrence.

The first of these perspectives is inevitably the least securely based. Patients may find it difficult accurately to anticipate their own likely responses and behaviours in hypothetical situations which they have not faced. There is even less reason to take their beliefs to be an accurate reflection of how other patients might behave in those hypothetical situations, particularly when many subjects were at pains to distance themselves from the behaviour of patients in the scenarios.

However there are also reasons to consider that the views of subjects in this study have some value. They were recruited from a clinical situation in which dilemmas of confidentiality could potentially arise: we can be reassured here that many of the subjects did in fact feel that the scenarios presented either related to their personal experience, or were circumstances that they could imagine occurring to them. Discussing their "own" scenario first should enable them to put themselves in the place of the patient in the scenario, and prime them to consider the subsequent scenarios from the first-person patient perspective. The "distancing" expressed may also have a positive side. The study was designed to allow subjects to discuss potentially sensitive or damaging information, and while distancing might represent a genuine lack of understanding of another person's situation, in some cases it may be a strategy for discussing personal beliefs in a safe and non-attributable way.

We should therefore give credence to subjects' perception of the scale of deterrence. Although no subject gave a specific quantified estimate, most felt that it would affect only a minority of patients. Even with the possible adverse consequences of a breach of confidentiality most subjects felt that patients would be willing to seek medical care and to disclose within a consultation. Consequential deterrence was more widely anticipated, but

again was expected to influence a minority of patients, or to have only limited effects. Based on the views of this sample we have grounds for optimism about the current level of trust that patients have in doctors.

The second perspective, however, should give us pause in reaching that conclusion. About 15% of subjects report that they have already been deterred from disclosing information to a doctor themselves. There are several reasons to believe that this is an underestimate. Subjects were not asked directly, and were even advised several times that they were not expected to reveal information about their own case, so we should anticipate that at least some of the subjects who had experienced deterrence kept silent about it. The nature of deterrence is such that patients who have felt inhibited from disclosing information in a clinical setting could be expected to have at least as much reluctance to do so in a research setting, probably more so, since there is no health-related benefit to the subject from making a disclosure. Thirdly the study sample represents patients who were attending a continuing health care setting, have a positive view of professionals, sufficient to engage in a voluntary study at some personal inconvenience, and agreed to an interview knowing that issues of confidentiality and trust in doctors would be discussed. All of these factors imply that the sample studied are likely, on balance, to have greater trust and are less likely to be deterred than the general population of patients.

We should tentatively conclude, therefore, that the rate of previous experience of deterrence from treatment in the patient population is at least of the order of 20%, and quite possibly significantly higher, an estimate broadly in line with (and towards the lower end of) previous findings. 1 patient in 5 is not an insignificant proportion of patients to have experienced deterrence. Since these are people who have in fact already been deterred, the proportion who might possibly be deterred by confidentiality breaches is higher to some indeterminate degree: in any event we must conclude that deterrence is not a rare and isolated occurrence, but one which has affected, and potentially will affect, large numbers of patients.

Our final estimation of the scale of deterrence may again serve as reassurance that it is not as damaging as may have been feared. Whatever the number of patients affected, we must also try to quantify how affected they are, and here the data from this study is grounds for

optimism. Subjects' opinions were generally that deterrence would be transient, with trust being rebuilt over a period of time, and also that it may be specific, leading patients to censor certain items of information, or become distrustful of a particular doctor, with other aspects of engagement with medical treatment continuing relatively unscathed. This may partly explain the view that only a few patients would be affected: larger numbers may be affected to a small degree, with only a few individuals becoming significantly alienated from treatment all together.

Subjects' own experience tends to support this: if (at least) one subject in six has experienced deterrence, yet all remain positively engaged with treatment, then the consequences of deterrence may not be as severe as many authors have assumed. Certainly it seems that effective medical treatment, and trust in individual doctors, can survive breaches of confidentiality

7.3 VALIDITY AND GENERALISABILITY

7.3.1 RELIABILITY

The value of any research, and any conclusions, rests ultimately on the validity of the data presented: does it represent “the truth, the whole truth, and nothing but the truth”?

Firstly, is the data true: did subjects express the views attributed to them? Although voice recordings and transcripts have been retained for audit purposes, the reader will generally be reliant on the much more limited data contained within the thesis. Even so, each significant point developed from the data has been illustrated with direct quotes from the subjects. As Appendix 4 makes clear, most of the key points were supported by numerous statements made by a number of individual subjects, reducing the possibility that the point made was not a true reflection of the views of at least some of the subjects. Almost without exception the concepts could have been illustrated with a much larger amount of quoted material, but frequency is not the most relevant measure here.

Secondly, is the whole truth being presented: were there significant views expressed within the interviews that have been omitted or marginalised? The coding process extracted an average of 67 concepts from each interview, which suggests that coding, if not completely exhaustive, did reflect the great majority of content from each interview. Data presented in Figure 7 also shows that a substantial proportion of the content of each interview was utilised in the coding process. The resulting nodes are listed in Appendix 4, from which it can be seen that (with the exception of some “process” or administrative categories) all the reported concepts relevant to the key issues have been described and incorporated in to the results and models presented. Further evidence comes from the nature of the coding framework: for most important concepts a contrary concept also exists within the framework. If significant views had been overlooked there would be examples of one-sided issues which are not in fact seen. Quotations are selective, in the sense that quotes have been chosen that in the view of the researcher best express or exemplify the concept being discussed, but not in the sense that alternative views have been suppressed.

Thirdly, is anything but the truth presented: are there results or conclusions presented that are not based in data, or that go beyond the views expressed by subjects? Again, by evidencing concepts with repeated direct quotations from interviews, it should be clear that nothing has been introduced which did not originate from the subjects. The development of theory and the drawing conclusions are creative actions that require extrapolation and interpretation, but throughout this thesis the attempt has been made to demonstrate that each such step rests ultimately on primary data.

7.3.2 VALIDITY

If the data itself can be considered reliable, what about the use to which that data has been put? Are the interpretations made of the data reasonable, and are they the best or most firmly based conclusions, or have better ones been overlooked?

As a starting point we should consider whether or not the models and theory proposed have face validity; whether they appear coherent, have internal consistency, and give a credible account of the phenomena investigated. The models presented in Chapter 5 and the theory developed in Chapter 6 provide good coverage of the concepts identified within the coding framework, without significant gaps, and do so in a way that incorporates and explains differences between subjects, rather than ignoring or conflating them. The various themes and sub-themes appear to have a good fit with the concerns and views expressed by subjects, and appear to have consistent and coherent content.

One issue relevant to the validity of the study is whether the data presented has succeeded in providing a detailed and “thick” description of subjects’ views, or whether it has instead presented anecdotes – narrative descriptions that have some plausibility but which lack depth and analytic credibility. The models proposed appear to have a degree of complexity that goes beyond a purely narrative description, and although the subsequent theory entails a considerable degree of simplification, this appears to have developed the original concepts significantly beyond the accounts of individual subjects, to achieve a genuine synthesis and deeper understanding.

We can also judge validity by the extent to which the theory proposed is genuinely emergent from the primary data, rather than being applied to it in a procrustean manner. Few of the concepts within the coding framework have been omitted from the models derived, and those that were generally reflected issues separate from the central phenomena of interest. Similarly, the variation and range of issues within the models have been incorporated in the theory with minimal loss, and the theory remains consistent with views expressed during the interviews, as exemplified by further illustrative quotes.

Constructs developed within the study can be checked for validity against external sources of information. Attention has been drawn to various ways in which the findings of this study have been consistent with previous literature both theoretical and empirical, and how these results can be understood as compatible with a wider context. As discussed in Section 6.4.3 the views expressed by subjects and the conclusions derived from these, are broadly in line with current professional guidelines, which themselves represent a distillation of professional and public opinion: consistency with these external views supports the conclusion that the models and theory presented have credibility and validity.

7.3.3 TRANSFERRABILITY

This study has drawn conclusions about the meaning and importance of confidentiality for the subjects interviewed, but will only be of more than very limited interest if there is good reason to believe that the findings can be applied more widely.

It is acknowledged that the subjects sampled are unlikely to be representative in a direct way of patients generally or the wider public. Indeed the groups studied were chosen because they were predicted to have specific confidentiality issues that would not be shared by other groups. Nonetheless there are reasons to believe the findings will have a wider applicability. The congruence of results with previous research and with existing theory, discussed above, is one indication that they are not an artefact of the specific study population, but are likely to be applicable to other patients and other settings. The sampling logic, while not intending to provide a group that was representative of the wider population, was intended to produce diversity of opinion within the sample, and appears to

have been successful in this. Replication of the study in other populations remains an important extension of this work, which may lead to refinement, validation, or rejection of the proposed theory

7.3.4 PERSONAL REFLECTIONS

As a final argument for the validity of this study, I return to the personal reflections discussed in Section 4.8.2.

I began this study from a position of having concern about the changing nature of medical confidentiality, particularly what I perceived as its erosion, and a belief that this would impede trusting the relationships between doctor and patient which are the basis of effective medical treatment.

At its conclusion, I have been compelled to change my views significantly, in response to views expressed by the subjects, which did not conform to my preconceptions. In particular, though recognising deterrence, subjects do not see it as a major barrier to reporting, and while valuing confidentiality, subjects see it as only one component of trust, and not always the most important. Current professional guidelines, which gave me concern, are broadly in line with most patients' views.

No study, particularly a qualitative one, is entirely free of subjective input from the researcher, and I would not claim that my views have not influenced aspects of this thesis, but by changing my views in response to the data obtained I hope I have demonstrated a degree of objectivity that enhances the credibility of the conclusions.

7.4 IMPLICATIONS FOR POLICY

The findings of this study indicate that subjects broadly support the current guidelines on confidentiality in terms of recognising its importance to medical practice, adopting a utilitarian approach which permits breach of confidentiality to prevent harm to others, and recognising the risks of deterrence.

However current guidelines do not go as far as patients would expect in stressing the exceptional nature of breach of confidentiality, and given that this has been a developing trend over recent years, regulators should be cautious before extending that trend any further. Evidence from this study suggests that patients expect reporting to be less common than may be the case in practice, and certainly would not support criteria for reporting that were significantly less restrictive than current rules.

The other main implication for policy from this study is that subjects clearly expect and require doctors to exercise discretion and judgement in making reporting decisions. Patients are generally willing for this to be done, and trust doctors to balance their interests with those of others in coming to an appropriate decision. However they expect that to be done within the context of an individual relationship between patient and doctor; there is considerably less support for the sort of mandatory reporting regimes that have increasingly been established over recent years, where such decisions are taken centrally. Patients' trust in doctors is founded on the personal nature of the relationship, and has been maintained despite evidence of reducing trust in wider systems and institutions. Policy makers need to recognise that applying inflexible, centrally determined rules to individual clinical situations, however carefully drafted, cannot replicate the trust that patients have in their individual doctors and may instead fatally undermine it.

This study has confirmed previous findings that different groups of patients can have different levels of concern about confidentiality. In particular those patients not directly affected by an issue tend to underestimate the frequency and consequences of deterrence compared to the views expressed by those directly affected. This implies that the general public will underestimate the consequences of limiting confidentiality for specific groups of patients. This is a significant problem in a democratic society, where popular support for a

particular policy may lead to unintended consequences. It is entirely possible that a policy supported by the majority, and intended to reduce harm to others, might have an effect on the minority directly affected which would result in increasing the very risk that it was intended to reduce.

Subjects overall also tended to underestimate the frequency with which deterrence occurred, even compared to the frequency with which this group had actually experienced it themselves. This strongly suggest that policy that is based on the views of the public, or of patients in general, is likely to underestimate the impact of policy on those who are directly affected. There is a role for policy makers to temper public opinion with an understanding of this, and a role for professionals to advocate on behalf of patients, particularly from marginalised or stigmatised groups, whose interests may otherwise be overridden.

Finally, a better understanding of the dynamics of the doctor-patient relationship, the role played by confidentiality, and the cognitions that appear to underlie people's attitudes, may assist policymakers in devising policies that would maximise benefits and minimise harm, and also in explaining that policy to the wider public. The doctor-patient relationship is at the heart of health care, producing immeasurable benefits both for individual patients and for the wider community. If policies such as mandatory reporting undermine that relationship the detriment to individual health care will be profound, and if frank disclosure is inhibited any benefit to public safety may turn out to be illusory.

7.5 FUTURE DEVELOPMENT OF WORK

This exploratory study has utilised qualitative techniques to explore subjects' perceptions with as few pre-conceptions or limitations as possible. Now that a provisional theoretical framework has been developed, further work to validate and refine that framework could adopt more quantitative methods.

The grounded theory approach adopted in this study has been largely atheoretical in orientation. Now that a possible theoretical model has been developed, it would be useful to reanalyse the data from that theoretical standpoint, to determine whether or not the proposed constructs can be identified in the data. If so, then replicating that analysis on a different data set would also add to the credibility of the proposed theory.

Future work should then explore the variables predicted to distinguish between the various cultural positions, by manipulating relevant variables within vignettes, by designing closed-question techniques that address the variables, or a combination of the two. There is scope for combining qualitative and quantitative techniques at this stage to deepen understanding of the phenomena identified qualitatively in this study.

If the proposed model can be validated then a further step will be to delineate the variation in cultural factors within the population, both to estimate the proportion of people adopting the various positions, and to see if discrete clusters of cultural orientation can define groups within the population with specific interests and concerns.

The current study has focussed on two specific areas of medical practice. Further work could usefully extend this to other patient populations, where other specific issues may arise.

Although the same range of cultural cognitions are likely to be found in patient populations as in the general public, there may be interactions between those positions and the sensitivities arising from specific health conditions which could be explored and delineated.

It would be particularly useful to explore concepts developed in this study with individuals who have chosen not to access medical treatment because of confidentiality concerns, but this presents significant methodological challenges for obvious reasons. One possible route would be to study the consequences of real-life breaches of confidentiality – for example

patients whose doctors have made a report to the DVLA – to see whether or not deterrence occurs, and what the consequences are.

*Yeh you've got to have trust cos if you don't have trust then
you're screwed. (laughs)*

(Mental Health subject; THREATS scenario)

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APPENDIX ONE: EMPIRICAL STUDIES

This Appendix summarises existing research which has presented empirical data on the views of various groups regarding confidentiality. For each paper brief details are given of the setting in which it was conducted, the number of subjects involved, the issues investigated, and very brief details of the main findings. The results are synthesised and some general conclusions drawn in Section 2.5.1. Details given here are taken from research notes and further simplified: for more detail the reader is referred to the original work.

Results are presented in 11 tables. The first group, Tables 1 – 3, present general views about confidentiality issues, obtained from samples of the public, professional, and patients respectively. Tables 4 – 6 present views about the reporting of confidential information expressed by the same three groups: Table 5 (Professional views of reporting) is divided into papers relating to hypothetical opinion (Table 5a) and those relating to actual reporting behaviour (Table 5b). Tables 7 – 9 present studies relating to deterrence, divided into the same three subject groups. Finally Table 10 present studies which have reported actual disclosure behaviour in experimental situations, and Table 11 present naturalistic studies of situations in which reporting rules have differed, termed “natural experiments” in Section 2.5.3.

Studies asking members of the public about their own attitude to health care are generally classified with “patient” rather than “public” studies. Because of the way these studies have been classified, some appear in more than one table: studies which include subjects from more than one group, or explore issues relating to more than one area, are repeated in each relevant table.

Appendix 1: Table 1: public views about confidentiality

REF	SUBJECTS	N	ISSUE	FINDING
Miller & Thelen, 1986	School students College students	508	What do public and patients believe to be the limits of confidentiality?	69% believed all information actually is confidential 75% believed all information should be confidential 20% supported reporting when danger to self/others No significant differences between groups
Lindenthal & Thomas, 1982b	General public	76	When should psychiatrists disclose information about patients?	48% were concerned about disclosures and 33% said this was a barrier to seeking help Public expected that psychiatrists would disclose more than psychiatrists said they actually would
Knowles & McMahon, 1995	Public	256	Should psychologists disclose information in various situations?	There was support for disclosure in cases of risk of murder or suicide, and child abuse, but less support when the issue was drug abuse or theft Least concern about disclosure to other clinicians, most concern about disclosure to family members
Ormrod & Ambrose, 1999	Public	153	Do people believe discussions with professionals are or should be confidential?	About 2/3 believed discussion with various doctors would be completely confidential, but 90% believed they should be Less for other professionals – subjects thought discussions should be confidential much more often than they thought they would be 53% supported disclosure (always or usually) for sexual abuse and 37% for murder; 43% and 39% thought this would happen
Hecht <i>et al.</i> , 2000	Public at “high risk” for HIV	2404	Are people at risk of HIV deterred from testing by notification to public health agencies?	Only 15% knew the local policy for reporting Of 17 reasons for avoiding testing, concern of reporting was the 9 th commonest – no different in states with named or anonymous reporting. Only 1% of untested individuals gave this as the main reason. No evidence of significant deterrence
Ford <i>et al.</i> , 2001	School students	53	Do adolescents expect that doctors will pass on details of consultation to parents?	In general subjects overestimated the amount of information that would be passed to parents.. Giving an assurances of confidentiality was only partially successful in overcoming this
Singer <i>et al.</i> , 1993	General public	3478	Exploration of reasons for census non-returns	Most subjects had few concerns about confidentiality, but those that did had higher rates of non-return
Ford <i>et al.</i> , 1997	School students	562	Does confidentiality affect willingness to consult/disclose?	When therapist promised confidentiality, he was rated as more acceptable, and subjects would be more willing to disclose to him. 17% of sample reported past avoidance of health care because of concerns about confidentiality
Collins & Knowles, 1995	School students	557	Breach of confidentiality by school counsellor	53% said confidentiality was essential; 42% important Majority supported disclosure when danger to self or others, not in cases involving sexual health

Braaten & Handelsman, 1997	Patients Former pts students	35 47 42	Information expected for informed consent	2 confidentiality issues ranked 2 and 4 out of 28 issues listed (ranked 1 and 2 by former clients but given as ns) – equivalent to “important or extremely important”. No demographic differences
Anon, 1962	Public Profs	108 151	Legal privilege	Most thought info was privileged, and should be. About half of patients anticipated deterrence. Support from subjects and authors for strong/absolute privilege
Cheng <i>et al.</i> , 1993	School students	1295	Is perceived lack of confidentiality a barrier to adolescent health care?	58% of subjects had health issues they wanted to keep from parents 25% had already foregone health care because of concerns 81% supported breach of confidentiality when patient at risk
Meyer & Smith, 1977	Psychol students	55	Confidentiality In group therapy	91% expected therapist to maintain confidentiality, and 65% expected group members to. 81% would not join group or would disclose less if not confidential; 45% even if this limited to court proceedings
Garside <i>et al.</i> , 2002	School students	430	Concerns about confidentiality	73% trusted GP but many had concerns about privacy in small communities
Thrall <i>et al.</i> , 2000	School students	1715	Effects of confidentiality on access to sexual health care	75% wanted confidential health care 45% had confidence that consultation would be confidential 9% had foregone health care because of concerns Those with concerns were less likely to have had appropriate care
Korts <i>et al.</i> , 2004	Public	?	Attitudes to DNA database	Trust is crucial. More trust in doctors than police/scientists
Anon, 1979	Public	2131	Trust in different groups	Public had most trust in doctors out of 18 groups, but 17% of subjects thought doctors should do more to protect confidentiality.
Shuman <i>et al.</i> , 1986	Psychiatrists Patients Judges College students	188 134 70 124	Effect of privilege rules on disclosure in therapy	Few differences between Ontario/Quebec, suggesting formal privilege laws have little effect Overall about 40% of psychiatrists had been asked to testify, about 10% had done so. Judges say this is always with consent, but psychiatrists disagree. About 40% of psychiatrists believe disclosure impairs treatment and 22% of breach led to termination. About half of patients report concern about confidentiality; few know the privilege laws. College students less likely to disclose if not offered privilege, but lack of knowledge suggests this is not a significant factor in actual therapy.
Ginsburg <i>et al.</i> , 1995	School children	6821	Barriers to accessing health care	Confidentiality ranked 11 th out of 31 possible factors – 83% rated it as probably or definitely a factor.
Jenkins <i>et al.</i> , 2005	Women – patients and public	85	Beliefs about confidentiality	Generally high levels of belief in strict confidentiality – many subjects expecting even sharing within immediate team only with consent. Some (?how many) subjects described withholding certain info (particularly sexual and mental health) because of concerns

				Some (probably most?) patients have unrealistic expectations/understanding
Slade <i>et al.</i> , 2007	MH profs Patients Carers	595	Information sharing with carers	Patients very concerned about confidentiality and less supportive of disclosure than other groups. No discussion of deterrence.
Hardin & Subich, 1985	Students Counselling clients	40 78	Expectations about counselling	High expectations of "trustworthiness" (no specific question about confidentiality). No differences between groups
4888Peck, 1994	General public	1000	Release of medical information	Concerns higher in MH patients
Kapphahn <i>et al.</i> , 1999	School pupils	6748	Preference for confidential care	Most subjects happy for parent to be present during consultation , but this was less (c30% vs 50%) for subjects with risk behaviour (sex, drugs) or history of abuse and lower for boys than girls
Nwokolo <i>et al.</i> , 2002	Secondary school pupils	744	Access to sexual health services	78% said confidentiality important (high on list, but less important than "staff are friendly" and "non-judgemental". Only 19% willing to consult GP
Robling <i>et al.</i> , 2004	Public	49	Use of medical information in research	Significant concerns about use without consent (qualitative study)
Ginsberg <i>et al.</i> , 1997	Teenagers	215	Barriers to health care	Subjects were "worried intensely" about confidentiality - ranked lower than cleanliness, friendliness and competence, but this related to "emphasising" confidentiality rather than providing/not providing it
Claiborn, 1994	Psychotherapy patients Public	96	Ethical practice	Patients and public both supported confidentiality

Appendix 1: Table 2: Professional views about confidentiality

REF	SUBJECTS	N	ISSUE	FINDING
Crenshaw & Lichtenberg, 1993	Mental Health professionals	428	Do professional warn patients of mandatory reporting of child abuse?	37% always forewarn 36% only forewarn if abuse suspected 20% only warn after abuse disclosed
Venier, 1998	Psychotherapists	50	Confidentiality practice	63% discussed clients with other profs outside supervision (teams etc), 10% only in supervision, 27% not at all Majority inform referring agencies of initial contact (87%) and discharge (70%) – much more than in a similar US survey
Lindenthal & Thomas, 1982b	Psychiatrists	192	Likelihood of disclosure in various situations	Psychiatrists were less likely to disclose than non-patients expected, but more likely than patients expected
Roback <i>et al.</i> , 1996	Group therapists	51	Experience of confidentiality breaches	69% had minor or no concerns about breach of confidentiality. 49% thought patients had moderate or great concern 73% had explicit discussion of confidentiality rules with patients – more likely in those who had experienced previous breaches. 90% thought these discussions had positive effect on treatment (none negative)
Beran, 2002	Medico-legal experts	42	Views about professional confidentiality in epilepsy	37/42 supported privilege, but only 6 thought it should be absolute (even then most thought doctor should have discretion to report) 28/42 thought there was a duty to report risky driver
Thelen <i>et al.</i> , 1994	Psychologists	330	Attitudes to confidentiality	25% believed in absolute confidentiality, 70% did not. Those who did were less likely to be willing to report in various situations, and more likely to anticipate damage to therapeutic relationship
Jagim <i>et al.</i> , 1978	Mental Health professionals	64	Attitudes to confidentiality	98% said confidentiality was essential to therapeutic relationship 98% said maintaining confidentiality was an ethical duty 95% said clients expect confidentiality 76% were prepared to report if third party at risk
Lindenthal <i>et al.</i> , 1985	Psychiatrists Psychologists	288 169	Support for confidentiality/disclosure in different countries	Differences small. Profession has more effect than country. Not possible to determine actual rates of support for reporting
Pope & Vetter, 1992	Psychologists	679	Ethical issues encountered in practice	703 incidents reported, categorized into 23 areas. Confidentiality (128 reports, 18%) was the most frequent reported of which 38 (5% of total) involved third party risks.
Wise, 1978	Psychiatrists Psychologists	179 1073	Effect of <i>Tarasoff</i> on practice	79% believed patients would be less likely to divulge info if not completely confidential 96% believed all or most patients believed confidentiality was absolute 11% always discussed confidentiality with patients, 70% “sometimes” 70% supported breach in certain circumstances, 26% supported absolute

				<p>confidentiality standard) 25% reported observing reluctance to disclose after learning about limits to conf 50% had given at least one warning pre-<i>Tarasoff</i>, 38% in the first year after 20% discussed confidentiality with patients more frequently than before., 27% focused more on dangerousness than before. 54% reported increased anxiety of being sued following <i>Tarasoff</i>. 16% reported avoiding particular issues, including dangerousness. “Several” reported no longer working with dangerous patients Overall 89% reported at least one aspect of change to behaviour resulting from <i>Tarasoff</i></p>
Anon, 1962	Public Profs	108 151	Legal privilege	Most thought info was privileged, and should be. About half of patients anticipated deterrence. Strong support from subjects and authors for strong/absolute privilege
Baird & Rupert, 1987	Psychologists	188	Informing of limits and breaching confidentiality	<p>61% usually discuss confidentiality from the onset of therapy – 12% of total telling clients that confidentiality is absolute. Those with experience of breach more likely to discuss limits. More likely to discuss these limits with a dangerous client. Only one subject would “never” breach conf with a dangerous client Almost 40% said they had become more willing to disclose, with <i>Tarasoff</i> the most frequently cited reason (only 49% overall said they were familiar with the case). 21% had become less likely to disclose, usually as a result of experience of poor outcome from a previous breach</p>
Abramson, 1990	Social workers	16	Dilemmas in working with HIV patients	<p>Secrecy/confidentiality was the most frequently mentioned and most problematic. Differing practice re 3rd party – support for disclosure and for confidentiality. No numbers given</p>
Garside <i>et al.</i> , 2000	GPs	235	Provision of contraception to under-16s	76% would prefer parents to know, but 92% agreed they owe same duty of confidentiality to adolescents as adults.
Weiss, 1982	Junior doctors Medical students	109 53	How likely to disclose patient information in different situations?	Doctors more likely to disclose info than patients expected (up to 4x in some circumstances). Medical students (in first 60 days of course) more like doctors than patients in their expectations
Lindsay & Colley, 1995	Psychologists	284	Ethical dilemmas encountered in practice	17% (largest category) related to confidentiality – similar to proportion in Pope & Vetter
Nicolai & Scott, 1994	Psychologists	204	Information giving practice and effect on disclosure	<p>54% always and 26% often provide info about limits to confidentiality – mostly oral only. 80% made some mention of specific circumstances such as child abuse.</p>

				52% would definitely or probably report – higher in those who always provide info in their own practice. Approx 40% of subjects would probably or definitely not report, even though 96% of them were certain abuse was occurring.
Pope <i>et al.</i> , 1987	Psychologists	456	Standards of ethical practice	6% say unethical to breach confidentiality if client homicidal; 58% have done it, 41% often 12% if client suicidal, 79% have done, 28% do it often 5% if child abuse, 62% have done, 30% do it often
Noll & Hanlon, 1976	MH services	118	Reporting of identifiable info	Approx half of MH centres report identifiable data to central authorities for admin purposes and 1/3 of those do not inform patients.
Ford & Millstein, 1997	Physicians	786	Forewarning practice with adolescents	Physicians discussed confidentiality with 53% of adolescent patients. When discussed, 64% promised unconditional confidentiality, 36% conditional 63% correctly identified legal guidelines, 31% unsure, 5% incorrect
Perez-Carceles <i>et al.</i> , 2005	Family doctors	277	Disclosure of info to families	95% provide information to other family members 35% do so without consent (contrary to Spanish law)
Perez-Carceles <i>et al.</i> , 2006	Family doctors	227	Informing parents of adolescents' health care	90% would always inform parents of life-threatening conditions (presumably even without consent but this is not clear) 39% would inform parents of <16 (?of all consultations?)
Marzanski <i>et al.</i> , 2006	Psychiatrists	40	Agreement with Hippocratic Oath	83% supported the HO as basis for practice Agreement with individual rules varied from 22% to 100% 75% "always" and 25% "frequently" maintained confidentiality
Resnick <i>et al.</i> , 1992	Primary care doctors Paediatricians	476	Support for disclosure to family	75% in favour of confidential services for adolescents. Doctors who regularly provided services to adolescents, particularly sexual health services, more likely to support confidentiality
McSherry, 2008	Mental health professionals	?	Attitude to confidentiality and reporting	Most felt that legal rules were only frameworks within which ethical judgments would be made and justified.
Elger, 2009	Doctors	508	Attitudes to confidentiality	Length of experience, education in health law, and working in private practice and being female were associated with correctly identifying confidentiality issues in vignettes. In different cases "substantial minority" or "majority" failed to identify breaches correctly
Claiborn, 1994	Psychotherapy patients Public	96	Ethical practice	Patients and public both supported confidentiality

Appendix 1: Table 3: Patient views about confidentiality

REF	SUBJECTS	N	ISSUE	FINDING
VandeCreek <i>et al.</i> , 1987	Student counselling service clients	116	Preferred level of confidentiality	Most subjects preferred confidential arrangements Options of disclosure to family, college staff etc
Schmid <i>et al.</i> , 1983	Psychiatric inpatients	30	Utilitarian value of confidentiality	23/30 wanted info kept confidential 20/30 objected to breach of confidence 5/30 said they would leave treatment if breached
Miller & Thelen, 1986	Student counselling service clients	74	Knowledge of limits to confidentiality	69% believed everything was confidential 74% believed everything should be confide 10% would leave/42% limit disclosure if not confide Only 20% agreed with breach if others at risk
Lindenthal & Thomas, 1982b	Mental health patients	76	Concerns about breach of confidence	45% concerned about disclosure 22% deterred by concerns (less than public sample in same study) Patients overestimated likelihood of disclosure
Mechanic & Meyer, 2000	mental health breast cancer Lyme disease	30 30 30	Factors influencing trust	Confidentiality not the most important factor Trust is iterative and develops over time Confidentiality significantly greater concern for MH than other groups
Appelbaum <i>et al.</i> , 1984	Mental health OP	58	Views about confidentiality	76% would object to disclosure of information Only 21% were concerned that this might happen 28% had knowledge of legal rules about breach
Wardman <i>et al.</i> , 2000	GP patients	750	Knowledge of limits to confidentiality	>80% did not want admin staff to have access to records Poor knowledge of limits to confidentiality
Whetten-Goldstein <i>et al.</i> , 2001	HIV Outpatients	15	Experience of confidentiality	13/15 had experience of others learning HIV status without their consent Some (?n) would avoid care to prevent this
Hallowell <i>et al.</i> , 2003	Breast cancer	30	Sharing info in family	All supported sharing info but found the process more ethically difficult than expected. All subjects had chosen to have testing - ? views of those who didn't may differ
McGuire <i>et al.</i> , 1985b	Psychotherapy patients	76	Attitude to confidentiality	Patients valued confidentiality more than controls
Shuman & Weiner, 1982	Psychotherapy patients	80	Knowledge about legal privilege	27% of patients knew about legal rules: little evidence that this affected willingness to disclose in therapy
Flynn <i>et al.</i> , 2003	Mental health OP	80	Electronic records	Those with concerns about confidentiality/IT security were more likely to object to introduction of electronic records. Most of those with concerns would consider seeking "alternative care"
Hegarty & Taft, 2001	GP patients	1836	Disclosure of domestic abuse	43% of those who had disclosed said confidentiality was of "great importance"

Jones, 2003	GP patients	30	Attitude to confidentiality	100% expect confidentiality Between 40% and 80% support public interest disclosure in various situations 17% have already been deterred from full disclosure because of concern Contradictory answers from questionnaire and vignettes
Davies & Casey, 1999	Adolescent GP patients	110	Barriers to seeking health care	Confidentiality was most common of 7 issues, identified by 37% of subjects
Braaten & Handelsman, 1997	Patients Former pts students	35 47 42	Information expected for informed consent	Current student counselling patients (35) former patients (47) and college students (42) asked about what information they would want to receive as part of informed consent for counselling 2 confidentiality issues ranked 2 and 4 out of 28 issues listed (ranked 1 and 2 by former clients but given as ns) – equivalent to “important or extremely important”. No demographic differences
Weiss <i>et al.</i> , 1986	Hospital IP Primary care	224 161	Expectations of physician behaviour	>90% anticipated MDT sharing of info
Stanford <i>et al.</i> , 2003	Research participants (adolescents)	438	Factors influencing recruitment to research	Privacy was 4 th most important of 13 items
Weiss, 1982	Primary care patients	177	Expectation of disclosure	Patients expected disclosure for clinical reasons (MDT, second opinions) Underestimated disclosure by up to x4 compared to doctors in same study
Shuman <i>et al.</i> , 1986	Psychiatrists Patients Judges College students	188 134 70 124	Effect of privilege rules on disclosure in therapy	Few differences between Ontario/Quebec, suggesting formal privilege laws have little effect Overall about 40% of psychiatrists had been asked to testify, about 10% had done so. Judges say this is always with consent, but psychiatrists disagree. About 40% of psychiatrists believe disclosure impairs treatment and 22% of breach led to termination. About half of patients report concern about confidentiality; few know the privilege laws. College students less likely to disclose if not offered privilege, but lack of knowledge suggests this is not a significant factor in actual therapy.
Torres <i>et al.</i> , 1980	Teenage patients	1676 2411	Effect of parental notification on access to services	23% of abortion service patients would not attend if parental notification was required. Of contraception patients, 23% would not attend if parental notification required. If notification was universal, 125,000 teenagers per year (US) would not access contraception and 42,000 would not be able to obtain a legal abortion
Jenkins <i>et al.</i> , 2005	Women – patients and public	85	Beliefs about confidentiality	Generally high levels of belief in strict confidentiality – many subjects expecting even sharing within immediate team only with consent. Some (?how many) subjects described withholding certain info (particularly sexual and mental health) because of concerns Some (probably most?) patients have unrealistic expectations/understanding
Howerton <i>et al.</i> ,	Prisoners with MH	35	Willingness to	Trust was the major factor-linked to “the system” rather than confidentiality.

2007	problems		access services	
Carlisle <i>et al.</i> , 2006	Adolescents in hospital	20	Views on confidentiality	Wanted sexual/drug issues kept from parents. Females and older subjects more concerned. Would be deterred from treatment. Concern about handling of records
Slade <i>et al.</i> , 2007	Patients	91	Information sharing with carers	Patients views "dominated by one issue: the importance of confidentiality" and less supportive of disclosure than other groups. No discussion of deterrence.
Rodriguez <i>et al.</i> , 1996	Battered women	51	Barriers to care	Widespread concern about mandatory reporting/loss of control over response
Bayley <i>et al.</i> , 2009	Teenagers	48	Access to emergency contraception	Confidentiality was "a prominent concern" with anxiety about deliberate parental notification and accidental some wrongly believed parental notification was required
Pollack <i>et al.</i> , 2010	Female victims of domestic violence	1765	Concern about confidentiality	Of those who used occupational health services c40% "were concerned" about their employers finding out details, but not explored or compared with non-users of services
Ford & Millstein, 1996	Adolescents	786	Confidentiality assurances	Physicians do not consistently discuss confidentiality with their adolescent patients, most of those who do assure unconditional confidentiality which is not consistent with their professional guidelines.
Lyren <i>et al.</i> , 2006	Adolescents Parents	50 50	Knowledge of confidentiality rules	36% of adolescents and 96% of parents thought parents would be told everything. 90% of adolescents and 76% of parents thought confidentiality was important
Marshall & Solomon, 2000	Mental health patients Relatives	64 185	Disclosure of information to family members	Most relatives received limited information, often without specific consent being sought
Erwin & Peters, 1999	Black African patients with HIV	44	Barriers to health care	Generally low levels of trust in doctors not related to confidentiality. Concerns that family/community will learn of status, but not specifically about medical breach of confidentiality. Some specific concerns about being reported to immigration authorities.
Lapham <i>et al.</i> , 1996	Members of genetic support groups	332	Use of genetic information	20 - 30% thought they had been discriminated against in insurance, 10-15% in employment. Only 11% wanted results shared with insurance and 6% with employer. 10% had refused testing because of fear info would be misused
McKee <i>et al.</i> , 2006	Adolescent girls mothers	18 22	Attitudes to confidentiality in sexual health	Mothers see confidentiality as promoting risky behaviour Girls report concern about breach and lack of trust in doctors as barriers (frequencies not given)
Petchey <i>et al.</i> , 2000	HIV +ve patients	20	Access to health care	GUM clinic was perceived as offering better confidentiality, which was highly valued
Thomas <i>et al.</i> , 2006	Adolescents	295	Access to sexual health services	56% gave confidentiality as the most important aspect of a sexual health service. Over half would not use a service if not confidential. 80% opposed reporting of patient at risk of abuse. 46% do not want Gp to be informed
Wadsworth & McCann, 1992	HIV +ve men	263	Disclosing status to GP	Some concern about confidentiality –release of information within GP practice or to insurers. Frequency not given
Hardin &	Students	40	Expectations about	High expectations of "trustworthiness" (no specific question about confidentiality).

Subich, 1985	Counselling clients	78	counselling	No differences between groups
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Appendix 1: Table 4: Public views about reporting

REF	SUBJECTS	N	ISSUE	FINDING
Miller & Thelen, 1986	School students College students	508	Knowledge of limits to confidentiality	69% believed everything was confidential 74% believed everything should be confide 10% would leave/42% limit disclosure if not confide Only 20% agreed with breach if others at risk
Lindenthal & Thomas, 1982b	General public	76	When should psychiatrists disclose information about patients?	48% were concerned about disclosures and 33% said this was a barrier to seeking help Public expected that psychiatrists would disclosure more than psychiatrists said they actually would
Knowles & McMahon, 1995	Public	256	Should psychologists disclose information in various situations?	There was support for disclosure in cases of risk of murder or suicide, and child abuse, but less support when the issue was drug abuse or theft Least concern about disclosure to other clinicians, most concern about disclosure to family members
Ormrod & Ambrose, 1999	Public	153	Do people believe discussions with professionals are or should be confidential?	About 2/3 believed discussion with various doctors would be completely confidential, but 90% believed they should be Less for other professionals – subjects thought discussions should be confidential much more often than they thought they would be 53% supported disclosure (always or usually) for sexual abuse and 37% for murder; 43% and 39% thought this would happen
Gielen <i>et al.</i> , 2000	General public, female	1988	Should health staff be obliged to report domestic violence?	86% support routine enquiry 67% believed MR would deter some victims from disclosing 53% opposed MR (higher in subjects who were victims) “Support for mandatory reporting was not high in this sample”
Faustman & Miller, 1987	College students	61	Should therapists report child abuse disclosed by client?	82% supported reporting 88% thought clients would be unlikely to disclose if they knew it would be reported
Rubanowitz, 1987	Public	104	Should therapist breach confidentiality in various hypothetical situations?	Majority favoured breach in 7 out of 8 situations where a third party was at risk Majority against disclosure in situations where no-one at risk
Collins & Knowles, 1995	School students	557	Breach of confidentiality by school counsellor	53% said confidentiality was essential; 42% important Majority supported disclosure when danger to self or others, not in cases involving sexual health
Cheng <i>et al.</i> , 1993	School students	1295	Is perceived lack of confidentiality a barrier to adolescent health care?	58% of subjects had health issues they wanted to keep from parents 25% had already foregone health care because of concerns 81% supported breach of confidentiality when patient at risk
Shuman <i>et al.</i> ,	Psychiatrists	188	Effect of privilege rules	Few differences between Ontario/Quebec, suggesting formal privilege laws

1986	Patients Judges College students	134 70 124	on disclosure in therapy	have little effect Overall about 40% of psychiatrists had been asked to testify, about 10% had done so. Judges say this is always with consent, but psychiatrists disagree. About 40% of psychiatrists believe disclosure impairs treatment and 22% of breach led to termination. About half of patients report concern about confidentiality; few know the privilege laws. College students less likely to disclose if not offered privilege, but lack of knowledge suggests this is not a significant factor in actual therapy.
Eisenberg <i>et al.</i> , 2005	Parents	1069	Attitude to parental notification laws	55% supported notification 96% anticipated at least one negative consequence (out of 6 possibilities presented) 56% anticipated deterrence to obtaining contraception 48% anticipated deterrence to attending clinic Significant number of contradictory responses which were not explored or reconciled
Guedj <i>et al.</i> , 2006	Public Psychologists/doctors	144 17/7	Notifying spouse of STD	French study. Doctors very opposed to disclosure. Public/psychologists split – a few always for or against; most influenced by various factors but supported balancing approach.
Slade <i>et al.</i> , 2007	MH profs Patients Carers	595	Information sharing with carers	Patients very concerned about confidentiality and less supportive of disclosure than other groups. No discussion of deterrence.
Sachs <i>et al.</i> , 2002	General public - women	?	Support for mandatory reporting of domestic violence	Abused women significantly less likely to support MR (59% vs 73%). Deterrence was the main reason for opposing MR (76% of all subjects recognized this), also resentment at loss of control, increased risk from partner
Fisher <i>et al.</i> , 1996	Adolescents	147	Whether researchers should report risk	Encouraging self-referral supported more than breach of confidentiality – support for breach in cases of child abuse and suicidal thoughts, not for drug abuse, delinquent behaviour and shyness
Guedj <i>et al.</i> , 2009	Public Various professionals	15 33	Willingness to breach confidentiality	Generally public more in favour of breach than profs. Overall, 12% always supported breach, 15% always supported confidentiality, 74% depended in circumstances
Ovens <i>et al.</i> , 2009	Emergency med doctors Public	267 1001	Mandatory reporting law for gunshot wounds	88% of doctors willing to comply. Only 6% thought it would decrease trust in doctors. 6 doctors had experience of patient delaying seeking care because of law 95% of public supported law, 18% said it would make them less likely to trust doctors

Appendix 1: Table 5a: Professional views about reporting

REF	SUBJECTS	N	ISSUE	FINDING
Lindenthal & Thomas, 1982b	Psychiatrists	192	Likelihood of disclosure in various situations	Psychiatrists were less likely to disclose than non-patients expected, but more likely than patients expected
Watson, 1999	MH workers	48	Threshold for reporting	High levels of support for disclosure 57% to 100%. Except in lowest risk case, 90%+ in other cases. Very diverse views about who to disclose to – generally no more than 20% for any one agency
Beran, 2002	Medico-legal experts	42	Views about professional confidentiality in epilepsy	37/42 supported privilege, but only 6 thought it should be absolute (even then most thought doctor should have discretion to report) 28/42 thought there was a duty to report risky driver
Goesling <i>et al.</i> , 2000	Psychologists	195	How do psychologists judge therapist's behaviour in breaching confidentiality?	Disclosure to insurance company less serious than disclosure to another client Disclosure in client's interest less serious than disclosure for other reasons
Miller <i>et al.</i> , 1999	Family Planning clinicians	68	Mandatory reporting of under-age sex	80% agreed with strong enforcement of statutory rape laws 40% believed that this would deter teenagers from health care 37% believed health care workers should be exempt from reporting laws
Thelen <i>et al.</i> , 1994	Psychologists	330	Attitudes to confidentiality	25% believed in absolute confidentiality, 70% did not. Those who did were less likely to be willing to report in various situations, and more likely to anticipate damage to therapeutic relationship
Simone & Fulero, 2001	Psychologists	253	Would psychologists notify public health and/or partner in case of HIV or hepatitis?	Overall 34% would notify a sexual partner, 39% would inform GP, 50% would inform public health. More likely in HIV than hepatitis
Rae <i>et al.</i> , 2002	Paediatric psychologists	80	Would psychologists report various risk behaviours in teenagers (risk to own health)	Generally low support in most situations; to some degree increased with more risky and more frequent behaviour
Sullivan <i>et al.</i> , 2002	Paediatric psychologists	74	What factors influence decision to inform parents of adolescent risk behaviour	Seriousness of risk was most significant factor. Risk of disrupting therapy came 11 th out of 13 factors
Schwartzbaum <i>et al.</i> , 1990	Primary care physicians	199	Would doctor report HIV status to public health board/sexual partner without consent?	28% would not report, 50% would report to health board, 22% to partners (these options were exclusive)
Morris <i>et al.</i> ,	Primary care physicians	58	Factors influencing decision to	Higher rates of reporting when considering case details than

1985	Paediatricians GPs	31 28	report various cases of possible NAI	when asked theoretically Only 22% referred to fear of patient leaving treatment as a consideration Reporting rates up to 95% for extreme bruising, but as low as 58% in one scenario authors rate as "definite report" and as low as 7% in one rated "probable report"
Weinstock & Weinstock, 1988	Forensic psychiatrists and psychologists	62	When should therapists report?	Past child abuse – 38% thought reporting unethical, 10% not Threats of violence when risk low – 66% thought report unethical, 29% not
Jagim <i>et al.</i> , 1978	Mental Health professionals	64	Attitudes to confidentiality	98% said confidentiality was essential to therapeutic relationship 98% said maintaining confidentiality was an ethical duty 95% said clients expect confidentiality 76% were prepared to report if third party at risk
Lindenthal <i>et al.</i> , 1988	Social workers	66	Likelihood of reporting in range of situations	More likely to disclose than doctors/psychologists in previous studies. No data on rates of willingness to report
Lindenthal & Thomas, 1982a	Junior doctors	131	Would risk be reported	Doctors more likely to breach confidentiality than patients either expected or wanted. Actual rates not reported
Lindenthal <i>et al.</i> , 1985	Psychiatrists Psychologists	288 169	Support for confidentiality/disclosure in different countries	Differences small. Profession has more effect than country. Not possible to determine actual rates of support for reporting
Palma & Iannelli, 2002	Doctoral psychology students	68	Reporting HIV positive status to sexual partners	10 vignettes about HIV patient at risk of infecting others, 8 varying by gender, sexual orientation, sexual practices, plus drug user and prostitute. Asked about disclosure to partners More likely to breach confidentiality with unsafe practice, in line with guidelines. Smaller effect of combination of gender and orientation suggests some bias
Lindenthal & Thomas, 1980	Psychiatrists Psychologists Physicians	388 203 477	Attitude to public interest disclosure	10 vignettes of clinical dilemmas – varying levels of risk Psychologists least likely to support breach, psychiatrists middle, physicians most. Psychiatrists closer to psychologists than physicians. Support for disclosure increased with increasing risk
Wise, 1978	Psychiatrists Psychologists	179 1073	Effect of <i>Tarasoff</i> on practice	79% believed patients would be less likely to divulge info if not completely confidential 96% believed all or most patients believed confidentiality was absolute 11% always discussed confidentiality with patients, 70% "sometimes"

				<p>70% supported breach in certain circumstances, 26% supported absolute confidentiality standard)</p> <p>25% reported observing reluctance to disclose after learning about limits to conf</p> <p>50% had given at least one warning pre-<i>Tarasoff</i>, 38% in the first year after</p> <p>20% discussed confidentiality with patients more frequently than before., 27% focused more on dangerousness than before.</p> <p>54% reported increased anxiety of being sued following <i>Tarasoff</i>.</p> <p>16% reported avoiding particular issues, including dangerousness. "Several" reported no longer working with dangerous patients</p> <p>Overall 89% reported at least one aspect of change to behaviour resulting from <i>Tarasoff</i></p>
Kalichman <i>et al.</i> , 1990	Psychologists	295	Do characteristics of abuser influence decision to report child abuse?	<p>Only very minor differences found</p> <p>All subjects had clinical experience of child abuse; only 65% had reported it</p>
Beran, 1997	Professionals	19	Reporting epileptic drivers	<p>Contradictory results. Most supported discretion but said doctor should have duty to report, but no be liable for failure to report</p>
Swoboda <i>et al.</i> , 1978	Psychologists Psychiatrists Social Workers	31 22 35	Knowledge of privilege & reporting law	<p>26% "unfamiliar" with privilege law, 17% with child abuse reporting – for both SW better than psychiatrists better than psychologists</p> <p>66% would NOT report abuse (psychologists 87%, psychiatrist 63%, SW 50%)</p> <p>63% of professionals familiar with child abuse reporting law would not follow it</p>
Muehleman & Kimmons, 1981	Psychologists	39	Factors influencing reporting of child abuse	<p>18(46%) would report immediately, 19(49%) would not, 2 unclear</p> <p>Non-reporters would all report eventually, but try other things first</p> <p>Only 33% spontaneously referred to confidentiality</p> <p>Given choice, 31% considered legal rules the most important thing, 61% considered child's life the most important, 0 considered confidentiality most important. A number felt "the law overrides personal ethics" – some concerned about liability</p>

				41% ranked law third (behind child and confidentiality) – none would report automatically
Jensen & Nicholas, 1984	Psychology students	385	Factors influencing reporting of child abuse	Varied in terms of social desirability of abuser/child Socially unattractive child more likely to be reported Unattractive child and adult was the combination most likely to be reported – other comparisons ns
Botkin & Nietzel, 1987	Psychologists	101	Options in managing dangerous patient	46 options combined into 9 subscales Confidentiality (4 options) was the 4 th most frequently chosen subscale (after hospitalisation, maintaining rapport and manipulating environment).
Baird & Rupert, 1987	Psychologists	188	Informing of limits and breaching confidentiality	61% usually discuss confidentiality from the onset of therapy – 12% of total telling clients that confidentiality is absolute. Those with experience of breach more likely to discuss limits. More likely to discuss these limits with a dangerous client. Only one subject would “never” breach conf with a dangerous client Almost 40% said they had become more willing to disclose, with Tarasoff the most frequently cited reason (only 49% overall said they were familiar with the case). 21% had become less likely to disclose, usually as a result of experience of poor outcome from a previous breach
Kalichman <i>et al.</i> , 1989	Psychologists	279	Factors influencing reporting of CSA	Vignette re child abuse, varying child male/female, father admits/denies, therapist expects positive/negative outcome from reporting. Admitting father and positive expectation more likely to be reported 37% expected reporting usually to have a negative effect on families, only 14% expected positive. 42% expected negative effect on therapy; 21% positive Less than 20% believed reporting laws provided the best alternative. Subjects aware of reporting laws but “few would definitely report the case”.
Kalichman & Craig, 1991	Psychologists	328	Factors influencing reporting of CSA	vignettes varying age, father/stepfather, physical/sexual abuse, explicit report by child and cooperative/uncooperative father.. Very high rates of anticipated reporting – c 70% definitely and 20% probably. “across all conditions only 3% of respondents indicated that they would tend not to report”. But 37% indicated

				a previous failure to report in practice. More likely to report younger, explicit complaint by child, refusal of father to cooperate Likelihood of reporting increased with increasing certainty of abuse taking place.
Totten <i>et al.</i> , 1990	Psychologists	241	Reporting decisions involving HIV	4 possible situations (high/low risk; identifiable/nonidentifiable victim) Much more likely to breach in high risk scenarios – v low support for breach in low risk Significant but small effect of identifiability (rather more likely to breach if identifiable) Those who did not work with HIV clients were more likely to support breach (but difference small)
Graham <i>et al.</i> , 2001	GPs	486	Provision of contraception without parental consent	Only 8 (1.6%) would inform parent
Perkins <i>et al.</i> , 1988	CMHT workers	95	Disclosure of confidential info	70-90% would maintain confidentiality in 4 separate situations (not risk to others).
Cable <i>et al.</i> , 2000	Geriatricians	386	Knowledge and practice in reporting dementia to driving authorities	29% do not know the local reporting procedures 76% agree physicians should be responsible for reporting 92% would contact authorities in a hypothetical case 86%/73% would do so even if patient/family objected.
Wiskoff, 1960	Psychologists	369	Willingness to disclose in interest of others	Industrial psychologists more likely to support breach than clinical/counseling psychologists but small differences Gives 3 examples – 64% would disclose in threatened homicide, 45% in treason, 42% in suicide. Not stated whether these were typical, or the highest figures.
Miller & Weinstock, 1987	SOTP therapists	50	Mandatory reporting of child abuse	Most knew rules, but significant numbers didn't. Few actual reports, and general reluctance to follow rules – clinical judgement used instead
Weiss, 1982	Junior doctors Medical students	109 53	How likely to disclose patient information in different situations?	Doctors more likely to disclose info than patients expected (up to 4x in some circumstances). Medical students (in first 60 days of course) more like doctors than patients in their expectations
Suarez & Balcanoff, 1966	Psychiatrists	487	Rules governing legal privilege	24% didn't know local rule. 92% wanted legal privilege – limited support for exceptions
Kalichman <i>et al.</i> , 1988	Mental Health Workers	101	Factors influencing reporting of child abuse	Child's reaction contributed to certainty that abuse was taking place. 81% would "tend to report" the presented case – more likely to

				<p>report with higher certainty that abuse was taking place/explicit report by child</p> <p>89% of non-reporters indicated doubt whether abuse was taking place was the major factor</p> <p>Although law requires reporting of suspicion, clinicians reluctant to do this when unsure</p> <p>Concern about therapeutic relationship was not reported by many subjects</p>
Givelber <i>et al.</i> , 1984	Psychiatrists, psychologists & SW	1722	Knowledge and response to <i>Tarasoff</i>	<p>Most knew of decision (90%+ in California) but most believed there was duty to warn. Compliance higher in California than elsewhere, but c 80% agreed with duty. Concluded that <i>Tarasoff</i> did lead to change in practice, despite misunderstandings (also reported in #3894)</p>
Rosenhan <i>et al.</i> , 1993	Psychiatrists/psychologists	1800	Knowledge and response to <i>Tarasoff</i>	<p>84% knew of case but <50% knew current rules. 60% believed some patients were deterred and 28% reported a patient leaving therapy. 46% avoided violent patients</p>
Crenshaw <i>et al.</i> , 1995	Teachers	664	Factors influencing decision to report abuse	<p>97% aware of MR rules; only 10% felt well-prepared to identify and report abuse</p> <p>Given 5 scenarios (suspected neglect; suspected emotional/physical/sexual abuse; disclosed abuse). 87%,35%, 91%,77%,96% would disclose</p> <p>Certainty/evidence was the strongest factor; damage to positive relationship with child generally a minor factor, and not significantly different between reporters and non-reporters.</p> <p>Legal rules were not a major factor</p>
Anderson <i>et al.</i> , 1993	Psychotherapists Child protection workers	30 25	Effects of mandated reporting	<p>Subjects accepted reporting as necessary but found it stressful: many had "serious doubts about whether a report actually helps the child". Resented intrusion of law on therapy; undermined professional responsibility</p> <p>Some therapists described positive outcomes in producing change</p> <p>Description of using reports to force attendance, but also of clients leaving therapy because of reports – generally coercive treatment seen as ineffective (particularly when therapy starts in consequence of a report)</p>
Nicolai & Scott, 1994	Psychologists	204	Information giving practice and effect on disclosure	<p>54% always and 26% often provide info about limits to confidentiality – mostly oral only.</p> <p>80% made some mention of specific circumstances such as</p>

				<p>child abuse. 52% would definitely or probably report – higher in those who always provide info in their own practice. Approx 40% of subjects would probably or definitely not report, even though 96% of them were certain abuse was occurring.</p>
Zellman, 1990b	Various professionals	1196	Factors influencing reporting	<p>“mean” likelihood of reporting was 68/100 (ie between 3 and 4 on the 5 point scale used) Not stated how many would/would not Scenarios with clear description of abuse more likely to be reported Seriousness of abuse, perceived legal requirement to report, anticipated benefit all positively correlated with likelihood of report. – legal requirement was strongest predictor. Higher rates of perceived legal requirement in cases of sexual abuse, but also perceived as reports more likely to be detrimental</p>
Shuman <i>et al.</i> , 1986	Psychiatrists Patients Judges College students	188 134 70 124	Effect of privilege rules on disclosure in therapy	<p>Few differences between Ontario/Quebec, suggesting formal privilege laws have little effect Overall about 40% of psychiatrists had been asked to testify, about 10% had done so. Judges say this is always with consent, but psychiatrists disagree. About 40% of psychiatrists believe disclosure impairs treatment and 22% of breach led to termination. About half of patients report concern about confidentiality; few know the privilege laws. College students less likely to disclose if not offered privilege, but lack of knowledge suggests this is not a significant factor in actual therapy.</p>
Rodriguez <i>et al.</i> , 1999	Physicians	508	Compliance with mandatory reporting of domestic violence	<p>All had high levels of knowledge of law (70-81%), experience of domestic violence patient (74-99%), recent training (19-45%). Emergency physicians higher than others in all of these. Overall willingness to report overriding objection was 41%, highest in emergency phys (75%) – 59% prepared to disregard MR law. 60-79% recognised risk of deterrence; 17-45% thought doctors are deterred from asking by MR laws. 59-80% perceived MR as violating ethical standards (but not all saw this as unacceptable)</p>
Pope <i>et al.</i> ,	Psychologists	456	Standards of ethical practice	6% say unethical to breach confidentiality if client homicidal;

1987				58% have done it, 41% often 12% if client suicidal, 79% have done, 28% do it often 5% if child abuse, 62% have done, 30% do it often
Ford & Millstein, 1997	Physicians	786	Forewarning practice with adolescents	Physicians discussed confidentiality with 53% of adolescent patients. When discussed, 64% promised unconditional confidentiality, 36% conditional 63% correctly identified legal guidelines, 31% unsure, 5% incorrect
Perez-Carceles <i>et al.</i> , 2006	Family doctors	227	Informing parents of adolescents' health care	90% would always inform parents of life-threatening conditions (presumably even without consent but this is not clear) 39% would inform parents of <16 (?of all consultations?)
Guedj <i>et al.</i> , 2006	Public Psychologists/doctors	144 17/7	Notifying spouse of STD	French study. Doctors very opposed to disclosure. Public/psychol split – a few always for or against; most influenced by various factors but supported balancing approach.
Rodriguez, 2002	MH/GP/psychol/teacher	255	Attitude to mandatory reporting	Generally high accuracy in reporting decision; resistance to MR associated with somewhat lower accuracy (presumably reluctance to report, bit not clear)
Slade <i>et al.</i> , 2007	MH profs Patients Carers	175 91 329	Information sharing with carers	90% would share information when risk to others (only 60% of patients support this). No discussion of deterrence.
Bowers <i>et al.</i> , 1986	Psychiatrists, psychologists & SW	1722	Knowledge and response to <i>Tarasoff</i> in 1980	Most knew of decision (90%+ in California) but most believed there was duty to warn. Compliance higher in California than elsewhere, but c 80% agreed with duty. Concluded that <i>Tarasoff</i> did lead to change in practice, despite misunderstandings (also reported in #3894)
Saulsbury & Campbell, 1985	Paediatricians/GPs	307	Reporting of child abuse	High support for reporting (>90%), but low levels of actual reporting, associated with uncertainty of diagnosis. Only 6% concerned about deterrence
Weinstock & Weinstock, 1989	Forensic psychiatrists	97	Reporting dilemmas	2/3 "saw ethical problem" associated with reporting past abuse of adult patient, and reporting non-imminent threats (v similar figures for both)
Anderson, 2008	Doctors in sports medicine	16	Confidentiality of health information from employer	Most (10/16) willing to keep health info confidential from employer/team
Attias & Goodwin, 1985	Psychologists, psychiatrists, paediatricians and family counsellors	108	Reporting to child protection	1/3 would not refer to protective services a child who made and then retracted an incest allegation. Females more likely to report than males.

Blower & Cohen, 1997	Psychiatrists	53	Confidentiality	Postal survey giving hypothetical scenarios – Psychiatrists do not in general warn, and are likely to respect confidentiality.
Isaacs & Stone, 2001	Mental Health counsellors	608	Attitudes to confidentiality with minor clients	Most would not breach for various behaviours including cannabis use and sexual activity, but would breach for significant depression, cocaine use or “shooting incidents” (98% report this). Willingness to breach increases with younger age of client
Isaacs, 1999	School guidance counsellors	627	Attitudes to confidentiality	General support for breach in various situations: Increases with degree of risk and with lower age of client. Around 60% for risk of harm/sexual activity and >90% for potentially fatal situations
James <i>et al.</i> , 1978	Primary care physicians Paediatricians	96	Reporting of child sexual abuse	Only 42% would report “any case”. For not reporting, 2/3 gave reason as reporting “would be harmful” 1978 paper generally supportive of discretion/non-report
Moatti <i>et al.</i>	French GPs	313	Disclosing information	>75% supported disclosure to other health profs <25% supported disclosure to other groups, inc sexual partners and public health and social workers
Roberts <i>et al.</i> , 2005	Medical students	955	Willingness to report impaired colleague	Overall only 13% would notify authorities : more for mental health problems, less for physical health
Guedj <i>et al.</i> , 2009	Public Various professionals	15 33	Willingness to breach confidentiality	Generally public more in favour of breach than profs. Overall, 12% always supported breach, 15% always supported confidentiality, 74% depended in circumstances
Ovens <i>et al.</i> , 2009	Emergency med doctors Public	267 1001	Mandatory reporting law for gunshot wounds	88% of doctors willing to comply. Only 6% thought it would decrease trust in doctors. 6 doctors had experience of patient delaying seeking care because of law 95% of public supported law, 18% said it would make them less likely to trust doctors

Appendix 1: Table 5b: Professional views about reporting – actual behaviour

REF	SUBJECTS	N	ISSUE	FINDING
Crenshaw & Lichtenberg, 1993	Mental Health professionals	428	Do professional warn patients of MR of child abuse	37% always forewarn 36% only forewarn if abuse suspected 20% only warn after abuse disclosed
McNeil <i>et al.</i> , 1998	Review of statutory notifications	337	Factors influencing reporting	C 100 reports/year in San Francisco compared to 4600 detentions for imminent dangerousness. Only half of reports led to detention. Disproportionate use in male, black, younger, crim record
Beck, 1982	Psychiatrists	38	Experience of reporting	Interview of 38 non-random psychiatrists 12 had considered giving warnings but hadn't, 10 had never considered it 16 had given warnings on 26 occasions; range of diagnosis Only 1 actually injured victim, that was 2 years later Effect on d-p relationship: 2 positive, 4 negative, 13 none, 7 warnings given after end of therapy 15 discussed before disclosure (1 negative outcome) 4 not discussed, 3 -ve
Pope & Bajt, 1988	Psychologists	100	Adherence to various ethical standards	57% admitted to breaking some ethical rules (inc breach of confidentiality and failure to report) 77% believed justified in breaking rules to promote patient welfare
Harper & Irvin, 1985	Psychologists	525	Factors influencing reporting of child abuse	Approx 1/3 had previous non-reporting. More likely to report if physical signs or explicit statement of abuse. Compared 2 states with diff laws about reporting adult pts. Non-sig trend to greater reporting in line with different rules, smaller effect than other factors.
Kalichman & Brosig, 1992	Psychologists	525	Factors influencing reporting of child abuse	Approx 1/3 had previous non-reporting. More likely to report if physical signs or explicit statement of abuse. Compared 2 states with different laws about reporting adult pts. Non-sig trend to greater reporting in line with different rules, smaller effect than other factors..
Kalichman & Brosig, 1993	Psychologists	246	Factors influencing reporting of child abuse	32% had failed to make mandatory report at least once Consistent reporters rated legal duties and concerns about child higher, inconsistent reporters rated effect on family/patient, degree of suspicion as more important
Pope & Vetter, 1992	Psychologists	679	Ethical issues encountered in practice	703 incidents reported, categorized into 23 areas. Confidentiality (128 reports, 18%) was the most frequent reported of which 38 (5% of total) involved third party risks. Discussion of civil disobedience.
Wise, 1978	Psychiatrists Psychologists	179 1073	Effect of <i>Tarasoff</i> on practice	79% believed patients would be less likely to divulge info if not completely confidential 96% believed all or most patients believed confidentiality was absolute

				<p>11% always discussed confidentiality with patients, 70% “sometimes” 70% supported breach in certain circumstances, 26% supported absolute confidentiality standard) reported observing reluctance to disclose after learning about limits to conf 50% had given at least one warning pre-<i>Tarasoff</i>, 38% in the first year after 20% discussed confidentiality with patients more frequently than before., 27% focused more on dangerousness than before. 54% reported increased anxiety of being sued following <i>Tarasoff</i>. 16% reported avoiding particular issues, including dangerousness. “Several” reported no longer working with dangerous patients Overall 89% reported at least one aspect of change to behaviour resulting from <i>Tarasoff</i></p>
Kalichman <i>et al.</i> , 1990	Psychologists	295	Do characteristics of abuser influence decision to report child abuse?	<p>Only very minor differences found All subjects had clinical experience of child abuse; only 65% had reported it</p>
Binder & McNeil, 1996	Psychiatrists	46	Frequency of <i>Tarasoff</i> reports	<p>Almost half had made a report – suggests about 1 report per 4 years of practice. 11 out of 15 victims warned already knew of danger 8 out of 23 patients were angry, negative impact on therapy in 5 cases</p>
Kalichman & Craig, 1991	Psychologists	328	Factors influencing reporting of CSA	<p>vignettes varying age, father/stepfather, physical/sexual abuse, explicit report by child and cooperative/uncooperative father.. Very high rates of anticipated reporting – c 70% definitely and 20% probably. “across all conditions only 3% of respondents indicated that they would tend not to report”. But 37% indicated a previous failure to report in practice. More likely to report younger, explicit complaint by child, refusal of father to cooperate Likelihood of reporting increased with increasing certainty of abuse taking place.</p>
Abramson, 1990	Social workers	16	Dilemmas in working with HIV patients	<p>Secrecy/confidentiality was the most frequently mentioned and most problematic. Differing practice re 3rd party – support for disclosure and for confidentiality. No numbers given</p>
Mclachlan, 1997	Neurologists	289	Reporting of seizures/other disorders to driver licensing agency	<p>50% reported seizures; 26% dementia; 4% stroke; 8% other Seizures reported (all or most of the time)by 84% in provinces with mandatory reporting, 19% in other provinces. 44% supported MR in principle</p>
Nicolai & Scott, 1994	Psychologists	204	Information giving practice and effect on disclosure	<p>54% always and 26% often provide info about limits to confidentiality – mostly oral only. 80% made some mention of specific circumstances such as child abuse.</p>

				52% would definitely or probably report – higher in those who always provide info in their own practice. Approx 40% of subjects would probably or definitely not report, even though 96% of them were certain abuse was occurring. Those who reported previous failure to report more likely not to report in the vignette.
Perez-Carceles <i>et al.</i> , 2005	Family doctors	277	Disclosure of info to families	95% provide information to other family members 35% do so without consent (contrary to Spanish law)
Zellman, 1990a	Child care professionals	1128	Failure to comply with mandatory reporting	Child MH professional had highest levels of non-reporting, 19% explicitly mentioned deterrence/effect on Rx
McNaughton <i>et al.</i> , 2006	Obstetricians	110	Reporting of illegal abortions	56% reported (authors argue this is unethical) 86% expect patients to be deterred by reporting

Appendix 1: Table 6 Patient views about reporting

REF	SUBJECTS	N	ISSUE	FINDING
Miller & Thelen, 1986	Student counselling service clients	74	Knowledge of limits to confidentiality	69% believed everything was confidential 74% believed everything should be confide 10% would leave/42% limit disclosure if not confide Only 20% agreed with breach if others at risk
Appelbaum <i>et al.</i> , 1984	Mental health OP	58	Views about confidentiality	76% would object to disclosure of information Only 21% were concerned that this might happen 28% had knowledge of legal rules about breach
Blatchford <i>et al.</i> , 2000	Patients treated by doctor with HepB	291	Notification of past exposure	93% always wanted to be notified of possible exposure, even if low risk. 3% unsure and 3% depended on circumstances.
Jones, 2003	GP patients	30	Attitude to confidentiality	100% expect confidentiality Between 40% and 80% support public interest disclosure in various situations 17% have already been deterred from full disclosure because of concern Contradictory answers from questionnaire and vignettes
Lindenthal & Thomas, 1982a	General medical in-patients	76	Deterrence from treatment	Patients were less likely than doctors/non-patients to support breach in vignettes 24% had been deterred from seeking treatment (higher in non-patient group)
Rodriguez <i>et al.</i> , 2001a	Emergency room patients	1218	Mandatory reporting of domestic violence	Non-abused subjects supported mandatory reporting (71%) but only 56% of abused subjects wanted this
Rodriguez <i>et al.</i> , 2002	Abused women	358	Attitude to mandatory reporting of domestic violence	68% opposed mandatory reporting but 92% favoured some form of reporting by physician Subjects with recent experience of abuse more likely to oppose MR Younger subjects more likely to oppose MR
Coulter & Chez, 1997	Victims of domestic violence	45	Attitude to mandatory reporting	Only 2% made first disclosure to health profession – most to friend/family 80% supported a duty for health professionals to report (NB much higher than other studies) and 73% thought this would help victims
Houry <i>et al.</i> , 1998	ER attenders Domestic Violence victims	517 60	Attitudes to Mandatory reporting	55% aware of MR rules 12% would be deterred from seeking treatment for DV because of MR rules more in men than women, which is unexpected. No greater in support group subjects.
Sullivan & Hagen, 2005	Survivors of domestic violence	61	Attitude to mandatory reporting	Strongly opposed by all but 1 of subjects
Rodriguez <i>et al.</i> , 1996	Battered women	51	Barriers to care	Widespread concern about mandatory reporting/loss of control over response

Sachs <i>et al.</i> , 1999	DV victims	95	Mandatory reporting	55% supported 41% opposed. 48% would be less likely to disclose.
Malecha <i>et al.</i> , 2000	Abused women	161	Mandatory reporting of domestic violence	81% supported – these were women who had reported to police/public protection agencies
Rodriguez <i>et al.</i> , 1998	Abused women	51	Mandatory reporting of domestic violence	Most opposed mandatory reporting and feared negative outcomes. Suggests that deterrence would be common
Benkendorf <i>et al.</i> , 1997	1st degree relatives of breast cancer patients	238	Reporting of genetic test info	%s opposing reporting without consent: to employer, 97%; to insurer, 95%; to spouse 84% to immediate family 87%
Lapham <i>et al.</i> , 1996	Members of genetic support groups	332	Use of genetic information	20 - 30% thought they had been discriminated against in insurance, 10-15% in employment. Only 11% wanted results shared with insurance and 6% with employer. 10% had refused testing because of fear info would be misused
Thomas <i>et al.</i> , 2006	Adolescents	295	Access to sexual health services	56% gave confidentiality as the most important aspect of a sexual health service. Over half would not use a service if not confidential. 80% opposed reporting of patient at risk of abuse. 46% do not want GP to be informed

Appendix 1: Table 7 Public views about deterrence

REF	SUBJECTS	N	ISSUE	FINDING
Miller & Thelen, 1986	School students College students	508	Knowledge of limits to confidentiality	69% believed everything was confidential 74% believed everything should be confide 10% would leave/42% limit disclosure if not confide Only 20% agreed with breach if others at risk
Lindenthal & Thomas, 1982b	General public	76	When should psychiatrists disclose information about patients?	48% were concerned about disclosures and 33% said this was a barrier to seeking help Public expected that psychiatrists would disclosure more than psychiatrists said they actually would
Hecht <i>et al.</i> , 2000	Public at "high risk" for HIV	2404	Are people at risk of HIV deterred from testing by notification to public health agencies?	Only 15% knew the local policy for reporting Of 17 reasons for avoiding testing, concern of reporting was the 9 th commonest – no different in states with named or anonymous reporting. Only 1% of untested individuals gave this as the main reason. No evidence of significant deterrence
Gielen <i>et al.</i> , 2000	General public, female	1988	Should health staff be obliged to report domestic violence?	86% support routine enquiry 67% believed MR would deter some victims from disclosing 53% opposed MR (higher in subjects who were victims) "Support for mandatory reporting was not high in this sample"
Nowell & Spruill, 1993	Students	75	Willingness to disclose in therapy	Less willing to disclose if given warning about limits to confidentiality, but increased detail didn't have additional effect
Ford <i>et al.</i> , 2001	School students	53	Do adolescents expect that doctors will pass on details of consultation to parents?	In general subjects overestimated the amount of information that would be passed to parents.. Giving an assurances of confidentiality was only partially successful in overcoming this
Faustman & Miller, 1987	College students	61	Should therapists report child abuse disclosed by client?	82% supported reporting 88% thought clients would be unlikely to disclose if they knew it would be reported
Shuman & Weiner, 1982	College students	121	Is legal privilege necessary for practice of psychotherapy?	Students were equally willing to enter therapy, but percentage willing to discuss sensitive topics would drop from 77% to 57% if no privilege offered
Merluzzi & Brischetto, 1983	College students	200	Would trust in therapist be reduced by breach of confidentiality?	Therapists who breached confidentiality were rated a significantly less trustworthy
O'Malley <i>et al.</i> , 2000	School students	34086	Would reporting of drug use vary when promised confidentiality or anonymity?	Offering anonymity produced moderate increase in reporting, mostly among younger age group.
Singer <i>et al.</i> ,	General public	3478	Exploration of reasons for	Most subjects had few concerns about confidentiality, but those that did had

1993			census non-returns	higher rates of non-return
Ford <i>et al.</i> , 1997	School students	562	Does confidentiality affect willingness to consult/disclose?	When therapist promised confidentiality, he was rated as more acceptable, and subjects would be more willing to disclose to him. 17% of sample reported past avoidance of health care because of concerns about confidentiality
Lindenthal & Thomas, 1982a	General public	76	Are concerns about breach of confidentiality a deterrent to treatment?	50% were concerned about possible breach of confidentiality, and 41% said they were deterred to some extent from seeking treatment
Anon, 1962	Public Profs	108 151	Legal privilege	Most thought info was privileged, and should be. About half of patients anticipated deterrence. Strong support from subjects and authors for strong/absolute privilege
Cheng <i>et al.</i> , 1993	School students	1295	Is perceived lack of confidentiality a barrier to adolescent health care?	58% of subjects had health issues they wanted to keep from parents 25% had already foregone health care because of concerns 81% supported breach of confidentiality when patient at risk
Kobocow <i>et al.</i> , 1983	School students	90	Does disclosure vary with degrees of confidentiality?	Subjects disclosed similar amounts despite being offered varying degrees of confidentiality Subjects recalled being promised confidentiality even when this was not the case
Meyer & Smith, 1977	Psychol students	55	Confidentiality In group therapy	91% expected therapist to maintain confidentiality, and 65% expected group members to. 81% would not join group or would disclose less if not confidential; 45% even if this limited to court proceedings
Thrall <i>et al.</i> , 2000	School students	1715	Effects of confidentiality on access to sexual health care	75% wanted confidential health care 45% had confidence that consultation would be confidential 9% had foregone health care because of concerns Those with concerns were less likely to have had appropriate care
Kegeles <i>et al.</i> , 1989	Homosexual men	574	Take-up of HIV testing	93% willing to have test if not notifiable; 31% if results were notifiable
Shuman <i>et al.</i> , 1986	Psychiatrists Patients Judges College students	188 134 70 124	Effect of privilege rules on disclosure in therapy	Few differences between Ontario/Quebec, suggesting formal privilege laws have little effect Overall about 40% of psychiatrists had been asked to testify, about 10% had done so. Judges say this is always with consent, but psychiatrists disagree. About 40% of psychiatrists believe disclosure impairs treatment and 22% of breach led to termination. About half of patients report concern about confidentiality; few know the privilege laws. College students less likely to disclose if not offered privilege, but lack of knowledge suggests this is not a significant factor in actual therapy.
Ginsburg <i>et</i>	School children	6821	Barriers to accessing health	Confidentiality ranked 11 th out of 31 possible factors – 83% rated it as probably

<i>al.</i> , 1995			care	or definitely a factor.
Jenkins <i>et al.</i> , 2005	Women – patients and public	85	Beliefs about confidentiality	Generally high levels of belief in strict confidentiality – many subjects expecting even sharing within immediate team only with consent. Some (?how many) subjects described withholding certain info (particularly sexual and mental health) because of concerns Some (probably most?) patients have unrealistic expectations/understanding
Eisenberg <i>et al.</i> , 2005	Parents	1069	Attitude to parental notification laws	55% supported notification 96% anticipated at least one negative consequence (out of 6 possibilities presented) 56% anticipated deterrence to obtaining contraception 48% anticipated deterrence to attending clinic Significant number of contradictory responses which were not explored or reconciled
Ford & Best, 2001	Adolescents (15-24)	342	Willingness to have STD test	92% willing if parents not informed; 38% if parents might be informed, 35% if parents definitely informed.
Kremer & Gesten, 1998	Psychotherapy patients students	92 148	Impact of managed care	Description of managed care process significantly reduced willingness to disclose in both groups (patients>students)
Klein <i>et al.</i> , 1999	School pupils	6748	Access to care/deterrence	29% of girls and 24% of boys had foregone health care. Confidentiality was commonest reason – 35% (ie 10% of population)
Allen <i>et al.</i> , 1998	Gay, lesbian bisexual young adults	102	Willingness to access health care	22% informed/aware of medical confidentiality when aged 14-18. Those not informed significantly less likely to discuss sexuality with doctor and said they would have been more likely if assured of confidentiality
Sachs <i>et al.</i> , 2002	General public - women	?	Support for Mandatory reporting of domestic violence	Abused women significantly less likely to support MR (59% vs 73%). Deterrence was the main reason for opposing MR (76% of all subjects recognized this), also resentment at loss of control, increased risk from partner
Ovens <i>et al.</i> , 2009	Emergency med doctors Public	267 1001	Mandatory reporting law for gunshot wounds	88% of doctors willing to comply. Only 6% thought it would decrease trust in doctors. 6 doctors had experience of patient delaying seeking care because of law 95% of public supported law, 18% said it would make them less likely to trust doctors

Appendix 1: Table 8: Professional views about deterrence

REF	SUBJECTS	N	ISSUE	FINDING
Beck, 1982	Psychiatrists	38	Experience of reporting	Interview of 38 non-random psychiatrists 12 had considered giving warnings but hadn't, 10 had never considered it 16 had given warnings on 26 occasions; range of diagnosis Only 1 actually injured victim, that was 2 years later Effect on d-p relationship: 2 positive, 4 negative, 13 none, 7 warnings given after end of therapy 15 discussed before disclosure (1 negative outcome) 4 not discussed, 3 -ve
Weinstein <i>et al.</i> , 2000	Mental Health professionals	158	Experience of reporting child abuse	1/3 of subjects had at least one client who refused or left therapy because of limits to confidentiality After disclosure, half of clients exhibited some resistance to continued therapy, and about 20% left therapy. Most clients in this study were not the abuser (either victim or third party)
Miller <i>et al.</i> , 1999	Family Planning clinicians	68	Mandatory reporting of under-age sex	80% agreed with strong enforcement of statutory rape laws 40% believed that this would deter teenagers from health care 37% believed health care workers should be exempt from reporting laws
Thelen <i>et al.</i> , 1994	Psychologists	330	Attitudes to confidentiality	25% believed in absolute confidentiality, 70% did not. Those who did were less likely to be willing to report in various situations, and more likely to anticipate damage to therapeutic relationship
Sullivan <i>et al.</i> , 2002	Paediatric psychologists	74	What factors influence decision to inform parents of adolescent risk behaviour?	Seriousness of risk was most significant factor. Risk of disrupting therapy came 11 th out of 13 factors
Morris <i>et al.</i> , 1985	Primary care doctors Paediatricians GPs	58 31 28	Factors influencing decision to report various cases of possible NAI	Higher rates of reporting when considering case details than when asked theoretically Only 22% referred to fear of patient leaving treatment as a consideration Reporting rates up to 95% for "extreme bruising", but as low as 58% in one scenario that authors rate as "definite report" and as low as 7% in one rated "probable report"
Watson & Levine, 1989	Child neglect professionals	18	Effect of disclosure on treatment	24% had negative effect on treatment – some terminated therapy

Haut & Muehleman, 1986	Psychologists	27	Would patients be deterred by forewarning about lack of confidentiality?	Subjects believed patients given explicit warning about limits to confidentiality would disclose less
Shuman & Weiner, 1982	Psychotherapists	84	Frequency of disclosure of details of therapy in court	12 psychologists had been required to disclose. 4 patients ended therapy
Taft <i>et al.</i> , 2004	GPs	28	Management of domestic violence	Doctors found managing domestic violence problematic. Where reports were made there were anxieties about deterring further treatment
Kalichman & Brosig, 1993	Psychologists	246	Factors influencing reporting of child abuse and compliance/non-compliance with mandatory reporting	32% had failed to make mandatory report at least once Consistent reporters rated legal duties and concerns about child higher, inconsistent reporters rated effect on family/patient, degree of suspicion as more important
Wise, 1978	Psychiatrists Psychologists	179 1073	Effect of <i>Tarasoff</i> on practice	79% believed patients would be less likely to divulge info if not completely confidential 96% believed all or most patients believed confidentiality was absolute 11% always discussed confid with patients, 70% "sometimes" 70% supported breach in certain circumstances, 26% supported absolute confidentiality standard) 25% reported observing reluctance to disclose after learning about limits to conf 50% had given at least one warning pre-Tarasoff, 38% in the first year after, but rates difficult to ascertain, also recall bias etc. More likely to warn potential victim, as opposed to Police etc, since Tarasoff 20% discussed confidentiality with patients more frequently than before., 27% focused more on dangerousness than before. 54% reported increased anxiety of being sued following Tarasoff. 16% reported avoiding particular issues, including dangerousness. "Several" reported no longer working with dangerous patients Overall 89% reported at least one aspect of change to behaviour resulting from Tarasoff
Anon, 1962	Public Profs	108 151	Legal privilege	Most thought info was privileged, and should be. About half of patients anticipated deterrence. Strong support from subjects and authors for strong/absolute privilege
Binder & McNeil, 1996	Psychiatrists	46	How often have trainee psychiatrists made <i>Tarasoff</i> reports and with what results?	Almost half had made a report – suggests about 1 report per 4 years of practice. 11 out of 15 victims warned already knew of danger 8 out of 23 patients were angry, negative impact on therapy in 5 cases

Kalichman <i>et al.</i> , 1989	Psychologists	279	Factors influencing reporting of CSA	Vignette re child abuse, varying child male/female, father admits/denies, therapist expects positive/negative outcome from reporting. Admitting father and positive expectation more likely to be reported 37% expected reporting usually to have a negative effect on families, only 14% expected positive. 42% expected negative effect on therapy; 21% positive Less than 20% believed reporting laws provided the best alternative. Subjects aware of reporting laws but “few would definitely report the case”.
Levine & Doueck, 1995	Child abuse professionals		Effect of reporting on therapy	27% drop-out following reporting of abuse
Kalichman <i>et al.</i> , 1988	Mental Health Workers	101	Factors influencing reporting of child abuse	Child’s reaction contributed to certainty that abuse was taking place. 81% would “tend to report” the presented case – more likely to report with higher certainty that abuse was taking place/explicit report by child 89% of non-reporters indicated doubt whether abuse was taking place was the major factor Although law requires reporting of suspicion, clinicians reluctant to do this when unsure Concern about therapeutic relationship was not reported by many subjects
Rosenhan <i>et al.</i> , 1993	Psychiatrists/psychologists	1800	Knowledge and response to <i>Tarasoff</i>	84% knew of case but <50% knew current rules. 60% believed some patients were deterred and 28% reported a patient leaving therapy. 46% avoided violent patients
Anderson <i>et al.</i> , 1993	Psychotherapists Child protection workers	30 25	Effects of mandated reporting	Subjects accepted reporting as necessary but found it stressful: many had “serious doubts about whether a report actually the child”. Resented intrusion of law on therapy; undermined professional responsibility, policing rather than treating. Anger towards rules and clients “for putting me in that position” – some reports of reporting as way of expressing anger at client Some therapists described positive outcomes in producing change but this could feel controlling rather than collaborative Description of using reports to force attendance, but also of clients leaving therapy because of reports – generally coercive treatment seen as ineffective (particularly when therapy starts in consequence of a report)
Shuman <i>et al.</i> ,	Psychiatrists	188	Effect of privilege rules on	Few differences between Ontario/Quebec, suggesting formal privilege

1986	Patients Judges College students	134 70 124	disclosure in therapy	laws have little effect Overall about 40% of psychiatrists had been asked to testify, about 10% had done so. Judges say this is always with consent, but psychiatrists disagree. About 40% of psychiatrists believe disclosure impairs treatment and 22% of breach led to termination. About half of patients report concern about confidentiality; few know the privilege laws. College students less likely to disclose if not offered privilege, but lack of knowledge suggests this is not a significant factor in actual therapy.
Rodriguez <i>et al.</i> , 1999	Various groups of physicians	508	Compliance with mandatory reporting of domestic violence	All had high levels of knowledge of law (70-81%), experience of domestic violence patient (74-99%), recent training (19-45%). Emergency physicians higher than others in all of these. Overall willingness to report overriding objection was 41%, highest in emergency phys (75%) – 59% prepared to disregard MR law. 60-79% recognised risk of deterrence; 17-45% thought doctors are deterred from asking by MR laws. 59-80% perceived MR as violating ethical standards (but not all saw this as unacceptable)
Greenhalgh <i>et al.</i> , 2006	GPs Interpreters Patients	13 21 9	Interactions in interviews with interpreters	GPs recognised concern that some patients were deterred from “talking freely or even at all” by lack of trust/confidentiality. Family members more trustworthy than professional interpreters: sometimes advantage in interp. not from local community Patients also studied but didn’t report this (not a focus of study)
Zellman, 1990a	Child care professionals	1128	Failure to comply with mandatory reporting	Child MH professional had highest levels of non-reporting, 19% explicitly mentioned deterrence/effect on Rx
Steinberg <i>et al.</i> , 1997	Psychologists	907	Outcome of mandatory reporting	Forewarning reduced bad emotional outcome but didn’t affect chance of withdrawal from therapy. Other variables mainly related to case (type of abuse, identity of perpetrator). Can’t tell from data what rate of withdrawal/bad reaction was
Saulsbury & Campbell, 1985	Paediatricians Primary care doctors	307	Support for reporting of child abuse	Generally high levels of support (90%+) for reporting sexual/physical abuse, lower support (c50%) for emotional abuse, neglect. Main reason for not reporting was uncertainty re diagnosis. Only 6% gave reason as fear of impairing relationship with family.
McNaughton <i>et al.</i> , 2006	Obstetricians	110	Reporting of illegal abortions	56% reported (authors argue this is unethical) 86% expect patients to be deterred by reporting
Ovens <i>et al.</i> , 2009	Emergency med doctors Public	267 1001	Mandatory reporting law for gunshot wounds	88% of doctors willing to comply. Only 6% thought it would decrease trust in doctors. 6 doctors had experience of patient delaying seeking care because of law

				95% of public supported law, 18% said it would make them less likely to trust doctors
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Appendix 1: Table 9: patient views about deterrence

REF	SUBJECTS	N	ISSUE	FINDING
Schmid <i>et al.</i> , 1983	Psychiatric inpatients	30	Utilitarian value of confidentiality	23/30 wanted info kept confidential 20/30 objected to breach of confidence 5/30 said they would leave treatment if breached
Miller & Thelen, 1986	Student counselling service clients	74	Knowledge of limits to confidentiality	69% believed everything was confidential 74% believed everything should be confide 10% would leave/42% limit disclosure if not confide Only 20% agreed with breach if others at risk
Lindenthal & Thomas, 1982b	Mental health patients	76	Concerns about breach of confidence	45% concerned about disclosure 22% deterred by concerns (less than public sample in same study) Patients overestimated likelihood of disclosure
Hecht <i>et al.</i> , 1997	People at HIV risk	2387	Willingness to have test	84% would have test if anonymous, 73% if confidential, 62% if named
Whetten-Goldstein <i>et al.</i> , 2001	HIV Outpatients	15	Experience of confidentiality	13/15 had experience of others learning HIV status without their consent Some (?n) would avoid care to prevent this
Rodriguez <i>et al.</i> , 2001b	Victims of domestic violence	375	Effect of mandatory reporting	Victims with concerns about confidentiality or police involvement were less likely to have presented for medical help
Gielen <i>et al.</i> , 2000	Victims of domestic violence	202 (part of larger study)	Effect of mandatory reporting	Victims with concerns about confidentiality or police involvement were less likely to have presented for medical help 67% believed MR would deter disclosure (commoner in those who had not disclosed themselves). 52% believed women would be a greater risk. Only 25% had sought medical advice/help
Ferri <i>et al.</i> , 2002	Cocaine users		Likelihood of deterrence from treatment	Users with confidentiality concerns were less likely to be in treatment than others
Phillips <i>et al.</i> , 1995	HIV outpatients		Attitude to anonymous testing	48% of untested high risk group would have test if guaranteed confidentiality
Elbogen <i>et al.</i> , 2003	In-patient sex offenders	40	Effect of community notification laws	56% reported increased motivation
Fordyce <i>et al.</i> , 1989	STD clinic patients	1047	Attitude to HIV testing	22% would refuse HIV tests if names were reported to public health authorities
Haut & Muehleman, 1986	Members of a "support group"	32	Do different levels of confidentiality result in different levels of disclosure?	No difference between 3 interview conditions. Anonymous questionnaire did result in significantly greater disclosure
Flynn <i>et al.</i> ,	Mental health OP	80	Electronic records	Those with concerns about confidentiality/IT security were more likely to

2003				object to introduction of electronic records. Most of those with concerns would consider seeking "alternative care"
Jones, 2003	GP patients	30	Attitude to confidentiality	100% expect confidentiality Between 40% and 80% support public interest disclosure in various situations 17% have already been deterred from full disclosure because of concern Contradictory answers from questionnaire and vignettes
Davies & Casey, 1999	Adolescent GP patients	110	Barriers to seeking health care	Confidentiality was most common of 7 issues, identified by 37% of subjects
Lindenthal & Thomas, 1982a	General medical in-patients	76	Deterrence from treatment	Patients were less likely than doctors/non-patients to support breach in vignettes 24% had been deterred from seeking treatment (higher in non-patient group)
Gossom, 1998	Counselling	15	Factors influencing disclosure	Lack of trust reduces disclosure – no direct discussion of confidentiality
Reddy <i>et al.</i> , 2002	Family planning clinic	950	Attitudes of adolescents to parental notification	59% would stop using service (greater effect in younger subjects)
Gerbert <i>et al.</i> , 1999	Primary care patients	1954	Willingness to disclose risk behaviour to researcher	No difference if results would/would not be given to primary care physician Small increase (c 5%) in disclosure with automated interviewing (eg computer-based)
Gerbert <i>et al.</i> , 1998	Primary care patients	452	HIV risk behaviour	Most behaviour reported equally whether or not results shared with GP, but reports of anal sex significantly less
Stanford <i>et al.</i> , 2003	Research participants (adolescents)	438	Factors influencing recruitment to research	Privacy was 4 th most important of 13 items
Maxwell & Leyshon, 1971	Neurology OP	n/a	Declaration of epilepsy to driver licensing	38% male and 15% female patients had been issued licence, inc 42% of those whose condition should have excluded them Suggests that only 4% of people who should disclose their condition did so, and that "9 out of 10 male epileptic drivers may have concealed their illness"
Torres <i>et al.</i> , 1980	Teenage patients of family planning/abortion services	2411	Effect of parental notification on access to services	23% of abortion service patients would not attend if parental notification was required. Of contraception patients, 23% would not attend if parental notification required. If notification was universal, 125,000 teenagers pre year (US) would not access contraception and 42,000 would not be able to obtain a legal abortion
Shuman <i>et al.</i> ,	Psychiatrists	188	Effect of privilege rules	Few differences between Ontario/Quebec, suggesting formal privilege

1986	Patients Judges College students	134 70 124	on disclosure in therapy	laws have little effect Overall about 40% of psychiatrists had been asked to testify, about 10% had done so. Judges say this is always with consent, but psychiatrists disagree. About 40% of psychiatrists believe disclosure impairs treatment and 22% of breach led to termination. About half of patients report concern about confidentiality; few know the privilege laws. College students less likely to disclose if not offered privilege, but lack of knowledge suggests this is not a significant factor in actual therapy.
Coulter & Chez, 1997	Victims of domestic violence	45	Attitude to mandatory reporting	Only 2% made first disclosure to health profession – most to friend/family 80% supported a duty for health professionals to report (NB much higher than other studies) and 73% thought this would help victims
Meehan <i>et al.</i> , 1997	Adolescents attending for HIV test	1601	Natural experiment - Effect of legal change on behaviour	Covered 12 months before and 12 months after a change in the law permitting testing and treatment without parental consent 44% increase between the 2 years (656 to 945) Overall 75% had test, increased from 60% to 85% Total tests increased from 392 to 801 No similar increase seen in 18-22 year olds in same period
Houry <i>et al.</i> , 1998	ER attenders Dom Violence victims	517 60	Attitudes to Mandatory reporting	55% aware of MR rules 12% would be deterred from seeking treatment for DV because of MR rules more in men than women, which is unexpected. No greater in support group subjects.
Culshaw <i>et al.</i> , 2005	Patients with alc abuse	56	Knowledge & deterrent effect of DVLA rules	Most continued to drive 48:86% Most unaware of DVLA regulations (4:7% gave accurate answer) 8:14% had discussed DVLA rules with health professional Told that doctors are expected to report, 22:39% would be deterred
Jenkins <i>et al.</i> , 2005	Women – patients and public	85	Beliefs about confidentiality	Generally high levels of belief in strict confidentiality – many subjects expecting even sharing within immediate team only with consent. Some (?how many) subjects described withholding certain info (particularly sexual and mental health) because of concerns Some (probably most?) patients have unrealistic expectations/understanding
Charlesbois <i>et al.</i> , 2005	HIV test-takers	208	Willingness to take test under different confidentiality rules	67% preferred anonymous If confidential rather than anonymous testing those likely to repeat test in next 12 months drops from 76% to 51%
Stone & Ingham, 2003	Young attenders at sexual health clinic	41	Delays in seeking contraceptive advice	20% of females and 3% of males had delayed seeking advice because of confidentiality concerns
Jones <i>et al.</i> , 2005	Young attenders at sexual health clinic	1526	Willingness to access services under	40% of parents were not aware 41% would be stop using service if parental notification was mandatory.

			mandatory parental notification	This figure highest in those whose parents do not know – 71% 18% would use no contraception if mandatory notification introduced but <5% would stop having sex
Howerton <i>et al.</i> , 2007	Prisoners with MH problems	35	Willingness to access services	Trust was the major factor-linked to “the system” rather than confidentiality.
Greenhalgh <i>et al.</i> , 2006	GPs Interpreters Patients	13 21 9	Interactions in interviews with interpreters	GPs recognised concern that some patients were deterred from “talking freely or even at all” by lack of trust/confidentiality. Family members more trustworthy than professional interpreters: sometimes advantage in interp. not from local community Patients also studied but didn’t report this (not a focus of study)
Carlisle <i>et al.</i> , 2006	Adolescents in hospital	20	Views on confidentiality	Wanted sexual/drug issues kept from parents. Females and older subjects more concerned. Would be deterred from treatment. Concern about handling of records
Kremer & Gesten, 1998	Psychotherapy patients students	92 148	Impact of managed care	Description of managed care process significantly reduced willingness to disclose in both groups (patients>students)
Sachs <i>et al.</i> , 1999	DV victims	95	Mandatory reporting	55% supported 41% opposed. 48% would be less likely to disclose.
Kegeles <i>et al.</i> , 1990	Anonymous HIV test patients	180	Willingness to take test	40% would not have had confidential test. 60% would not have had test if contact notification was in place.
Hoxworth <i>et al.</i> , 1994	Patients taking anonymous HIV test	?	Reasons for delaying test	14% had delayed testing and would not have had confidential test – commoner in those who tested positive.
Kaplan <i>et al.</i> , 1990	Sex offenders on parole	?	Disclosure of past offences	Subjects underreported offences and severity in parole interview (compared to official records) but in psychology session reported 20x more offences than were officially recorded Subjects perceived the psychol interview as more confidential, but not clear if this was offered explicitly.
Ryder & McNulty, 2009	STD clinic patients	270	Choice of service provider	Expressed concern about confidentiality but that was not a major reason for choosing clinic over visiting GP (more to do with expertise). Most patients happy for info to be shared within health professionals. 1/3 had concerns about partner being made aware of attendance
Charbonneau <i>et al.</i> , 1999	HIV +ve patients	463	Reporting status to dentist	only 54% reported always disclosing their statue, 25% reported never disclosing this information. 83% said they would like the dentist to know their status.
DePhillipis <i>et al.</i> , 1992	Methadone users	196	Mandatory contact tracing	HIV+ve patients significantly less likely to take test if mandatory contact tracing in place
Donovan <i>et al.</i> , 1997	15-16 year olds	4481	Expectations of GP confidentiality	26% believed sexual health information would be shared with parents – significant barrier to access

Meyers <i>et al.</i> , 1993	Homosexual men	1295	Reasons for seeking/avoiding HIV test	77% gave confidentiality concerns as reasons for avoiding test (some of these had had test, ?under anonymous conditions) – concerns about effect on relationships, insurance and “being on a government list”
Zabin & Clark, 1981	Teenagers attending family planning clinic	1200	Reasons for delaying attendance	“Most important reason” was fear of family being notified but only 31% mentioned this – many subjects wrongly believed parental notification was mandatory (but didn’t ask this directly)
Zabin & Clark, 1983	Teenagers attending family planning clinic	1243	Reasons for delaying attendance	“Doesn’t tell parents” was commonest factor cited as reason for choosing particular clinic
Adams <i>et al.</i> , 2010	GPs Psychiatrists	1488 152	Willingness of doctors to seek help for depression	Lack of confidentiality was a barrier to help for 53%
Berger <i>et al.</i> , 1999	Patients having HIV tests (all +ve)	251	Differences between confidential and anonymous testing	Anonymous testees less likely to accept ongoing care but no difference in partner notification or return for follow-up
Coker <i>et al.</i> , 2010	Adolescents Parents	77 21	Barriers to seeking health care	Confidentiality was “important” but not possible to tell how many people raised this – very descriptive qualitative study
Madge <i>et al.</i> , 1999	Patients having HIV test	946	Reason for using specialist clinic rather than GP	20% had concerns about confidentiality (particularly in relation to insurance) and 38% didn’t want result recorded in notes
Marks <i>et al.</i> , 1995	HIV +ve men	632	Willingness to disclose HIV status to doctors	21% did not disclose when consulting doctor/dentist about other health problems
McDaniel <i>et al.</i> , 1995	Dental patients	170	Willingness to disclose health information to dentist	23% would not disclose drug abuse. 3% would not disclose HIV or TB
Meckler <i>et al.</i> , 2006	LGB adolescents	131	Disclosure of sexuality to GP	35% had disclosed. Of those who hadn’t. 44% gave confidentiality concerns (parents being informed) as reason
Mollen <i>et al.</i> , 2008	Adolescent girls	30	Access to emergency contraception	Some expressed concern that parents would be informed as a barrier to access (no frequencies given)
Osmond <i>et al.</i> , 1999	Patients with HIV +ve test	441	Reasons for delaying further health care	9% reported concern about name-based reporting as a barrier to care
Sankar & Jones	Primary care patients	85	Willingness to disclose sensitive information	Patients censored information for various reasons, including concern about breach of confidence. Frequencies not given
Sugerman <i>et al.</i> , 2000	Family planning patients	790	Reasons for provider choice	Adolescent patients (16%) more likely than adults (6%) to cite concern about breach of confidence (to family) as reason for avoiding primary care provider
Bayley <i>et al.</i> , 2009	Teenagers	48	Access to emergency contraception	Confidentiality was “a prominent concern” with anxiety about deliberate parental notification and accidental some wrongly believed parental notification was required

McKee <i>et al.</i> , 2006	Adolescent girls mothers	18 22	Attitudes to confidentiality in sexual health	Mothers see confidentiality as promoting risky behaviour Girls report concern about breach and lack of trust in doctors as barriers (frequencies not given)
Petchey <i>et al.</i> , 2000	HIV +ve patients	20	Access to health care	GUM clinic was perceived as offering better confidentiality, which was highly valued
Rodriguez <i>et al.</i> , 1998	Abused women	51	Attitudes to mandatory reporting of domestic violence	Most opposed mandatory reporting and feared negative outcomes. Suggests that deterrence would be common
Lapham <i>et al.</i> , 1996	Members of genetic support groups	332	Use of genetic information	20 - 30% thought they had been discriminated against in insurance, 10-15% in employment. Only 11% wanted results shared with insurance and 6% with employer. 10% had refused testing because of fear info would be misused
Thomas <i>et al.</i> , 2006	Adolescents	295	Access to sexual health services	56% gave confidentiality as the most important aspect of a sexual health service. Over half would not use a service if not confidential. 80% opposed reporting of patient at risk of abuse. 46% do not want GP to be informed

Appendix 1: Table 10: Actual disclosure in experimental situations

REF	SUBJECTS	N	ISSUE	FINDING
Woods & McNamara, 1980	College students	60	Do assurances about confidentiality result in greater self-disclosure?	"Confidentiality had a very strong effect on the depth of self-disclosure"
Kremer & Gesten, 1998	College students	148	Does degree of self-disclosure vary with degree of confidentiality?	Willingness to disclose reduced significantly under conditions of limited confidentiality, compared to full confidentiality
Taube & Elwork, 1990	Psychotherapy patients	42	Effect on disclosure of different assurances	2 groups given different level of info about confidentiality – more info associated with less self-disclosure
Muehleman <i>et al.</i> , 1985	College students	24	Do assurances about confidentiality result in greater self-disclosure?	In a very artificial situation, confidentiality did increase the amount of disclosure
Haut & Muehleman, 1986	Members of a "support group"	32	Do different levels of confidentiality result in different levels of disclosure?	No difference between 3 interview conditions. Anonymous questionnaire did result in significantly greater disclosure
Meyer & Willage, 1980	College students	63	Do assurances about confidentiality result in greater self-disclosure?	Subjects denied confidentiality gave more socially desirable responses and reported fewer symptoms
Holahan & Slaikou, 1977	College students	74	Do subjects disclose less when interview room is not private?	Self-disclosure greater and interview rated more positively when room was private
Corcoran, 1988	College students	139	Does trustworthiness of interview influence disclosure?	Subjects who rated the interview as highly trustworthy disclosed more than those giving low rating
Marsh, 2003	General public	129	Willingness to disclose in hypothetical therapy situation	In 5 scenarios, subjects offered confidentiality were more likely to disclose than those who were not
Zagumny <i>et al.</i> , 1996	College students	291	Does anonymity affect disclosure of risk behaviour?	In 4 different conditions of anonymity, subjects reported similar levels of HIV-risk behaviour in each
Singer <i>et al.</i> , 1992	College students General public	207 125	Willingness to participate in survey	Students asked to participate in survey were less likely to do so, and anticipated more intrusive/personal questions, if confidentiality was emphasised
McGuire <i>et al.</i> , 1985a	College students	96	Degree of disclosure in interview	No significant effect of confidentiality condition or presence/absence of videotaping
Dauser <i>et al.</i> , 1995	Counselling service patients	63	Effect of forewarning	No difference in willingness to enter therapy in subjects given 2 different levels of information about confidentiality
Ford <i>et al.</i> , 1996	High school students	562	Assurance of confidentiality from GP	Played audiotape of GP consultation with differing confidentiality assurance. Subjects played tape with assurances more willing to disclose.

Appendix 1: Table 11 Natural experiments

REF	SUBJECTS	N	ISSUE	FINDING
Berlin <i>et al.</i> , 1991	Sex offender treatment		Effect of mandatory reporting	Introduction of mandatory reporting: disclosure of abuse by SOTP group members dropped from 20 per year to 0. Self-referral dropped from 7 per year to 0
Fehrs <i>et al.</i> , 1988	HIV test rates		Change in test rates after introduction of anonymous reporting	No of tests increased x3 when anonymous testing was introduced – greater increase in high risk groups.
Lothen-Kleine <i>et al.</i> , 2003	Adolescents	444	Effect of different confidentiality assurances	When guaranteed confidentiality 8% reported suicidal thoughts, when told things would be reported, only 1% did. No change in participation rates.
Nakashima <i>et al.</i> , 1998	HIV testing	6 US states	Uptake of testing when name reporting introduced	No significant reduction in testing – increased in some states. Changes in line with underlying trends.
Hertz-Picciotto <i>et al.</i> , 1996	HIV testing		Uptake of testing	Compared counties in North Carolina which restricted anonymous testing with those that did not. Testing increased in all areas, but greater increase where anonymity retained. Difference greatest in high-risk groups
Hirano <i>et al.</i> , 1994	HIV testing		Uptake of testing	Uptake increased after Arizona introduced anonymous testing
Paton, 2002			Effect of Gillick on access to sexual health services	Adolescent attendance at clinics declined by 30% after first judgement (removing confidentiality) but pregnancy rates stayed constant
Phillips, 1994			Comparison of uptake of HIV testing in different states	Uptake varied with adoption of anti-discrimination laws in different states but not with confidentiality/anonymity rules
McLachlan <i>et al.</i> , 2007	Patients with epilepsy	425	Effect of mandatory reporting law	46% of epileptic patients had been advised not to drive. No difference in accident rates between a mandatory reporting state and a non-mr state, but twice as many people were driving unlicensed in the mr state and more (9% vs 5%) would withhold information from doctor

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APPENDIX TWO: VIGNETTE WORDING

SCENARIO: DRIVING

A woman suffers from epilepsy.

It is well-controlled with medication and she has had no seizures for over 10 years.

She tells her doctor that she is trying to get pregnant, and he advises her to stop taking the anticonvulsants, in case the baby is damaged. She agrees with this.

The doctor tells her that she should stop driving until she is back on medication. She says she can't do this, and that she will carry on driving at work, but will stop at other times.

Should the doctor inform the DVLA?

A woman	The four scenarios were designed to include two male and two female patients. A female was chosen for the epilepsy scenario to enable the dilemma to arise in the course of planning a pregnancy
It is well-controlled with medication and she has had no seizures for over 10 years.	To establish a low baseline risk for seizures, well within the criteria accepted for driving by the DVLA
She tells	She is voluntarily raising this issue
that she is trying to get pregnant, and he advises her to stop taking the anticonvulsants, in case the baby is damaged.	Some subjects questioned whether this was accurate or appropriate advice: the scenario was written without input from a neurologist to confirm this. This is a potential confounding factor, since some subjects may feel it is more acceptable to reject medical advice if that advice is not considered to be well-founded
She agrees with this	She is willing to listen to advice, even if she is not fully compliant with it
The doctor tells her that she should stop driving until she is back on medication.	Generally accepted by subjects as appropriate advice, although some subjects felt that any driving, even on medication is unacceptable
She says she can't do this, and that she will carry on driving at work	She has a significant reason for driving and potential detriment to her if reported
but will stop at other times	Partial compliance, may suggest scope for further negotiation or persuasion

SCENARIO: THREATS

A man has mental health problems, and has been coming to the out-patient clinic for several years.

He tells the psychiatrist that his neighbours are spying on him, and poisoning the water supply with X-rays. He says that if it doesn't stop "I'll sort them out once and for all. I'll fix them".

The psychiatrist is worried that the neighbours might be at risk from this man, who refuses to take more medication or go into hospital. He has been violent in the past.

Should the doctor tell the Police?

A man	This scenario is relatively gender-neutral (although violence is generally more common by males). A male patient was chosen to keep the gender balance between scenarios
has been coming to the out-patient clinic	Locating the dilemma within the management of a community patient, rather than in inpatient, congruent with the other scenarios
for several years	Suggesting a degree of compliance, engagement with treatment, and that the psychiatrist may be familiar with the risk issues
He tells	Suggesting some cooperation or treatment-seeking
the psychiatrist	Clearly establishing the nature of the doctor – referring to "the doctor", as in the Epilepsy scenario, may have been more comparable, but issues of expertise/referral would probably have been more marked in this situation (see comments on "sexual" scenario)
neighbours are spying on him	Not in itself implausible or delusional. Several subjects commented that this may be true
poisoning the water supply with X-rays	Intended to be a clearly delusional belief. However a few subjects explicitly considered that this might be true, or should be further investigated.
if it doesn't stop	Suggests some delay before action is contemplated, which may leave room for negotiation or therapeutic involvement rather than an immediate disclosure
I'll sort them out once and for all. I'll fix them.	Deliberately non-specific, and not necessarily implying violence, although subjects seem to have assumed this, perhaps because of the following wording
The psychiatrist is worried	Intended to bypass any discussion of whether or not there is a risk – what should the response be once the psychiatrist has decided there is?
the neighbours might be at risk	Again non-specific, without clear indication of the nature of any risk, but subjects clearly inferred risk of violence from this
refuses to take	Patient is rejecting medical advice/help

more medication	This was intended to represent extra or increased medication, but some subjects interpreted this to mean a refusal to take any medication from this point onwards. This may impact on perception of the magnitude of risk, although the underlying issue of rejecting advice is similar
or go into hospital	The disclosure dilemma is more acute if admission is not an option. This statement was intended to remove, or at least minimise that option, so as to focus the subjects on the issue of whether or not to disclose when a patient is in the community, but many subjects clearly saw admission as the most appropriate response
He has been violent in the past.	Most subjects commented on this factor as increasing the risk, as intended. Arguably including this information may skew the scenario too much in favour of disclosure, but it aims to balance the uncertainty of the threat, to ensure that there was a tangible risk that might be reported

SCENARIO: SEXUAL THOUGHTS

A teacher is worried because he feels sexually attracted to some of his pupils, although he has never acted on these thoughts. He feels that the thoughts are starting to get stronger. He says he never has these thoughts about his own children.

He asks his GP if he could be referred to a psychologist to stop him feeling this way.

Should the GP report this man to the Child Protection team?

A teacher	Significant both because of his access to potential victims from a position of trust and responsibility, and also because he potentially has more to lose from being reported
is worried	In contrast to the other three scenarios this patient is actively concerned about the risk
he	Men are generally considered to represent a higher risk of sexual offending against children. While a female patient might have challenged stereotypes, this might introduce an unhelpful confounding variable into subjects' deliberations
feels sexually attracted	Identifying potential sexual abuse as the central issue. This is an emotive issue, with high levels of recognition expressed by the subjects
some	Intending to identify this as a general problem rather than linked to a specific individual, with implications both for the individual (he is attracted to children, rather than having developed some sort of relationship with a specific child) and for risk management (not a single identifiable victim who might be protected)
of his pupils	Emphasising the relationship of trust and responsibility at issue
never acted on these thoughts	Emphasising potential future risk rather than actual current risk, to leave room for recognition of a potential dilemma
He feels that the thoughts are starting to get stronger	In the absence of prior abuse, the thoughts getting stronger suggests that abuse is likely to occur if nothing is done
never has these thoughts about his own children	Partly to limit the potential risk, by demonstrating that his feelings are not indiscriminate, but also to introduce another dimension of risk (another group of children potentially at risk) and also another area where he might suffer considerable harm from disclosure

He asks	Unlike the other scenarios this man is actively seeking to reduce the risk himself
his GP	By locating the dilemma with the GP rather than the specialist this was intended to avoid conclusions that deferred to a specialist assessment – the GP has to make a decision without specialist knowledge
Should the GP report this man	This also introduced the issue of division of responsibility: once the patient is referred can the GP leave decisions to the specialist, or does the GP have a separate responsibility to consider reporting, irrespective of the specialist opinion?

SCENARIO: DOMESTIC VIOLENCE

A woman sees her GP to ask for sleeping tablets.

The GP notices that she has several bruises. The woman tells the GP that her husband has a drink problem, and when he is drunk he often hits her.

The woman doesn't want the GP to report this, because she is frightened of how her husband will react, and because she doesn't want him to be sent to prison.

Should the GP report this?

A woman	Despite evidence of male victims of domestic violence, it is predominantly seen as involving female victims. As with the "sexual" scenario, challenging that stereotype may have added confounding attitudes
her GP	Most debate about mandatory reporting of domestic violence has focussed on decision-making in Casualty Departments. However the ongoing nature of the GP relationship allows more comparison with the other scenarios, and a wider range of response options
to ask for sleeping tablets.	The presenting problem is one with probable psychosocial dimensions, to raise the possibility of a "cry for help" or ambivalence on the patient's part
The GP notices	The scenario is deliberately constructed so that the patient is not directly seeking a consultation about domestic violence
several bruises	Suggesting injuries that are significant, but not immediately life-threatening, and a possibility of assaults on more than one occasion
The woman tells	Suggesting a significant degree of openness/cooperation from the patient, rather than total denial or defensiveness
husband	Again, conformity with a potential stereotype was chosen so as not to raise potential extraneous factors. The "family" setting implies a possibility of children at risk as well as the patient herself
has a drink problem	By giving an external "reason" for the behaviour it was intended to make the patient's wish for non-disclosure seem more reasonable. This also introduced the possibility of providing help/treatment for the husband as a potential concern for the GP
often	Emphasising the likelihood of ongoing assaults.
hits	Again suggesting a degree of violence that is significant, but not as extreme as, for example, assaults involving weapons
her	This scenario differs from the other three in that the patient herself is the person primarily at risk

<p>doesn't want the GP to report this</p>	<p>Central to this scenario is the issue of whether the patient should retain control over this decision, so her view was explicitly stated</p>
<p>she is frightened of how her husband will react</p>	<p>This introduces the possibility that reporting might have unintended consequences increasing risk. Conversely, her fear might be seen as being a factor supporting disclosure if she is considered to be unable to protect herself</p>
<p>doesn't want him to be sent to prison</p>	<p>In contrast to the "fear", this may imply a positive relationship which is worth protecting/preserving, and which may be a valid or understandable reason for her decision. It also emphasises the criminal nature of the assaults</p>

APPENDIX THREE: PATIENT INFORMATION AND INTERVIEW SCHEDULE

Patients who expressed an interest in participating following initial contact were given an information sheet, which was piloted and amended in response to input from the Patient and Public Involvement in Research Group (PPIRes) organised by the Norfolk and Waveney Research Consortium. Amongst other things it stressed that subjects would not be expected to disclose personal information during the interview.

Subjects who agreed to participate were reminded verbally of the above points, and offered an opportunity to ask any questions before consenting to participate. Information was then read to them, included in the digital voice recording for audit purposes, which again emphasised that personal disclosure was not expected.

Subjects were then presented with the first scenario, and again reminded that they were being asked to consider how patients in general would react to the situation.

Copies of the information sheets and interview schedule are given on the following pages for reference.

Norfolk and Waveney 
Mental Health Partnership
NHS Trust

Forensic Psychiatric Services for East Anglia

The Norvic Clinic
St Andrew's Business Park
Thorpe St Andrew
Norwich
NR7 0HT

DATE

ADDRESS

Tel: 01603 421025

Dear

THE EFFECTS OF DISCLOSURE PRACTICE ON PATIENT BEHAVIOUR

I am a doctor carrying out some research into medical confidentiality. Dr [consultant] has agreed to send this letter to you on my behalf, but I will not see any of your details, or even know that this letter has been sent to you, unless you decide to return the slip below.

The research is part of the work that I am doing for a degree at the University of East Anglia, and has been reviewed and approved by the University, the East Norfolk and Waveney Research Governance Committee, and the Norfolk Research Ethics Committee.

I would like to arrange to meet with you after one of your regular appointments at the hospital. I would explain the research to you in more detail, and answer any questions you have, before you decide whether or not to take part.

If you do take part, I will talk to you for about 30 minutes. I will not ask you any details about your own case, or your medical history. I am interested in whether patients consider confidentiality is important, and whether there ever are circumstances in which it should be broken.

If you would be interested in taking part in this research, please complete and return the slip at the bottom of this letter using the envelope enclosed.

Thank you for taking the time to read this letter.

Yours sincerely

Dr Chris Jones

I am willing to meet with Dr Jones, at the Norfolk & Norwich Hospital, to find out more about the research he is doing. I understand that I do not have to take part unless I want to, after hearing more details.

Name _____

Address _____

My next appointment with Dr [consultant] is on _____

THE EFFECTS OF DISCLOSURE PRACTICE ON PATIENT BEHAVIOUR

WHAT IS THE RESEARCH ABOUT?

I am interested in whether patients think it is important that doctors keep their medical details confidential, and whether there are any circumstances in which patients think it would be right for doctors to report that information to others.

In particular, I am interested in patients whose health problems might make them a risk to other people, and whether doctors should give information to the authorities to protect the public. There are sometimes legal requirements for doctors to report certain information, and I would like to find out what patients think about this.

I would also like to find out whether patients would be less likely to talk freely with their doctor, if they were not sure the information would be kept confidential.

DO I HAVE TO TAKE PART?

No. When we meet, I will explain the research to you, and answer any questions you have. It will be entirely up to you whether or not you want to go ahead after that. If you agree, you will still be able to change your mind, and stop the interview, at any point. Once the interview is finished the things you have told me will be stored anonymously, and combined with things other people have said, so I would not be able to take your comments out at a later stage.

Whatever you decide, it will have no effect on your treatment.

IF I AGREE, WHAT WILL HAPPEN?

I will talk to you for about 30 minutes, in an interview room at the hospital or clinic that you usually attend. The conversation will be recorded, and later on my secretary will type out the conversation, so that I can remember exactly what you said. No-one else will listen to the recording, or see the typed copy. I will not keep a record of your name, or date of birth, or any other identifying information. You will need to sign a consent form, but that will be kept separate from the record of the interview. The recordings and printouts will be kept securely by the Norfolk and Waveney Mental Health Trust, in the same way that medical records are kept.

During the interview I will give you examples of situations in which doctors might pass on information about a patient. I will ask you what you think about it, and how you think people in that situation might behave. I will not ask you any details about your own case, and you do not have to tell me anything about yourself if you don't want to, but if you have had a similar experience yourself, and want to tell me about it, that might help me to understand your views.

WHO WILL SEE THE RESULTS?

Once the study is completed the results will be written up as a thesis that will be submitted to the University of East Anglia. Some of the results will probably be included in articles published in medical journals, so that doctors and other professionals can learn from the findings. I may also present some of the results in meetings or conferences. All of the information will be anonymous when it is published, and no-one will be able to identify who took part in the study, or what individual participants said.

WHO IS DOING THE RESEARCH, AND WHY

I am a psychiatrist working in Norwich, who is interested in understanding more about what patients think about confidentiality and how this affects their decision to seek medical help. The research is not funded or supported by any other agency, and I am funding the costs of the research myself.

I am registered as a student at the University of East Anglia, and the results of the research will be submitted to the University, which I hope will qualify for a Doctor of Medicine degree. Some of the study will be carried out as part of my work for the NHS, for which I am paid my normal salary, but I will not get any additional payment for doing this study. The rest of the work will be done in my own time.

The study has been reviewed and approved by the East Norfolk and Waveney Research Governance Committee and the Norfolk Research Ethics Committee. If you have any questions or concerns about the research you can contact me, and my full contact details are given below. If I am not able to resolve your concerns, and you want to complain about any aspect of this study, then you should contact Mary Cubitt, Research Manager, Hellesdon Hospital, Norwich NR6 5BE (01603 421421), who will follow the Trust's complaint procedure.

Dr Chris Jones
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EFFECTS OF DISCLOSURE PRACTICE ON PATIENT BEHAVIOUR

INTERVIEW FRAMEWORK

Use the following framework to structure the interview. Note on the form any significant non-verbal communication or explanatory detail that may not be apparent on the transcript.

Items in CAPITALS should be asked of all subjects

Items in lowercase are possible prompts/exploratory questions to consider if relevant.

STUDY ID # _____ INTERVIEWER _____
DATE _____ LOCATION _____
MALE / FEMALE
AGE GROUP 18-30 / 31-45 / 46-60 / over 60

BEGIN RECORDING

IT IS [date]

INTERVIEW HELD AT [location]

SUBJECT NUMBER [Study #]

INTERVIEWER [name]

I AM GOING TO ASK YOU TO TALK ABOUT THE CONFIDENTIALITY PATIENTS EXPECT FROM THEIR DOCTOR.

I AM GOING TO GIVE YOU SOME EXAMPLES OF SITUATIONS IN WHICH DOCTORS MIGHT THINK ABOUT DISCLOSING INFORMATION ABOUT THEIR PATIENTS TO OTHER PEOPLE.

I DON'T KNOW WHETHER OR NOT YOU'VE EVER BEEN IN ONE OF THESE SITUATIONS, AND I'M NOT EXPECTING YOU TO TELL ME.

WHAT I WOULD LIKE YOU TO THINK ABOUT IS HOW PATIENTS IN GENERAL MIGHT FEEL OR BEHAVE IN THESE SITUATIONS.

YOU DO NOT HAVE TO TELL ME ANYTHING ABOUT YOUR OWN CASE, UNLESS YOU WANT TO.

Check understanding at this point.

SCENARIO 1

SCENARIO NAME _____

HAND OVER SCENARIO

THIS IS THE FIRST SITUATION. IT'S THE SORT OF ISSUE THAT MIGHT COME UP WITH SOME OF THE PATIENTS COMING HERE.

I'M NOT ASKING YOU WHETHER IT HAS EVER HAPPENED TO YOU, ONLY HOW YOU THINK PATIENTS IN GENERAL MIGHT FEEL ABOUT THE SITUATION.

HOW DO YOU THINK THE PATIENT IN THIS SITUATION MIGHT FEEL?

Why do you think that?

Would they talk to the doctor about it?

Might the patient be frightened to talk to the doctor? – Why?

How would they decide what to do?

Is there anyone else they might talk to?

HOW DO YOU THINK A DOCTOR SHOULD DEAL WITH THIS?

Should they report? - Why?

Who to? - Why?

What things might make a difference? - explore variations as necessary

What do you think most doctors would do in this situation?

IF DOCTORS DID REPORT THIS SORT OF THING, WHAT EFFECT WOULD THAT HAVE ON PATIENTS?

Why do you think that?

Would some patients be put off talking to their doctor?

Would patients tell their doctor just as much as they do now?

What would that do to [nature of risk]

SCENARIO 2

SCENARIO NAME _____

HAND OVER SCENARIO

HOW DO YOU THINK THE PATIENT IN THIS SITUATION MIGHT FEEL?

Why do you think that?

Would they talk to the doctor about it?

Might the patient be frightened to talk to the doctor? – Why?

How would they decide what to do?

Is there anyone else they might talk to?

HOW DO YOU THINK A DOCTOR SHOULD DEAL WITH THIS?

Should they report? - Why?

Who to? - Why?

What things might make a difference? - explore variations as necessary

What do you think most doctors would do in this situation?

IF DOCTORS DID REPORT THIS SORT OF THING, WHAT EFFECT WOULD THAT HAVE ON PATIENTS?

Why do you think that?

Would some patients be put off talking to their doctor?

Would patients tell their doctor just as much as they do now?

What would that do to [nature of risk]

SCENARIO 3

SCENARIO NAME _____

HAND OVER SCENARIO

HOW DO YOU THINK THE PATIENT IN THIS SITUATION MIGHT FEEL?

Why do you think that?

Would they talk to the doctor about it?

Might the patient be frightened to talk to the doctor? – Why?

How would they decide what to do?

Is there anyone else they might talk to?

HOW DO YOU THINK A DOCTOR SHOULD DEAL WITH THIS?

Should they report? - Why?

Who to? - Why?

What things might make a difference? - explore variations as necessary

What do you think most doctors would do in this situation?

IF DOCTORS DID REPORT THIS SORT OF THING, WHAT EFFECT WOULD THAT HAVE ON PATIENTS?

Why do you think that?

Would some patients be put off talking to their doctor?

Would patients tell their doctor just as much as they do now?

What would that do to [nature of risk]

SCENARIO 4

SCENARIO NAME _____

HAND OVER SCENARIO

HOW DO YOU THINK THE PATIENT IN THIS SITUATION MIGHT FEEL?

Why do you think that?

Would they talk to the doctor about it?

Might the patient be frightened to talk to the doctor? – Why?

How would they decide what to do?

Is there anyone else they might talk to?

HOW DO YOU THINK A DOCTOR SHOULD DEAL WITH THIS?

Should they report? - Why?

Who to? - Why?

What things might make a difference? - explore variations as necessary

What do you think most doctors would do in this situation?

IF DOCTORS DID REPORT THIS SORT OF THING, WHAT EFFECT WOULD THAT HAVE ON PATIENTS?

Why do you think that?

Would some patients be put off talking to their doctor?

Would patients tell their doctor just as much as they do now?

What would that do to [nature of risk]

IN GENERAL, HOW IMPORTANT DO YOU THINK IT IS THAT DOCTORS KEEP MOST THINGS CONFIDENTIAL?

Why is that?

What would happen if things weren't confidential

DO YOU THINK DOCTORS SHOULD EVER REPORT THINGS ABOUT THEIR PATIENTS?

Why?/Why not?

What sort of things?

Do you think reporting those things would make the rest of us safer?

IS THERE ANYTHING ELSE YOU LIKE TO SAY ABOUT THESE THINGS?

THANK YOU VERY MUCH FOR TALKING TO ME, IT'S BEEN VERY HELPFUL.

ARE YOU STILL HAPPY FOR OUR CONVERSATION TO BE INCLUDED IN THE RESEARCH?

END

APPENDIX FOUR: CODING FRAMEWORK

In this summary, “sources” refers to the number of interviews in which a concept was coded, and “references” refers to the total number of occurrences. So a concept that was coded twice in one interview and three times in another would be listed as 2 sources and 5 references.

Node names in uppercase are headings and subheadings not used for coding or analysis: only nodes in lowercase represent concepts that were coded and analysed.

Name		Sources	Refs
ACTION OR DECISION			
	AMBIVALENCE OR UNCERTAINTY		
	Acceptance of some mistakes or bad outcomes	2	2
	Ambivalence or uncertainty about action	29	64
	Clearly stating contradictory views	14	19
	Different decisions in different situations	24	62
	Dilemma, recognizing difficulty of decision	31	77
	Doctor having discretion over reporting	13	23
	NOT REPORTING		
	Patient to have control over reporting decision	27	82
	Support for not reporting, maintain confidentiality	31	97
	REPORTING		
	Crossing a line, threshold	22	48
	Limiting disclosure to relevant info	3	3
	Report despite possible deterrence	25	56
	Reporting for info not action	11	28
	Reporting options	18	29
	Support for reporting	37	211
	WAITING		
	Consulting with others	3	3
	Further clinical input before report	23	54
	Need for expert assessment of risk	14	23
	Possibility of negotiating or persuading	24	48
	Taking time or waiting for developments	18	46
AUTHORITY			
	Contrasting clinical advice and legal rule	3	3
	Deferring to law	12	26
	Explicit disagreement with rule	8	10
	Not knowing legal rule	6	14

Name		Sources	Refs
CONFIDENTIALITY			
	Confidentiality not that important	9	11
	Confidentiality promoting disclosure	17	24
	Confidentiality valued or important	31	82
	Expectation of confidentiality	11	18
DETERRENCE			
ANTICIPATORY			
	Anticipatory deterrence	35	168
	Anticipatory deterrence unlikely	18	31
	People who don't present at all	7	9
	Calculus rejected - deal with individual	2	2
	Calculus-balance of risk & benefits	6	12
	Calculus-can't know the overall effect	4	6
CONSEQUENTIAL			
	Consequential deterrence	37	211
	Rebuilding trust over time	6	10
	Risk less managed if trust or cooperation lost	23	56
	Risk of alienation from doctor	31	108
	Deterrence impairing treatment	32	98
	Deterrence increasing risk	32	75
	Deterrence unlikely	31	112
	Direct example of real life deterrence	7	8
	Existing risk not increased by reporting	4	4
	Importance of promoting therapeutic options	5	10
	Not blaming doc for DVLA or police action	4	7
	Patient grateful later or when well	19	38
	Reporting seen as helpful or caring	7	10
	Risk of deterrence as reason for not reporting	19	34
	Some people won't take advice anyway	7	7
DOCTOR BEHAVIOUR			
	Answering enquiry different from reporting	1	2
	Confidence in doctor doing right thing	17	30
	Doctor advisor not decider	8	24
	Doctor has no choice or discretion	2	3
	Doctor turning blind eye	2	3
	Dual role or role conflict	1	3
	Stressful for doctor	13	15
	Unsure whether doctors do right thing	6	6
FOREWARNING			
	Forewarning not usual or common	3	4
INFORMING AFTER DISCLOURE			
	Difficulty or bad outcome of forewarning	3	3
	Discussion leading patient to reconsider	7	10
	Discussion or forewarning reducing negative impact	12	20

Name		Sources	Refs
	Going behind back	4	12
	Not going behind back	17	43
INFORMING PRE-DISCLOSURE			
	Better not to be too explicit	2	3
	Need to have clear rules known in advance	12	39
	Patient deceived into disclosure	3	5
ORIENTATION			
	Confidentiality concern High	23	48
	Confidentiality concern Low	14	21
	Risk Perception High	35	113
	Risk perception Low	13	26
PATIENT EXPERIENCE			
	Individual variables	7	12
	Non-professional support	15	26
	Patient (should) take personal responsibility	25	40
	Patient experiencing conflict, dilemma	6	8
	Patients not following advice	16	23
PRIOR EXPECTATION OR ANTICIPATION			
	Consultation as cry for help	11	19
	General reluctance to talk to doctor about certain things	22	48
	Need to get treatment even if worried about reporting	18	35
	Patient censoring or choosing what to reveal	28	51
	Patient frightened or worried by situation	21	33
	Patient reluctant to talk to doctor	31	73
	Patient willing to talk to doctor	17	33
	Patients already know or expect to be reported	12	26
	Patients not expecting to be reported	12	26
	Willing to forego treatment to avoid reporting	6	8
RELATIONSHIP WITH DOCTOR			
	Differential trust in MDT or professions	5	10
	Doctors having social power	3	4
	Importance of quality of pre-existing relationship	14	35
	Taking sides - adversarial or oppositional	7	10
	Trust already reduced	9	15
	Trust in doctor	25	67
	Value of doc/pat relationship	21	43
	Value of medical advice	14	23
	Self-deception; finding reason to justify decision	2	2
PRACTICAL OR PROCESS ISSUES			
	Clarifying scenario	17	24
	Difficulty following or understanding	8	17
INTERVIEWER PRESENTING ALTERNATIVE VIEW			

Name		Sources	Refs
	Maintaining position when challenged by Int	23	39
	Shifting position when challenged by Int	16	22
	Misreading or misunderstanding scenario	13	29
	Off-topic or personal things	15	57
	Rereading or checking scenario	13	30
	SELFDISCLOSURE		
	Direct personal experience	29	82
	Distancing self from risk behaviour	27	71
	Personal experience of other people's behaviour	7	17
	Putting self in scenario	13	30
	Scenario applies directly to subject	9	13
	Self-disclosure	21	40
	Self-disclosure - ref to confidentiality of interview	4	4
	Trust in own doctor or team	17	32
REPORTING			
	REASONS FOR NOT REPORTING		
	Actively seeking help	23	60
	Doctor naive about true situation	9	13
	Loss of control over process once reported	22	49
	Maintaining doc/pat relationship	6	8
	Not done anything yet	15	23
	Other people know, less need to report	2	2
	Patient not to blame or at fault	12	18
	Pre-existing risk not increased by non-disclosure	3	3
	Report increasing risk	26	48
	Reporting - negative consequences for patient	29	69
	Reporting causing public panic	2	2
	Reporting ineffective if no treatment	4	5
	Reporting not making a difference	9	13
	Risk management as alternative to reporting	23	42
	Thoughts distinguished from action or intent	14	24
	Treatment as primary concern	35	117
	Treatment reducing risk	24	36
	Uncertainty of degree of risk	7	10
	REASONS FOR REPORTING		
	Children are different	23	35
	Confidentiality leaves risk unmanaged	10	16
	Doc responsible or liable for outcome	11	17
	Implied consent for disclosure (licensing)	1	1
	Importance of preventing harm	35	127
	Lack of control of noncompliant patient	24	59
	Lack of therapeutic or other options	7	8
	Makes patient take it more seriously	4	5
	Mental health is different; irrationality	25	69

Name		Sources	Refs
	Needs doc to take control or make decision	17	33
	Patient at fault	18	35
	Patient unreasonable or making bad decision	15	21
	Public interest more important than patient	7	11
	Refusal of treatment or advice	22	35
	Reporting as way of accessing help or in patient's best interest	35	124
	Reporting likely to reduce risk	12	24
	Treatment not impaired by reporting	5	5
	Treatment not reducing risk	3	5
	Will soon become known anyway	3	3
NOT INCLUDED IN FINAL 145-NODE FRAMEWORK			
SCENARIO SPECIFIC ISSUES			
	DOMESTIC VIOLENCE		
	DV - blaming husband	3	4
	DV - blaming victim	3	4
	DV - leaving as alt to reporting	2	2
	DV - need to engage husband in treatment	13	18
	DV - overriding patient wishes	8	13
	DV - patient frightened	10	11
	DV - patient has to live with consequences	7	8
	DV - possible children	6	7
	DV - quality of relationship with husband	1	1
	DV - reason for consult, sleeping tabs	2	2
	DV - refuge or support groups	3	4
	DV - likely to continue or escalate	10	15
	DV - patient is accepting the risk	8	15
	DV - protectionism rejected	4	5
	DV - reporting as deterrent to abuser	2	2
	DV - reporting depends on severity or duration	20	30
	DV - victim disempowered or helpless	8	15
	DV - difficulty of engaging husband in Rx	3	3
	EPILEPSY		
	EP - continuing to drive against advice	14	22
	EP - disagreeing with advice given	6	14
	EP - DVLA rules unfair	6	7
	EP - making life decisions without medical advice	3	3
	EP - patient may not have expected driving to be affected	1	2
	EP - patient willing to discuss issues	2	2
	EP - patient's duty to report	8	14

Name		Sources	Refs
	EP - reluctance to follow unfair rules	2	2
	EP - reporting likely to stop her driving	2	2
	EP - risk to patient or child	8	10
	EP - risks of driving	25	40
	EP - risks of driving, not considering or realizing	2	2
	EP - strong desire for pregnancy	1	1
	EP - treatment(advice) not reducing risk	1	1
	EP - accommodating not driving	4	6
	EP - contrasting clinical advice and DVLA rule	4	4
	EP - driving restrictions common	1	1
	EP - DVLA may allow driving	2	2
	EP - long period of stability	3	3
	EP - may not have fit off med	6	6
	EP - not driving very restrictive	11	18
	MENTAL HEALTH		
	MH - accepting patient account at face value	9	13
	MH - attitude or response of neighbour	2	3
	MH - care in community issues	3	4
	MH - conflict with team	1	1
	MH - delusional beliefs not likely to resolve or improve	3	3
	MH - different role than in other health	2	4
	MH - judging seriousness of threat	3	4
	MH - patient may have insight	2	2
	MH - police seen as helpful	8	14
	MH - responsibility for incompetent patient	4	5
	MH - stigma	2	4
	MH - MHA options or admission	17	21
	MH - patient not rational	22	49
	MH - patient welcoming police protection	8	9
	MH - willingness to disclose to neighbour	7	9
	MH - cooperation is issue	4	5
	MH - difficult to reframe discussion	2	2
	MH - threats calculated not impulsive	1	2
	MH - history of past violence	13	17
	MH - negative view of Police	4	4
	MH - patient scared or afraid	13	16
	SEXUAL THOUGHTS		
	SX - leaving school as alt to reporting	3	4
	SX - manipulative or devious behaviour	1	2
	SX - may cause harm without acting on thoughts	1	1
	SX - may not really want to change	3	5
	SX - punished for seeking help	5	7
	SX - age of pupils	6	8

Name			Sources	Refs
		SX - attraction to more than one pupil	1	1
		SX - blaming pupils	3	4
		SX - may not be that serious	8	14
		SX - own children	2	2
		SX - trusted role of teacher	2	2

APPENDIX FIVE: EXPLANATORY MODELS

CONCEPT	THEMES	SUBTHEMES
Support for reporting	Importance of preventing harm	Risk perception high Reporting likely to reduce risk Public interest more important than patient
	Lack of therapeutic options	Refusal of treatment/advice Treatment not reducing risk
	Patient at fault	Distancing self from risk behaviour Patient should take responsibility Patient unreasonable
	Deferring to law/rules	Doctor liable for outcome
	Reporting not harmful	Patient understanding/accepting Confidentiality concern low Reporting to protect patient
	Minimising impact	Reporting options Reporting for info not action Discussion/forewarning reducing impact
Support for confidentiality	Risk Perception Low	Not done anything yet Actively seeking help Uncertainty of risk Thoughts distinguished from action Treatment reducing risk
	Treatment as primary concern	Treatment reducing risk Deterrence as reason for not reporting Reporting ineffective of no treatment Deterrence impairing treatment
	Harm caused by reporting	Increasing risk Public panic/overreaction Negative consequences for patient
	Confidentiality concern High	Confidentiality valued Patient deceived into disclosure
	Patient to have control	Doctor advisor not decider
	Reporting not making a difference	Pre-existing risk not increased Other people know anyway
	Patient not at fault	Not done anything yet Actively seeking help
Taking time or waiting	Consulting with others Risk management as alternative Further clinical input before report	

CONCEPT	THEMES	SUBTHEMES
Deterrence	Anticipatory deterrence	Bad outcome of forewarning Reluctant to talk to doctor People who don't present at all
	Consequential deterrence	Deterrence impairing treatment Risk less managed if trust lost Deterrence increasing risk Alienation from doctor
	Calculus of risk and benefits	Report despite deterrence Deterrence as reason for not reporting Can't know overall effect
	Deterrence unlikely	Willing to talk to doctor Need for treatment even if worried Treatment not impaired by reporting Anticipatory deterrence unlikely
	Mitigating the effects	Maintaining doctor-patient relationship Rebuilding trust over time
Forewarning	Informing pre-disclosure	Bad outcome of forewarning Need to have clear rules Forewarning not usual
	Informing after disclosure	Rebuilding trust over time Reducing negative impact Not going behind back
	Going behind back	
Relationship with doctor	Value of relationship	Confidentiality important Value of medical advice Quality of pre-existing relationship
	Trust in doctor	Willing to talk to doctor Confidence in doctor Trust in own doctor
	Trust already reduced	Reluctant to talk to doctor Taking sides
	Stressful for doctor	Liability for outcome Difficulty of dilemma
	Role of doctor	Advisor not decider Dual role or conflict Social power

GLOSSARY

Anticipatory deterrence	Deterrence arising before any actual breach of confidentiality has taken place. Includes patients who do not present at all, and those who conceal relevant information or concerns
Breach of confidence	Any communication of information about a patient to a third party without implicit or explicit patient consent. Includes communication to other official agencies, even though guidelines refer to sharing of information with DVLA, MAPP, etc as being done “in confidence”
Consequential deterrence	Deterrence arising after an initial breach of confidence, following which the patient affected becomes less willing to seek health care or to disclose information
Convergent breach	Breach of confidence in circumstances or for a purpose similar to that envisaged when information was originally disclosed , such as sharing of health information within a clinical team without specific consent
Deterrence	The possibility that patients might be reluctant to seek health care, or to make full disclosure to their doctor, as a consequence of actual or potential breach of confidentiality
Disclosure	The imparting of information by a patient to a doctor for the purposes of health care
Divergent breach	Breach of confidence in circumstances or for a purpose different to that envisaged when information was originally disclosed , such as reporting of health information to public safety agencies
Forewarning	Advising a patient that certain information will be reported outside the doctor-patient relationship. May take place before the patient has made a specific disclosure , after disclosure but before reporting , or after the report has been made

Reporting	The imparting of information by a doctor to an external person or agency, for the purposes of risk reduction
Scenario	A hypothetical clinical situation chosen to illustrate aspects of a confidentiality dilemma and to serve as a basis for further discussion with subjects
Utilitarian calculus	The balancing of risks and benefits of different alternatives in order to decide the best course of action from a utilitarian perspective
Vignette	The actual wording of a scenario description given to subjects, and designed to engage specific issues likely to be relevant to the research questions