GENETIC PRIVACY

A Challenge to Medico-Legal Norms

GRAEME LAURIE

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1

Health care, patient rights and privacy

Privacy as a problem

Privacy is a problem. Or rather, privacy causes problems. It causes problems for sociologists,[1] psychologists,[2] anthropologists,[3] philosophers,[4] politicians,[5] doctors,[6] lawyers,[7] governments,[8] states,[9] communities,[10] groups[11] and individuals.[12] The problems that it causes relate to its definition,[13] its function,[14] its nature,[15] its utility,[16] its value[17] and its protection.[18] The sheer extent of the difficulties is revealed by the length of the first few notes to this text.

[1] S. I. Benn and G. F. Gaus (eds.), *Public and Private in Social Life* (London, Croom Helm; New York, St. Martin's Press, 1983).

[2] See E. Goffman, *The Presentation of Self in Everyday Life* (London, Pelican Books, 1971), R. Ingham, 'Privacy and Psychology', in Y. D. Young (ed.), *Privacy* (Chichester, Wiley & Sons, 1979), ch. 2, S. M. Jouard, 'Some Psychological Aspects of Privacy' (1966) 31 *Law and Contemporary Problems* 307, P. A. Kelvin, 'Social Psychological Examination of Privacy' (1973) 12 *British Journal of Social and Clinical Psychology* 248, S. T. Margulis (ed.), 'Privacy as a Behavioural Phenomenon' (1977) 33 *Journal of Social Issues*, Issue No. 3.

[3] See B. Moore, *Privacy: Studies in Social and Cultural History* (New York, M. E. Sharpe Inc., 1984), R. F. Murphy, 'Social Distance and the Veil' (1964) 6(1) *American Anthropologist* 1257, and A. Westin, 'The Origins of Modern Claims to Privacy', in F. D. Schoeman (ed.), *Philosophical Dimensions of Privacy* (Cambridge, Cambridge University Press, 1984), at 56–74, H. Arendt, *The Human Condition* (Chicago, University of Chicago Press, 1958).

[4] J. Kupfer, 'Privacy, Autonomy and Self Concept' (1987) 24 *American Philosophical Quarterly* 81, G. Negley, 'Philosophical Views on the Value of Privacy' (1966) 31 *Law and Contemporary Problems* 319, J. H. Reiman, 'Privacy, Intimacy and Personhood' (1976) 6 *Philosophy and Public Affairs* 26, and generally, F. Schoeman (ed.), *Philosophical Dimensions of Privacy: An Anthology* (Cambridge, Cambridge University Press, 1984).

[5] See J. Ames, 'Privacy Law Forced Back on the Agenda' (1992) 89(6) *Law Society's Gazette* 8.

[6] K. Berg, 'Confidentiality Issues in Medical Genetics: The Need for Laws, Rules and Good Practices to Secure Optimal Disease Control', Second Symposium of the Council of Europe on Bioethics, Strasbourg, 30 November–2 December 1993, CDBI-SY-SP (93) 3, D. C. Wertz and J. C. Fletcher, 'Privacy and Disclosure in Medical Genetics Examined in an Ethics of Care' (1991) 5 *Bioethics* 212, G. Dworkin, 'Access to Medical Records: Discovery, Confidentiality and Privacy' (1979) 42 *Modern Law Review* 88, and T. Cantrell, 'Privacy: The Medical Problems', in Young, *Privacy*, ch. 9.

[7] For example, G. Dworkin, 'Privacy and the Law', in Young, *Privacy*, ch. 5, R. Gavison, 'Privacy and the Limits of the Law' (1980) 89 *Yale Law Review* 421, B. S. Markesinis, 'Our Patchy Law of Privacy – Time to do Something about it' (1990) 53 *Modern Law Review* 802,

One might wonder, as a result, what another text on privacy could meaningfully contribute to the debate. A first step to answering this question is to realise that the scope of privacy is so wide-ranging that no reasonable attempt can be made to analyse the concept in all of its facets and guises. This book examines the role of privacy in a health care setting. It considers patient privacy and the interface between medicine and law in the protection of individual rights as regards the provision of health care. In particular, the contribution of this work to the general debate about privacy lies in an examination of the privacy issues raised by what has been termed the New Genetics.

W. A. Parent, 'A New Definition for Privacy for the Law' (1983) 2 *Law and Philosophy* 305, W. L. Prosser, 'Privacy: A Legal Analysis' (1960) 48 *California Law Review* 338, R. Wacks, *Personal Information, Privacy and the Law* (Oxford, Clarendon Press, 1989), and S. D. Warren and L. D. Brandeis, 'The Right to Privacy' (1890–91) 4 *Harvard Law Review* 193.

[8] See R. F. Hixson, *Privacy in a Public Society* (New York, Oxford University Press, 1987), J. P. Gould, 'Privacy and the Economics of Information' (1980) 9 *Journal of Legal Studies* 827, C. Mellors, 'Governments and the Individual: Their Secrecy and His Privacy', in Young, *Privacy*, p. 87, J. F. Handler and M. K. Rosenheim, 'Privacy in Welfare: Public Assistance and Juvenile Justice' (1966) 31 *Law and Contemporary Problems* 377, and W. A. Creech, 'The Privacy of Government Employees' (1966) 31 *Law and Contemporary Problems* 413.

[9] See, for example, Article 8 of the European Convention for the Protection of Human Rights and Article 12 of the Universal Declaration of Human Rights, both of which provide for the protection of personal privacy. For comment on the former see L. G. Loucaides, 'Personality and Privacy Under the European Convention on Human Rights' (1990) 61 *British Yearbook of International Law* 175.

[10] As Westin has commented, 'Needs for individual and group privacy and resulting social norms are present in virtually every society. Encompassing a vast range of activities, these needs affect basic areas of life for the individual, the intimate family group, and the community as a whole', A. Westin, *Privacy and Freedom* (London, Bodley Head, 1967), p. 13.

[11] F. D. Schoeman, 'Adolescent Confidentiality and Family Privacy', in G. Graham and H. LaFollette (eds.), *Person to Person* (Philadelphia, Temple University Press, 1989), pp. 213–34, I. N. Walden and R. N. Savage, 'Data Protection and Privacy Laws: Should Organisations Be Protected?' (1988) 37 *International and Comparative Law Quarterly* 337.

[12] L. Blom-Cooper, 'The Right to be Let Alone' (1989) 10 *Journal of Media Law and Practice* 53, J. Kupfer, 'Privacy, Autonomy and Self Concept' (1987) 24 *American Philosophical Quarterly* 81, S. I. Benn, 'Privacy, Freedom and Respect for Persons', in Schoeman, *Philosophical Dimensions of Privacy*, Gavison, 'Privacy and the Limits of Law', H. Gross, 'Privacy and Autonomy', in J. Feinberg and H. Gross, *Philosophy of Law* (2nd edn, Wadsworth Inc., USA, 1980), L. Henkin, 'Privacy and Autonomy' (1974) 74 *Columbia Law Review* 1410, C. Fried, 'Privacy' (1968) 77 *Yale Law Journal* 475.

[13] W. A. Parent, 'A New Definition for Privacy for the Law' (1983) 2 *Law and Philosophy* 305, W. A. Parent, 'Recent Work on the Concept of Privacy' (1993) 20 *American Philosophical Quarterly* 341, Gavison, 'Privacy and the Limits of Law', R. A. Posner, 'The Right to Privacy' (1978) 12 *Georgia Law Review* 393, D. N. McCormick, 'Privacy: A Problem of Definition' (1974) 1 *British Journal of Law and Society* 75, Fried, 'Privacy'.

[14] J. C. Innes, *Privacy, Intimacy and Isolation* (New York, Oxford University Press, 1992), S. I. Benn, 'Privacy, Freedom and Respect for Persons', in Schoeman, *Philosophical Dimensions of Privacy*, Gavison, 'Privacy and the Limits of Law', Fried, 'Privacy', and Murphy, 'Social Distance and the Veil'.

The advent of modern genetic science and genetic testing has given rise to acute problems in the health care context, some real and others imaginary. For example, the discovery of a predisposition to a genetic condition in one individual often also reveals potential risks to the blood relatives of that individual. Thus, individual genetic information can unlock many secrets within the wider genetic family. There is, therefore, potential for conflict over access to, and control of, such information. Traditionally, the duty of confidentiality owed by a health care professional to a patient has provided an appropriate means by which personal health information has been kept secure. There are serious doubts, however, whether the issues that surround genetic information in the familial milieu can be adequately dealt with within the envelope of confidentiality. This is an amorphous and ill-defined duty that is compromised by its twin roles of protecting both the confidential relationship and the confidential information which arises from that relationship. Moreover, to the extent that the duty of confidentiality is solely concerned with keeping confidential information out of the public sphere, it says nothing about the duties that might be owed within the confidential relationship towards the subjects of the information so as to ensure, inter alia, that the personal interests of these individuals are not treated with a lack of respect by unwarranted uses of information with regard to the subjects themselves.

[15] Much debate centres on the philosophical nature of privacy. Is it a right, a claim, an interest, an issue of control or a state of being? For a discussion of the possibilities and a review of the literature, see Schoeman, *Philosophical Dimensions of Privacy: An Anthology*, ch. 1.

[16] J. H. Reiman, 'Privacy, Intimacy and Personhood' (1976) 6 *Philosophy and Public Affairs* 26, J. Rachels, 'Why Privacy Is Important' (1975) 4 *Philosophy and Public Affairs* 323, J. J. Thomson, 'The Right to Privacy' (1975) 4 *Philosophy and Public Affairs* 295, T. Scanlon, 'Thomson on Privacy' (1975) 4 *Philosophy and Public Affairs* 315.

[17] Wacks, *Personal Information, Privacy and the Law*, Hixson, *Privacy in a Public Society*, Thomson, 'The Right to Privacy', Scanlon, 'Thomson on Privacy', and Negley, 'Philosophical Views on the Value of Privacy'.

[18] Historically, this issue has given rise to much concern, but little productive action, in the United Kingdom. In the latter part of the twentieth century numerous attempts were made to pass some form of legislation to protect privacy. None succeeded. Several committees were established to examine the matter and report, such as the Younger Committee, Report of the Committee on Privacy, Cmnd 5012 (1972), and the Calcutt Committee, Report of the Committee on Privacy and Related Matters, Cm 1102 (1990), and in 1993 Calcutt re-examined the question of privacy legislation and recommended Parliamentary intervention (Review of Press Regulation, Cm 2135 (1993)). No direct legal protection resulted. It was not until the passing of the Data Protection Act 1998 in March 2000 and the Human Rights Act 1998 in October 2000 that anything approximating proper recognition and protection of privacy in the United Kingdom was realised.

The principle of respect for patient autonomy – which has been described as the guiding ethical principle in health care and which has received unprecedented recognition by the laws of most Western states – is similarly ill-equipped to provide a comprehensive solution to the problems posed by familial genetic information. This is because the focus of an autonomy-based argument is largely on the individual and her ability to control aspects of her life. The 'group' nature of claims concerning family information poses a serious conceptual threat to this paradigm. Moreover, health care professionals frequently confuse the desire to respect autonomous patient choices with a desire to facilitate those choices and, as a result, patients are often placed in the invidious position of having to make choices that they might otherwise have avoided.

This book examines these, and other, problems and argues for the value of an appeal to privacy in seeking to resolve some of the more intractable issues. A unique definition of privacy is offered by which to address these dilemmas. The construct is also intended to enrich the discourse on the role and the limits of established principles in medical law and ethics, such as respect for patient autonomy and confidentiality. The work advocates a greater role for privacy in the health care setting; more specifically, it examines the need for stronger legal protection of privacy in the shadow of new challenges arising from advances in human genetics.

Establishing parameters

The quest for the essential character of the concept of privacy centres on the search for a means to establish an identifiable and sustainable interface between the public and private spheres of human life.[19] Furthermore, because human lives are not passed in a social vacuum, privacy is also concerned with the regulation of the relationship between an individual and the society in which she lives.[20] Indeed, the two concepts of individual and society are inextricably linked – the definition of one provides, almost by analogy, the definition of the other. For example, Giddens defines *society* as 'a cluster, or system, of institutionalised modes of conduct. To speak of "institutionalised" forms of social conduct is to refer to modes of belief and behaviour that occur and recur – or, as

[19] See generally Benn and Gaus, *Public and Private in Social Life.*

[20] See Wacks, *Personal Information, Privacy and the Law*, p. 7, and J. P. Tomlinson, 'Privacy and Law Enforcement', in Young, *Privacy*, ch. 6.

the terminology of modern social theory would have it, are socially *reproduced* – across long spans of time and space.'[21] Yet, as he states, 'societies only exist in so far as they are created and re-created in our actions as human beings. In social theory we cannot treat human activities as though they were determined by causes in the same way as natural events are. We have to grasp what I would call the *double involvement* of individuals and institutions: we create society as we are created by it.'[22]

For the purposes of this book, privacy will be treated in the context of the relationship between the individual and Western liberal society, with its central tenets of democracy and commitment to individualism, and its concern for personal privacy. A specific context for privacy has to be supplied, because as a purely abstract concept it can only be defined meaningfully in terms of the cultural norms of a particular society and the position of the individual within that society. As Benn has stated, 'The judgements we make about our privacy arrangements must take the rest of our cultural ideals largely as we find them. Individuals like ourselves in our kind of culture, then, do have an interest in privacy in the management of the internal economy of their own personalities and of their personal relations with others.'[23]

In a developed, technologically advanced society information can be disseminated with great rapidity. People share their lives not only with family and friends but also with many other persons who live or work in the same places, who frequent the same establishments or who communicate over the internet. Strangers become pseudo-intimates, and vast tracts of a person's life can be shared with people for whom she may feel very little, yet about whom she may know a great deal. But because individuals often do not choose these pseudo-intimates, and because they cannot necessarily control the flow of information about themselves between such persons and others, they can experience an increasing sense of loss in relation to a side of their lives that has come to epitomise the private sphere, namely, the realm of personal information.[24] At the same time, the physical division between the workplace and the

[21] A. Giddens, *Sociology: A Brief But Critical Introduction*, 2nd edn (London, Macmillan, 1986), p. 8. Social systems he defines as: '[involving] patterns of relationships among individuals and groups', p. 12.

[22] *Ibid.*, p. 11.

[23] S. I. Benn, *A Theory of Freedom* (Cambridge University Press, New York, 1988), p. 287.

[24] See A. Charlesworth, 'Data Privacy in Cyberspace: Not National vs. International but Commercial vs. Individual', in L. Edwards and C. Waelde (eds.), *Law and the Internet: A Framework for Electronic Commerce* (Oxford, Hart Publishing, 2000), pp. 79–122.

home has led to a greater separation between the two environments in people's minds,[25] with an increased reluctance to allow one to encroach on the other. Indeed, Prost has documented the spread of privacy concerns through all strata of society in the twentieth century. As he says, 'the twentieth century may be seen as a period during which the differentiation of public and private, at first limited to the bourgeoisie, slowly spread throughout the population. Thus, in one sense the history of private life is a history of democratization.'[26]

Privacy: a definition

The notions of privacy considered above embody two conceptions of privacy. First, it can be viewed as a state of non-access to the individual's physical or psychological self – what can be called *spatial privacy*. Second, privacy can be seen as a state in which personal information about an individual is in a state of non-access from others – *informational privacy*.[27] One unifying definition can be deduced from these two concepts: privacy is a state of separateness from others. This is the definition of privacy that is adopted in this book and the reasons for this choice will be more fully considered and justified in chapter 2. For the moment, privacy should be taken to refer to a state in which an individual is apart from others, either in a bodily or psychological sense or by reference to the inaccessibility of certain intimate adjuncts to their individuality, such as personal information.

Why protect privacy?

Private interests

It has been posited that a need for individual privacy arose in tandem with the evolution of Western liberal democracy. It has also been suggested that the privacy interests of individuals are of two distinct kinds.

[25] See A. Prost, 'Public and Private Spheres in France', in A. Prost and G. Vincent (eds.), *A History of Private Life* (London, Belknap Press, 1991), V, pp. 9–49.

[26] A. Prost, 'Introduction', in Prost and Vincent, *A History of Private Life*, p. 7.

[27] This view of privacy corresponds largely with a layman's view of the concept. The Younger Committee on privacy found that the responses of individuals to questions in a commissioned survey about what constituted invasions of privacy tended to place the notion of privacy into one or both of two groups: freedom from intrusion or privacy of information, see Younger Committee, *Report of the Committee on Privacy*, Cmnd 5012 (1972), p. 32.

What has not been explained is why individuals need privacy. Several arguments can be made.

First, a state of physical separateness from others is necessary in order to allow personal relationships to begin and to grow. The levels of intimacy that typify the modern personal relationship can only be achieved by ensuring and securing separateness from others. Trust – which is essential to the establishment and maintenance of all relationships – requires not only a degree of intimacy to develop but also a currency in which to deal. An important part of that currency is personal information. Individuals trade private information both as a sign of trust and on the basis of trust. The security of the information is guaranteed by the tacit undertaking that it will not be noised abroad. In this way personal and professional relationships flourish and an important part of the fabric of society is woven more tightly.[28] As Fried has said,

> Love and friendship . . . involve the initial respect for the rights of others which morality requires of everyone. They further involve the voluntary and spontaneous relinquishment of something between friend and friend, lover and lover. The title to information about oneself conferred by privacy provides the necessary something. To be friends or lovers persons must be intimate to some degree with each other. Intimacy is the sharing of information about one's actions, beliefs, or emotions which one does not share with all, and which one has the right not to share with anyone.[29]

Second, a degree of separateness allows the individual personality to reflect on experiences and to learn from them. Constant company requires unceasing interaction and this in turn deprives the individual of time to assimilate life experiences and to identify her own individuality.[30]

Third, it has been said that the modern psychological make-up of individuals is such that a degree of separateness is required to ensure that individuals retain a degree of mental stability. Jouard has put a forceful argument that (Western) public life puts considerable strain on individuals, who must assume personae in order to integrate successfully with others.[31] These personae, being designed to conceal the true

[28] See Fried, 'Privacy'.

[29] C. Fried, *An Anatomy of Values: Problems of Personal and Social Choice* (Cambridge, MA, Harvard University Press, 1970), p. 142.

[30] M. Van Manen and B. Levering, *Childhood's Secrets: Intimacy, Privacy and the Self Reconsidered* (Williston, VT, Teachers College Press, 1996).

[31] Jouard, 'Some Psychological Aspects of Privacy', and see generally n. 2 above.

personality of the individual, cannot be maintained indefinitely without serious psychological consequences. A state of privacy allows the masks to be dropped and a degree of release to be obtained.

Fourth, tangible harm can come to an individual who is not granted a degree of privacy. Concerning spatial privacy, unauthorised invasion of the body is disrespectful of the individual and may cause physical harm. The criminal and civil laws of assault recognise and protect the inviolability of the physical self in this regard. Perhaps less obvious but no less valid, however, is the psychological harm that can arise if spatial privacy is not respected. For example, clandestine observation can produce profound feelings of violation in individuals even when no actual physical contact occurs.[32] Similarly, even within a paradigm of the private sphere such as the family home, an individual's psychological spatial privacy can be invaded if she is subjected to imposed stimuli, such as another family member's choice of music. Considerable mental anguish can occur as a result.[33]

Beyond spatial privacy concerns, the invasion of one's *informational* privacy can also lead to harm to individuals. Information about one's personal condition, behaviour or habits that others find distasteful can lead to individuals being ostracised by communities or becoming the object of violence and discrimination. As Greenawalt puts it, 'One reason why information control seems so important is precisely because society is as intolerant as it is, precisely because there are so many kinds of activity that are subject to overt government regulation or to the informal sanctions of loss of job or reputation.'[34]

Public interests

One final argument in support of protection of privacy can be offered. The above points concentrate on individual private interests. But there are also public interests in privacy protection. It can be argued, for example, that it is in the public (societal) interest to have a community inhabited by rounded individuals as opposed to two-dimensional

[32] See Benn, 'Privacy, Freedom and Respect for Persons', 230–1, and this is equally true when no personal information is gathered.

[33] C. M. Gurney, 'Transgressing Private–Public Boundaries in the Home: A Sociological Analysis of the Coital Noise Taboo' (2000) 13 *Venereology – The Interdisciplinary International Journal of Sexual Health* 39.

[34] K. Greenawalt, 'Privacy and its Legal Protections' (1974) 2 *Hastings Center Studies* 45, 53.

characters.[35] Similarly, it is clearly in the interests of a society which holds the individual in esteem to reduce all potential harm to individuals to a minimum.

Paradoxically, however, it is the development of a public interest in the welfare of individuals that has proved to be one of the greatest threats to individual privacy in the last century. This might be termed the phenomenon of the interventionist state, and it is a trend that has emerged as a central tenet of the Western liberal tradition. It is born out of democratic developments in the twentieth century that heralded an expanding role for the state and a marked increase in the interest which states show in the lives of their citizens. For example, most Western states have assumed a degree of responsibility for the provision of basic services such as housing and utilities, subsistence benefits, education and child welfare. The provision of health care is of primary importance among these; indeed, with the notable exception of the United States, a national health service is a key feature of many Western democracies. On another level, Western societies are typified by a glut of legislation stemming from paternalistic attitudes of the state towards its citizens. Thus, we find legislation prohibiting or severely restricting sales of alcohol and other drugs, limiting the purchase of lottery tickets, and requiring the wearing of seat belts or safety helmets when using motor vehicles. Such legislation comes in a variety of forms ranging from prohibition with the threat of criminal sanction, through civil liability, to the use of fiscal means to control citizens' behaviour. Strömholm explains this in part when he writes:

> prevailing democratic ideologies stress the need for continuous debate on matters of public interest . . . the complexity of modern society and the subtle interwovenness of facts and interests within its framework have led to the feeling that almost everything concerns everyone in one sense or another. Thus, any unimportant event may touch upon matters in which the public may claim a legitimate interest.[36]

[35] Benn notes that 'the children of the kibbutz have been found by some observers defective as persons, precisely because their emotional stability has been purchased at the cost of an incapacity to establish deep personal relations. Perhaps we have to choose between the sensitive, human understanding that we achieve only by the cultivation of our relations within a confined circle and the extrovert assurance and adjustment that a *Gemeinschaft* can offer. However this may be, to the extent that we value the former, we shall be committed to valuing the right of privacy', in 'Privacy, Freedom and Respect for Persons', p. 237.

[36] S. Strömholm, *Rights of Privacy and Rights of the Personality: A Comparative Study* (P. A. Norstedt and Söners Forlag, Stockholm, 1967), p. 17.

Hence, while individual interests are given more importance in democratic communities, public interests are, at the same time, afforded greater weight. This increases tension at the interface between the public and private areas of life and requires that we define as clearly as possible where the boundaries of the two spheres lie. It is a function of privacy to provide a mechanism to ensure that such boundaries are well constituted. Privacy also forces recognition of the fact that at times certain areas of life can, and should, be kept separate. As Schoeman states, 'respect for privacy signifies our recognition that not all dimensions of persons or relationships need to serve some independently valid social purpose'.[37]

Finally, it should not be overlooked that harm can come to society itself if privacy is not respected. Important and valuable information will not be communicated if the element of trust that is so crucial to the development of relationships is lost because individuals cannot be guaranteed security of information. This can render important social organs impotent. An apposite example of this can be seen in the medical confidentiality decision of *X* v. *Y*.[38] A newspaper gained access to the medical files of two doctors suffering from AIDS who were continuing to work in general practice. The newspaper sought to disclose this information and argued that it was justified in doing so because the public had a right to know the facts. The court, however, rejected this argument and, in issuing an injunction, held that there was an overriding public interest in respecting the confidences of people such as the two doctors. Rose J summed up his reasoning as follows: 'In the long run, preservation of confidentiality is the only way of securing public health; otherwise doctors will be discredited as a source of information, for future patients "will not come forward if doctors are going to squeal on them".'[39] Similarly, in *Jaffee* v. *Redmond*[40] the US Supreme Court opined that the public good would be best served by protecting the confidentiality of mental health records and so preserving the special relationship of trust between psychotherapist and patient.

As these sentiments indicate, just as there are public and private reasons to protect privacy, the effective protection of privacy can serve both public and private ends.

[37] See F. D. Schoeman, 'Privacy and Intimate Information', in Schoeman, *Philosophical Dimensions of Privacy*, ch. 17, p. 413.
[38] *X* v. *Y* [1988] 2 All ER 648. [39] *Ibid.*, at 653.
[40] *Jaffee* v. *Redmond* 518 US 1; 116 S. Ct. 1923 (1996).

Privacy in context: the health care setting

Because there is a differing role for privacy in very many areas of life, it is necessary, in order to carry out a worthwhile study of it, to focus on a single area, that is, a single aspect of the relationship between the individual and society.

The need to choose a context at all is dictated by the nature of the concept of privacy. Privacy is exceptionally difficult to define. An extremely wide variety of definitions can be offered, some of which conflict and some of which are antithetical. Yet almost all are plausible and defensible on some level.[41] This book is not intended as a philosophical discussion of this range of possible meanings, nor is its aim to provide a definitive account of privacy. Rather, it offers a particular concept of privacy that will help us to understand the kinds of interests that are at stake in the health care context and to appreciate the role that the law might have in recognising and protecting such interests. To achieve this, we require a particular setting, the limits of which are relatively certain and within which the function of privacy is relatively clear.

Health promotion and the cult of the body

The reasons for choosing the health care setting as a context for this discussion of privacy mirror to a large extent the reasons for setting this entire work within the broad context of the Western liberal tradition. The rise of Western liberal democracy has spawned a very egocentric society and, for the majority, one's private life takes precedence over social or community matters. In particular, Prost has argued that 'There is no more telling sign of the primacy of individual life than the modern cult of the body.'[42]

This is a reference to the near-obsessional interest displayed by many individuals in the Western world concerning personal appearance and body management. Prost cites increases in concern with personal hygiene, physical fitness and healthy eating as evidence of the development of such a cult.[43] The consequence of all of this, he notes, is that the body

[41] This will be discussed further in ch. 2.
[42] A. Prost, 'The Family and the Individual', in Prost and Vincent, *The History of Private Life*, p. 93.
[43] *Ibid.*, pp. 87–101.

has become the focal point of personal identity: 'To be ashamed of one's body is to be ashamed of oneself.'[44]

Increased interest in the body leads to increased concern with threats to the body. Arguably, the most consistent and persistent of threats is illness. Not surprisingly, therefore, concerns about ill health have escalated in recent times,[45] to such an extent that the promotion of health and wellbeing has become of paramount importance. Of course, the health of individuals is of importance to all societies, but it is with unwavering conviction that Western states place the pursuit of health as primary among the prerequisites of a good life. Further, health has come to mean, not just the absence of illness, but the attainment of a state of wellbeing that includes an entire range of desirable features and characteristics, including physical fitness, attractiveness to others, correctness of proportions and psychological stability.[46] Technological advances have allowed the boundaries of medicine to be pushed ever further forward, making the treatment of actual ill health but one option in a range of possible options offered to patients. As more can be done for the health of the populace, so more interest is taken by the populace in its health.[47]

Body, self and privacy

Not only is the body seen to house the self and be governed by it, it is a tangible and real manifestation of the abstract that we call the self. Body and self are inextricably linked, and often the two are perceived as being one and the same. Protection of the body therefore becomes synonymous with protection of the self. Individuals can experience feelings of deep violation of their inner self when the body is under threat from disease or illness, and there is a corresponding sense of profound invasion of a sphere of their lives over which they thought they had exclusive control. As the Danish Council of Ethics has put it,

[44] *Ibid.*, p. 93. [45] *Ibid.*, pp. 95–8.

[46] The World Health Organisation (WHO) defined 'health' in its Constitution of 1946 as a 'state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity', World Health Organisation, *Constitution* (New York, WHO, 1946).

[47] The habit of turning to medicine for the promotion of health has been called the 'medicalisation of health' and it is not always perceived as appropriate or desirable, see, for example, R. S. Downie, C. Fyfe, and A. Tannahill, *Health Promotion: Models and Values* (Oxford, Oxford University Press, 1990), p. 1.

> Disease – especially severe disease – is a personal matter in the sense that it concerns fundamental aspects of a human being's person: the potentiality for physical development, pain, suffering and, ultimately, death. A person's outlook on his own disease is therefore a decisive part of his relationship with himself. To a very great degree, this relationship is instrumental in determining an individual's personal sphere, that part of life which a person is entitled to keep to himself.[48]

Moreover, the process of subjecting themselves to health care may exacerbate any feelings of violation or invasion that have already been experienced. Intimate aspects of the self often have to be revealed to health care professionals (HCP). Thus, the body must be exposed to detailed examination, personal details must be disclosed, family histories must be recounted, and humiliating procedures must be braved. The end result of all of this may or may not be an improvement in health and the ultimate goal of health care may or may not be achieved. But, in the process, the individual has revealed her inner self to others, has given away personal information and knowledge, and has been exposed to incursions on her body. This is not to say that health care is necessarily a threat to the individual's private life, but it does highlight how the two are intimately connected and also how the health care system is itself a potential conduit for serious invasions of privacy.

Threats to patient privacy in the health care setting

There are many ways in which the provision of modern health care and the machine of modern medicine can invade privacy. The use of wards to care for patients provides an example. A system that places patients together in the same room with no separation between them save a flimsy curtain affords easy access to their persons, yet some of the most personal moments of one's life are experienced in hospitals. Conversations about diagnosis, prognosis and treatment can be overheard, notes are left at the end of patients' beds where they can easily be read, and generally, the practice of everyday medicine is conducted before an audience consisting not only of other patients, but also of their families and friends and other visitors to the institution. The position is not much

[48] See Danish Council of Ethics, *Ethics and Mapping the Human Genome* (Copenhagen, Notex, 1993), p. 52.

improved when patients have private rooms. Access to their person and information about their condition is freely available to a range of hospital staff, both clinical and ancillary. Doctors, nurses, auxiliaries, support staff, cleaners and administrators can all gain such access.[49] Even unauthorised visitors can easily breach the security of hospitals to invade the privacy of patients. One of the most celebrated privacy cases to be heard in the UK courts involved just such a scenario.

In *Kaye* v. *Robertson*[50] a British television actor, Gorden Kaye, had been seriously injured during the winter storms of 1990 and underwent brain surgery at Charing Cross Hospital in London. While he was recovering in a private room, two reporters from a tabloid newspaper gained access to the room, carried out an interview and took some photographs intended for publication. Kaye, however, had no recollection of the interview minutes after it had taken place and, in any event, was in no state to give valid consent to its use. Yet he was, in effect, unsuccessful in obtaining a remedy to prevent publication. In the absence of specific legal protection of privacy in the United Kingdom, Kaye relied on four different existing forms of action – libel, malicious falsehood, trespass to the person and passing off. Only malicious falsehood was considered to be of any relevance, but no damages were awarded and the injunction that was granted was limited to a prohibition on publishing anything which 'could be reasonably understood or convey to any person reading or looking at the Defendant's *Sunday Sport* newspaper that the Plaintiff had voluntarily permitted any photographs to be taken for publication in that newspaper or had voluntarily permitted representatives of the Defendants to interview him while a patient in the Charing Cross Hospital undergoing treatment'.[51] In other words, Kaye could not prevent publication of the story or photograph, merely publication of his consent. In his judgment Leggatt LJ made the following comments: '[the] right [of privacy] has so long been disregarded here that it can be recognised now only by the legislature . . . it is to be hoped that the making good of this signal shortcoming in our law will not be long delayed'.[52]

This case more than any other highlights the historically woeful inadequacy of English law in relation to the legal protection of personal

[49] N. Okino Sawada *et al.*, 'Personal and Territorial Space of the Patients: A Nursing Ethics Question' (1996) 15 *Medicine and Law* 261.
[50] *Kaye* v. *Robertson* [1991] FSR 62. [51] *Ibid.*, at 66. [52] *Ibid.*, at 71.

privacy, and no better protection has been accorded by the Scottish courts. It is significant that the circumstances which gave rise to this case took place in a health care setting. As Bingham LJ said, 'If ever a person has a right to be let alone by strangers with no public interest to pursue it must surely be when he lies in hospital recovering from brain surgery and in no more than partial command of his faculties.'[53]

The vulnerable position in which persons find themselves in the health care context makes all the more pressing the need for adequate and effective protection of their interests, including those of privacy. Moreover, the Kaye case provides a good example of how the privacy interests that patients have in the health care setting are of two distinct, yet related, kinds – both informational privacy and spatial privacy are at stake. The invasion of Gorden Kaye's privacy occurred at two levels: the invasion of personal space by uninvited parties and the invasion of his privacy interests in personal information by the publication of photographs of him and details about his condition. The plaintiff's failure to secure adequate legal protection of either of these interests is lamentable. And, while very recent judicial and legislative initiatives have now created express privacy protection in the United Kingdom,[54] the absence of a tradition of such protection will have ramifications for a significant time to come.[55]

More sensitivity to the vulnerable state of patients has been shown in the United States. In *Berthiaume* v. *Pratt* it was held to be a violation of a moribund patient's right to privacy when clinical staff took photographs of him without his consent.[56] In *Noble* v. *Sears, Roebuck & Co.*[57] the plaintiff was successful in convincing the court that she had 'an exclusive right of occupancy of her hospital room', at least as against an investigator who gained unauthorised access in order to obtain information pertaining to the plaintiff's suit against the defendant. Such

[53] *Ibid.*, at 70. In like manner, in *Barber* v. *Time*, 348 Mo. 1199; 159 S. W. 2d 291 (1942) the Supreme Court of Missouri confirmed that 'Certainly if there is any right of privacy at all, it should include the right to obtain medical treatment at home or in a hospital for an individual personal condition (at least if it is not contagious or dangerous to others) without personal publicity', at 1207; 295.

[54] A common law right of privacy was eventually recognised in 2000 by the Court of Appeal in *Douglas and Others* v. *Hello! Ltd.* [2001] 2 All ER 289. Moreover, in the course of the same year the Data Protection Act 1998 and the Human Rights Act 1998 came into force. These developments are discussed in ch. 5.

[55] See further ch. 5.

[56] *Berthiaume* v. *Pratt* 365 A 2d 792 (Me., 1976).

[57] *Noble* v. *Sears, Roebuck & Co.*, 33 Cal. App. 3d 654 109 Cal. Rptr. 269 (1973).

an unreasonably intrusive investigation was directly actionable as an invasion of privacy. Similarly, in *Shulman* v. *Group W. Productions Inc.*[58] the California Supreme Court upheld as triable the plaintiff's argument that she was entitled to a degree of privacy during the rescue of her and her son from the scene of a car accident. While the plaintiff could not legitimately expect to be free from intrusion by the media at the scene of the accident itself, she was entitled to a higher degree of protection once in the air ambulance, for this was clearly a zone of intimacy where her suffering and conversations could reasonably be considered as private. This can easily be seen as protection of a spatial privacy interest. However, the court was not willing to hold that the filming of the rescue and its subsequent broadcast on television was an actionable cause on the basis of publication of private facts (an informational privacy interest). In this regard the court was bound to balance the plaintiff's privacy interests with the strong public interest in press freedom and the publication of matters of legitimate public concern. After weighing the various arguments, the court found that the broadcast of the disputed material was 'newsworthy as a matter of law'.[59] Thus, while strong public interests might well support protection of privacy as has been argued above, so too can those interests be challenged by competing public interests of equal or greater weight. We shall return to this dilemma presently.

Privacy, state interest and health care provision

We have seen that one sign of a democratic system is the extent to which the state takes an interest in the lives of individuals, and it is clear that one of the primary ways in which this occurs is in relation to health care. As Prost comments, 'sickness, a central concern of private life, has become the focus of much public policy. Nothing is as private as health, yet nothing is so readily made the responsibility of the public authorities. Health is now a public as well as private affair.'[60]

The interest of the state in health matters has consequences for patient privacy in at least two ways. First, in those countries that provide state-run health care, the public nature of the enterprise takes away

[58] *Shulman* v. *Group W. Productions Inc.*, 18 Cal. 4th 200; 955 P. 2d 469 (1998).
[59] *Ibid.*, at 228; 488. [60] Prost, 'The Family and the Individual', p. 98.

from the individual patient control of the environment. While such a system might facilitate the chances of every individual of gaining access to medical care, it does little to address concerns for individual privacy that flow from this. Second, states take it upon themselves to intervene in the lives of individuals in circumstances where interference is thought to be justified on public health grounds (usually invoking a best interests argument) or when the individual is perceived as a threat to the health of the community at large (usually invoking a public interest argument).[61]

Notifiable diseases

Consider the concept of notifiable disease as an example of state intervention on health grounds. All states pass legislation requiring the notification of cases of specified infectious and contagious diseases to public authorities,[62] it being argued that the threat to privacy that notification poses is justified by the (greater) threat of the spread of disease in the wider community. In many cases this is undoubtedly true. However, the choice of the diseases that are deemed to be notifiable is sometimes open to question. In some states AIDS has been made a notifiable disease.[63] Yet AIDS – or rather its causative virus HIV – cannot be transmitted by casual contact. Individuals must engage in high risk behaviour before transmission is possible.[64] In fact, this disease has been labelled by American clinicians as 'the least infectious disease we have

[61] See, for example, the US Supreme Court decision in *Jacobson* v. *Massachusetts,* 197 US 11 (1905), at 24–30 in which it was held that the court could balance the interests of the individual in refusing smallpox vaccine (protected under the Constitution) against the state's interest in preventing disease. The conclusion of the court was that the state interest was sufficiently compelling not to render unconstitutional a law requiring compulsory vaccination against smallpox save in circumstances where the individual could show significant disadvantage or threat to life.

[62] For a critical account of disease control legislation in England, Germany, the Netherlands, Sweden and Switzerland, see J. Dute, 'Affected By The Tooth of Time: Legislation on Infectious Diseases Control in Five European Countries' (1993) 12 *Medicine and Law* 101.

[63] For comment on this issue and various other legislative responses to HIV/AIDS, see J. Keown, 'AIDS: Should It Be Made a Notifiable Disease?' (1989) July/August *Professional Negligence* 121, and M. D. Kirby, 'AIDS Legislation – Turning Up the Heat?' (1986) 12 *Journal of Medical Ethics* 187. Places where AIDS is notifiable include Denmark, Norway, Sweden and most US states. Neither HIV nor AIDS is notifiable in the United Kingdom.

[64] There are only three methods of transmission of HIV, which were identified in 1982. They are: unprotected anal or vaginal sex, the mixing of infected bodily fluids with the bloodstream of another person, and the infection by a mother of her unborn child. No other verified method of transmission has been identified.

ever come across'.[65] While data collection is undoubtedly beneficial to epidemiological research, the significant risks of stigmatisation and/or ostracisation that are attendant on disclosure of HIV status suggest to some that the balance between public interests in public health and public and private interests in personal privacy is not being struck in an acceptable manner in those states requiring notification.[66]

Moreover, the continued existence of such legislation becomes questionable if it is not supported by additional provisions designed to ensure that individual rights are protected.[67] A survey of the legislative provisions of five European countries concluded:

> In many respects current legislation on infectious diseases control appears to be outdated. For at least two reasons legal provisions need modernization: First, there has been a considerable increase in medical knowledge of disease transmission and as a consequence the methods of interrupting the spread of disease are today much more refined than they were in the past; second, in current legal analysis greater emphasis is placed on the protection of individual rights, especially the right to privacy and the right to physical integrity.[68]

Other examples of state interest in health matters include the regulation of abortion,[69] compulsory vaccination programmes,[70] the denial

[65] D. Jeffries, 'AIDS – The New Black Death?' (1986) *Medico-Legal Journal* 158, 158.

[66] This is especially true given the consequences of making a disease notifiable. Not only does this mean that all clinicians are legally obliged to pass patient information onto authorities, but also it means that the same authorities have considerable powers to collect further information through compulsory examination and contact tracing. Furthermore, in the name of disease management, such authorities can exercise strong control powers over individuals, including quarantine and compulsory treatment, see Dute, 'Affected By the Tooth of Time', 101. See also S. Guttmacher, 'HIV Infection: Individual Rights v. Disease Control' (1990) 17 *Journal of Law and Society* 66.

[67] M. Brazier and J. Harris, 'Public Health and Private Lives' (1996) 4 *Medical Law Review* 171.

[68] Dute, 'Affected By the Tooth of Time', 107–8.

[69] In the United States the debate about the legality of abortion has largely been conducted in the context of the constitutionally protected right of privacy: see ch. 2.

[70] Most Western states require, or strongly encourage, parents to inoculate their children against a range of diseases including measles, polio, rubella, tuberculosis and whooping cough. This is not, however, a litigation-free zone. In 1973, in the United Kingdom, the Association for Vaccine Damaged Children was established to lobby for compensation for children harmed as a result of vaccination. A Royal Commission was established in 1978, leading to the Vaccine Damage Payments Act 1979, which provided for a no fault scheme for the compensation of vaccine damaged individuals. The no fault nature of the scheme directly reflects the public nature of the vaccination enterprise. Vaccination is encouraged as a public good and our participation is therefore required as a duty to the community,

of property rights in one's own body[71] and the prohibition of assisted suicide and euthanasia.[72]

It is not argued here that all of these examples necessarily relate exclusively to an invasion of personal privacy – for issues of personal liberty and autonomy also arise – but each instance does involves a blurring of the division between the public and private spheres of life. In this regard, it is important to recognise and understand the inevitable tension that exists between public and private interests in the health sphere and to ensure that the case for striking acceptable balances between the two is made as strongly and clearly as possible.

Current threats to patient privacy

The justification for examining privacy in the health care setting at the present time is found in the increased threat that technological medical advances pose to patient privacy. Just as it has been argued elsewhere that technological advances have given rise to more concerns about privacy generally,[73] so too it can be seen that medical advances have heightened patient concern for privacy in a clinical context.

but the few individuals who are harmed as a result should not be unduly burdened in the search for compensation by trying to prove fault on the part of a third party.

[71] See *Moore* v. *The Regents of the University of California* 793 P 2d 479 (1990). For comment, see Nuffield Council on Bioethics, *Human Tissue: Ethical and Legal Issues*, 1995, pp. 2, 5, 10–12, 55, 67, 72–3, 123, 139–40.

[72] Most Western states expressly forbid assistance in the taking of one's own life. Generally the criminal law acts as the sanction, as in the United Kingdom, *R* v. *Cox* (1992) 12 BMLR 38. In the United States the Supreme Court has expressly rejected argument on a constitutional 'right to die', *State of Washington* v. *Glucksberg et al.* 138 L. Ed. 2d. 777 (1997), and *Vacco et al.* v. *Quill et al.* 138 L. Ed. 2d. 834 (1997), although the Oregon Death with Dignity Act 1994 has withstood constitutional challenge and now permits physician-assisted suicide in that state. In the Northern Territory of Australia the Rights of the Terminally Ill Act was enacted in 1995. It allowed active euthanasia and physician-assisted suicide for certain classes of patient, and was the first piece of legislation anywhere in the world to do so. However, a Private Member's Bill introduced in 1996, which sought to relieve territories of any power to pass legislation of this kind, was successful in the federal legislature, and its passing effectively rendered the euthanasia legislation defunct. The Netherlands legalised euthanasia within strictly controlled limits in 2000. For general comment on this area, see M. Otlowski, *Voluntary Euthanasia and the Common Law* (Oxford, Oxford University Press, 2000 [1997]).

[73] For discussion of the general trends in concern for privacy in recent times see P. Birks (ed.), *Privacy and Loyalty* (Oxford, Clarendon Press, 1997), chs. 1–6, A. M. Froomkin, 'The Death of Privacy?' (2000) 52 *Stanford Law Review* 1461, B. S. Markesinis (ed.), *Protecting Privacy* (Oxford, Clarendon Press, 1999), and R. Wacks, *Privacy and Press Freedom* (London, Blackstone Press, 1995).

Advances in medical technology and the threat to patient informational and spatial privacy

As medical science pushes ever forward it reveals new and seemingly never-ending knowledge about homo sapiens. We understand better than ever before how we reproduce, grow, develop and die. In particular, the advent of modern genetic science has generally been heralded as one of the greatest advances in human history. Unfortunately, it is also perceived as one of the biggest threats to individual interests in the contemporary private sphere.

In the public realm, advances in genomic research are widely recognised as being in the interests of the collective good. The promise of considerable clinical benefit from genetics is a rarely-questioned given. The ability to gain knowledge about one's own genetic make-up can, however, be a frightening prospect for the individual. Such information might reveal an underlying disease or dysfunction, or indicate a predisposition to future ill health. It could also have implications for one's relatives, given the common genetic heritage that family members share. Moreover, once such information is discovered, a question arises over its use and possible misuse. Family members, the state, researchers, insurers and employers could all claim an interest in knowing the genetic information relating to individuals. The basis and legitimacy of such interests will be discussed in chapter 3. That such claims might be put, however, means that potential invasions of the informational privacy of the individuals to whom the data relate are very much more likely.

The profusion of electronic medical records serves only to exacerbate concerns, because these databases greatly facilitate the use and manipulation of personal health data. Such systems open up many potential uses of health data beyond the immediate care and treatment of the patient and facilitate their dissemination and use on a much wider scale than was possible previously. Databanks of health information have been proposed in various jurisdictions,[74] not least the United Kingdom, where a National Health Service super database of patient details offers multiple access points throughout the country.[75]

[74] See L. Gostin, 'Genetic Privacy' (1995) 23 *Journal of Law, Medicine and Ethics* 320.

[75] See A. Tonks, 'Information Management and Patient Privacy in the NHS' (1993) 307 *British Medical Journal* 1227. The handling and management of NHS data is governed by the NHS Information Authority, which sets standards and benchmarks for all users of NHS data.