

Moral Interests, Privacy and Medical Research

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Abstract

This article examines the relationship between the values of research and privacy in the context of medical research on patient data. An analytical framework is developed by interpreting the conception of privacy advanced in the jurisprudence of the European Court of Human Rights by reference to the Principle of Generic Consistency, seminally argued to be the supreme principle of morality by Alan Gewirth. This framework is used to uncloak the iniquity of positions uncompromisingly prioritising research values over privacy values or vice versa—research worship and consent worship, respectively. We then apply this framework to three hypothetical studies to show how apparent conflicts between research and privacy values can be resolved.

Keywords: consent, interests, rights, research, Principle of Generic Consistency, privacy

I Introduction

Medical research on personal data involves a conflict between moral interests or values. On the one hand, research promises moral benefits that flow from the acquisition of generalisable knowledge related to human health or treatment. On the other hand, research participants have interests in being able to control the flow and use of private information about themselves. However, precisely how these values relate to each other, and how conflicts between them are to be resolved, stands in need of analysis.

To focus our discussion we will examine three hypothetical studies. The first, the *infectious disease study*, involves the use of the data of recipients of blood transfusions for the purpose of investigating the spread of a specific infectious disease by transfusions. The second, the *cancer study*, uses data from patients diagnosed with cancer for the purpose of investigating cancer. The third, the *contraceptive study*, involves the use of data from patients diagnosed with severe fertility problems and associated conditions for the purpose of investigating future avenues for research into chemical contraceptives.

The identification and relative weight of the moral factors evoked by these studies will differ from one moral theory to another. We will, therefore, say no more about these hypothetical studies until we will have outlined the features of the moral theory that we intend to apply. In Part II, we will outline our reasons for applying the Principle of Generic Consistency (PGC), which Alan Gewirth (1978) has argued—to our minds successfully—to be the supreme principle of morality. In Part III we will outline a *framework* for viewing the relationship between privacy and medical research values with reference to the jurisprudence of the European Convention on Human Rights (ECHR)—which we contend is broadly in line with the requirements set by the PGC, and its conception of privacy. We will argue that privacy and research

values, while capable of conflicting are also capable of supporting each other and that to an important extent research values are privacy values and vice versa. Not to see this distorts the nature of the relationship. Nevertheless, conflicts can exist between these values and, in Part IV we analyse the three hypothetical studies by reference to the PGC, in order to illustrate how the PGC may be used to balance the conflicting values involved therein.

II The PGC and its derivation

The PGC grants all agents¹ rights to the generic conditions of agency, so-called “generic rights”. The generic conditions of agency consist of what agents need, *irrespective of what their purposes might be*, in order to be able to act at all or in order to be able to act with general chances of success. The former category comprises “basic” generic needs, termed “basic goods” by Gewirth. The latter category is divided into non-subtractive and additive generic needs. Whereas lack of or interference with a basic generic need precludes action altogether (or at least diminishes an agent’s chances of being able to act at all), lack of a non-subtractive generic need adversely affects the agent’s ability to maintain his or her capacity to act, and interference with an additive generic good affects the agent’s capacity to increase its capacity to act—in all three cases, *regardless of the purposes involved*.

The generic conditions of agency (and consequently the generic rights) are hierarchically ordered according to a criterion of needfulness for agency (see Gewirth 1978, ch. 2 and 1996, 45–46). According to this criterion, basic rights override non-subtractive rights, which, in turn, trump additive rights in cases of conflict.²

For reasons that will become clear when we present Gewirth’s argument, the generic rights granted by the PGC are rights under the “will” or “choice” theory or conception of rights. According to this conception, agents may always waive the benefits they are granted by the rights they have (though not the generic rights themselves, which Gewirth’s argument renders inalienable).

The generic rights are essentially Hohfeldian claim-rights (Hohfeld 1964). They are also, in principle, positive as well as negative. That the rights are positive means that agents have rights to be assisted (by those able to do so without *comparable cost* to themselves) to secure/protect their having the generic conditions of agency when they are unable to do so by their *own unaided efforts*. That they are negative means that agents have rights to non-interference by other agents with their having the generic conditions of agency. That the generic rights are claim-rights under the will conception, however, means that duties imposed on other agents by the positive rights are subject to the rights-holder wishing assistance, while duties imposed by negative rights are subject to interference being against the rights-holder’s will.

According to Gewirth, agents who do not accept and act according to the PGC contradict that they are agents (i.e. he argues that the PGC is “dialectically necessary” for any agent: Gewirth 1978, 42–47). His argument has three main stages. First, he argues that it is dialectically necessary for an agent A to accept that A ought to defend and pursue A’s having the generic conditions of agency on the grounds that A needs these conditions in order to be able to pursue the purposes A wishes to pursue, either at all or with any general chances of success, regardless of what these purposes might

be. This “ought” is not a moral “ought”, but a categorically (or unconditionally) instrumental one. Secondly, from this, he claims that it is dialectically necessary for A to accept that all other agents B ought not to interfere with A’s possession of the generic conditions against A’s will and ought to assist A to pursue or defend having these conditions when A is unable to do so by A’s unaided efforts if A wishes this assistance (the instrumental nature of the “ought” in the premise being responsible for the “will” provisos). This “ought” is, again, not a moral one. It is propounded by A on the basis that, because the generic conditions are unconditionally needed by A, A unconditionally needs the generic conditions in order to pursue/defend A’s having these conditions. Correlative to this, Gewirth claims that it is dialectically necessary for A to hold that A has both a positive and a negative “prudential” right to the generic conditions. Thirdly, he argues by “The Argument from the Sufficiency of Agency” (see Gewirth 1978, 110) that it follows purely logically from the dialectical necessity of A’s claim to have the generic rights that A must not only claim the generic rights on pain of contradicting that A is an agent, but must hold that A has the generic rights just because A is an agent on pain of contradicting that A is an agent. On this basis, it follows purely logically that A must grant that all agents have the generic rights (just because they are agents). By virtue of this recognition the correlative “ought” that A must accept not to interfere with B’s generic conditions etc. is a moral “ought” as only at this point is A shown to be required to have positive regard for B’s (generic) interests.

While we consider Gewirth’s argument to be sound (see, in particular, Beyleveld 1991), it has not received widespread acceptance. However, there are alternative arguments for the PGC which, if valid, would be rationally compelling for those who are prepared to accept certain dialectically contingent premises. These include arguments directed at agents who accept the idea that:

- (1) there are morally binding requirements on action, defined as categorically binding *impartial* ones (i.e. categorically binding requirements that require the agents to take equal account of the interests of all agents in determining what they themselves may do); or
- (2) there are categorically binding requirements on action; or
- (3) I (any agent) have a human right to do X; or
- (4) practical rationality is impartial.

The first three of these arguments have been explored in depth elsewhere (see Beyleveld and Brownsword 2001, 72–86, 91–94). The argument from the third claim is worth emphasising because of its obvious implications for legal systems that recognise human rights. This argument proceeds on the basis that acceptance of a right to do X requires acceptance of a right to the necessary means to do X, and hence to the generic conditions of agency *whatever X might be*. Consequently, anyone who recognises that there are human rights to do anything at all, must recognise that there are human rights to the generic conditions of agency. Hence, human rights (to do things) must be structured in line with the generic conditions of agency.

Human rights must be thought of as having a number of features if the mere acceptance of human rights is to require these rights to be interpreted in accordance with the PGC. First they must be thought of as overriding all competing considerations in case of conflict. Secondly, being human must be regarded, at least centrally, as being an agent. Thirdly, human rights must be held to be rights under the

will conception. Fourthly, human rights must impose duties not only on the State and its arms, but on all individuals who are capable of acting so as to affect rights-holders abilities to enjoy the benefits of their human rights. Finally, human rights must be considered (where agents are capable of obeying the correlative duties) to be positive as well as negative. While we consider that a good case can be made for holding these to be features of the European Convention of Human Rights (ECHR) space prevents our detailing this case here (see further Beyleveld and Brownsword 2001, 79–86). However, on the assumption that we are correct about this, *interpretation* of the ECHR must be in accordance with the PGC so that the PGC can be used to assist with interpretation of the ECHR and not merely as an external resource for ethical critique.

Finally, the fourth argument simply combines the first stage of Gewirth's dialectically necessary argument with the assumption that practical rationality is impartial in requiring agents to take equal account of the interests of all agents, from which acceptance of the PGC follows immediately as a requirement of practical rationality. Should we be wrong that the ECHR jurisprudence supports the will-conception of rights, this consideration may be used to argue that any coherent application of human rights to agents requires the European Court of Human Rights to adopt the will-conception.

III Research, privacy, and consent

Any discussion of the right to privacy needs to specify what this right covers. For our purposes, the right to privacy will be identified as the right that is granted by Article 8 of the ECHR. Consequently, our first concern is whether the protections granted under this Article are in line with the PGC (or, alternatively, what interpretation of Article 8 must be given to render it consistent with the PGC's requirements). What then is the right to privacy under the ECHR?

The concept of privacy in the ECHR

For some time the UK courts have supported a narrow conception of the right to privacy. This is exemplified in the *Source Informatics* case,³ which concerned the use of non-identifying (i.e. anonymised) patient data. In addition to dealing with the matter before them on the law of confidentiality, the Court of Appeal of England and Wales made a number of *obiter* comments (i.e. non-binding asides) about Directive 95/46/EC (the European Union's Data Protection Directive), which aims in its Article 1(1) to protect fundamental rights and freedoms, in particular privacy, in the processing of personal data. In particular, the Court claimed that anonymisation of data needs to be brought to the attention of patients only if it would be contrary to their interests in relation to treatment they are receiving (where, e.g., it would prevent them being informed of a diagnosis of a serious treatable condition). In giving this opinion, the Court adopted a *narrow conception of privacy*, according to which, except in circumstances covered by the example just given, the only privacy interests that patients have in use made of their data is in concealment of their identities.

However, such a conception of privacy is inconsistent with the broader conception utilised in the jurisprudence of the ECHR (as well as with the decision of the House of Lords in *Campbell*,⁴ in which their Lordships considered the matter of disclosure by the Mirror Newspaper Group of pictures taken of the supermodel Naomi Campbell

leaving a drug addiction clinic). According to Jacques Velu (1973, 92), the right to respect for private life under Article 8(1) of the European Convention on Human Rights

protects the individual against:

1. Attacks on his physical or mental integrity or his moral or intellectual freedom.
2. Attacks on his honour and reputation and similar torts.
3. The use of his name, identity or likeness.
4. Being spied upon, watched or harassed.
5. The disclosure of information protected by the duty of professional secrecy.

More specifically, according to the Commission of the Council of Europe, while

[f]or numerous Anglo-Saxon and French authors the right to respect for “private life” is . . . the right to live as far as one wishes, protected from publicity . . . the right to respect for private life does not end there [but includes also the right to] . . . the development and fulfilment of one’s own personality. (Application No. 6825/74 DR5, 87)

This was recognised in the *Campbell* case, with Lord Nicholls declaring that the right is wider than protection of private information ([2004] UKHL 22, para 15) and Lord Hoffmann holding that the right is an aspect of human autonomy and dignity (para 50) in accordance with which Lord Hope declared that breaches are to be measured by what is offensive in the eyes of the individual rights-holder not in the eyes of the reasonable person (para 99).

So wide, indeed, is the right recognised under Article 8 that it has become commonplace to say that Article 8(1) grants covers all rights that the European Court of Human Rights is prepared to recognise that are not expressly provided for in the other Articles of the Convention (see Loucaides 1990, 196).

Is such a broad conception of privacy consistent with the PGC? Since “privacy” is just a label for a cluster of rights, the answer depends on what rights the European Court of Human Rights is prepared to recognise. Quite simply, under the PGC a right is to be granted to any generic condition of action. Undoubtedly there are generic conditions of action that do not find expression in the other rights of the ECHR. Similarly it is not to be doubted that the activities listed above by Velu are capable of affecting the generic conditions of agency at one or other level. Indeed, at this level, the PGC can assist the Court. This is because the Court surely needs a rationale for identifying the rights captured by Article 8 beyond those expressly recognised in the other Articles of the ECHR, and the PGC, in conceptualising a fundamental right and freedom as a generic one, does the job.

There is at least one other feature of ECHR jurisprudence that we need to consider. This is that under the jurisprudence of the European Court of Human Rights, any use of sensitive personal data without the explicit consent of the individual concerned engages Article 8(1),⁵ which means that the use will constitute a violation of Article 8 unless it is justified under Article 8(2), according to which

There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

In principle, the idea that explicit consent is required accords fully with the idea that the generic rights are rights under the will-conception. Under this conception free and informed consent to an activity that impinges on the individual's right will negate any wrong done; but, without such consent a wrong will be done to the individual unless it can be justified as required to defend the more important conflicting rights of others. However, it does follow from this that exempting conditions mentioned under Article 8(2) must all be conceived of as serving generic rights of others. This is because only generic rights can override generic rights under the PGC (and then only in a distributive, not an aggregative way). However, there is no conflict here with the jurisprudence of the ECHR, for a fundamental right and freedom can only be overridden by a conflicting fundamental right and freedom.¹ Consequently, things like public safety and economic well-being must, under ECHR jurisprudence, be viewed as things that, in a standing way, are necessary to protect fundamental rights, and the explicit reference to the rights and freedoms of others in Article 8(2) must be viewed as to rights and freedoms not implicated in a standing way.. Consistency with the PGC then requires that protection of public safety etc. must involve protection of generic rights of others in a standing way. This is surely the case. Unsafe public conditions, economic collapse, public disorder and crime, disease, and immorality are all things with negative effects in a generic way.

The relationship between privacy and medical research values: a framework

Some medical researchers consider privacy and recognition of the rights of the participant to be a hindrance to the much more important concerns of medical research. Consider, for example, the rhetoric of epidemiological researchers, at least as reported by the press, to the effect that the UK Data Protection Act 1998 and the UK law on confidentiality are killing patients, and should, therefore be rendered inapplicable to medical research.⁶

Such *research worship* assumes that research is indubitably of overriding value. However, some research objectives are trivial or even ignoble and the likelihood that research projects will successfully achieve their objectives can be speculative or even fanciful. The historical abuses associated with Nazi Germany are in no way representative, but it should not be forgotten that the resolution of uncertainty is the driving force of research and even the best designed projects hold few guarantees.

Those inclined towards research worship are prone to point to the practical difficulties raised by obtaining consent as a reason for dispensing with consent altogether. Obtaining consent can, in particular, have a negative impact on the practicality or usefulness of conducting the research. The usefulness of the research will, for example, be severely impeded where the sample is reduced to one that is unrepresentative or statistically below optimal. Such dangers must, however, be kept in their proper place. The potential effects of requesting consent and complying with refusals do not render research projects statistically insufficient or unrepresentative *merely because* the sample will be below 100%. Research into conditions that are not isolated to a small, easily identifiable group or geographical cluster will inevitably

¹ This follows directly from the idea that human rights in instruments like the ECHR that have their roots in the American Declaration of Independence of 1776 and in the French Declaration of the Rights of Man and the Citizen of 1789, are conceived of as "by nature inherent, universal and inalienable" (Davidson 1993, 5).

involve an incomplete sample of those with the condition because of international borders and other practical restrictions. Moreover, the non-aggregative nature of the PGC means that practical difficulties obtaining consent from a large number cannot justify dispensing with the need for consent where to do so will seriously endanger even a single hierarchically more important right of one of the participants. Thus, contrary to the research worship position, practical difficulties in distinguishing those from whom consent is required from those from whom it is not will sometimes justify a more stringent consent mechanism than would be required to protect the rights of the majority of participants.

There are also those who take a position diametrically opposed to research worship and consider the consent of the research participant to be sacrosanct and never capable of being overridden by anything. Such *consent worship* is equally inimical to the proper application of the PGC. Obtaining consent is supererogatory and sometimes even contrary to the PGC where no relevant right is otherwise infringed (i.e. there is no threat of generic harm to an agent) or where the relevant right is validly overridden by a more important (negative or positive) right. This is because there is no right to consent as such under the PGC. The requirement for consent is essentially a function of the will-conception of rights supported by the PGC. Hence ignoring consent only engages a right when the activity requiring consent impinges negatively on the generic conditions of agency. (i.e. it constitutes a generic harm).

Consent worship is a danger suggested by paragraph five of the 2000 version of the World Medical Association's Helsinki Declaration, which proclaims that "the wellbeing of the human subject *should take precedence* over the interests of science and society",⁷ and perhaps even more so by the 1996 version, which states that "the interests of the subject *must always prevail* over the interests of science and society" (our emphasis). Read literally, these provisions elevate the interests of potential participants over all other interests, irrespective of their relative hierarchical importance. This reading is bolstered by the fact that the 2000 version of the Declaration goes on to state that the participant's "free-given informed consent" must be obtained (para 22) and ostensibly makes only one exception, namely, "research on individuals from whom it is not possible to obtain consent" (and then only "if the physical/mental condition that prevents obtaining informed consent is a necessary characteristic of the research population") (para 26). A close reading, however, reveals that the Helsinki Declaration does not offer wholesale support for consent worship with regard to *research on patient data*, because paragraph 1 defines medical research to include research on "identifiable data", rather than research on patient data *as such*. Thus, the Helsinki Declaration treats consent as having absolute value where the participant is capable of giving consent and the data remains identifiable, but places no limitations on the research use of data rendered non-identifiable. The result is a position that, paradoxically, seems to both overvalue and undervalue the rights of the participant.

Consent worship rides roughshod over positive rights. Subject to the own unaided effort and comparable cost provisos, the PGC-derived duty to assist in the achievement of appropriate research objectives implies a *duty to participate* in suitably designed research projects. Where such a duty exists, to insist upon consent is to deny the positive right underpinning the duty. In principle, an agent has a positive duty to participate in a research trial that is properly designed for the purpose of

preventing generic harm or providing generic needs where the burden of participation carries no realistic prospect of the same or higher generic harm. A *prima facie* duty to participate will, for example, exist where the research project is well-designed, non-interventional, and aimed at preventing basic generic harm to others. Research on patient data is non-interventional, unlike many related medical activities directed at protecting or advancing the generic needs of others—including morally important activities such as participation in pharmaceutical trials, vaccination programmes, and blood donation programmes. It would, nonetheless, be a mistake to assume that non-consensual participation in data research programmes cannot cause generic harm to participants (see below) and this will clearly limit any positive obligations. Constraints on the enforcement of the participant's positive obligations will also need to take account of those situations where individual duty bearers cannot be proportionately identified or distinguished from others. It is important that any mechanism seeking to encourage or enforce positive obligations is itself consistent with the requirements of the PGC, taking into account the danger of abuse and misuse. In particular, procedures need to be in place to address the fact that researchers will often have considerable self-interests in conducting and publishing research, and, if given opportunity, commercial entities are likely to seek to profit from the moral commitments of others.

It is arguable that the tendency of research and consent worshippers to ignore relevant considerations is a function of treating the values of research and the values of privacy as necessarily in conflict and seeking to side with one set of values over the other (see further Beyleveld 2006). However, once we use the shorthand of privacy to capture the participant's rights to control the use of that person's data (which is a function of the broad conception of privacy in ECHR jurisprudence), we need to recognise that many research values, particularly those concerned with increasing life choices and improved quality of life, are also privacy values. Conversely, it follows that protecting the participant's privacy by obtaining consent to the use of personal data for research permits more accurate research data to be obtained, and contributes to better co-operation from research participants, both of which enhance or facilitate research. The latter is the case because respect for privacy facilitates public trust, which is positively necessary for research, not merely facilitative of better quality research. Indeed, public trust is necessary for society to be governed by the rule of law/human rights. This, in turn, is necessary for effective democracy. So, viewed through the lens of a broad concept of privacy, a picture emerges that while conflicts between values protected by privacy and research values can still arise, when they do, the conflict might better be viewed as a conflict between different privacy values or as a conflict between different research values. So, how are such conflicts to be adjudicated?

IV The hypothetical studies considered

In Part I, we outlined three hypothetical studies: the infectious disease study, the cancer study, and the contraceptive study. These studies involve use of data from specific categories of patients for research. While these studies share many features, there are evident differences in the expected benefits of the research, and each study potentially raises different objections and counter considerations to participation. These differences are relevant to whether dispensing with consent is consistent with a proper attempt to apply the PGC or amounts to research worship.

The infectious disease study

The infectious disease study seeks to use the data of recipients of blood transfusions to investigate the spread of a specific serious disease through transfusions, where there is suggestive but inconclusive evidence of a link. This study is one for which the results could be of immediate benefit to other patients, especially if the spread of the disease in question is preventable. As envisaged, such a study would track basic generic rights by seeking to protect future recipients of blood transfusions and those potentially exposed to secondary infection or dangers caused by damage to public confidence in blood transfusions. In contrast, with appropriate safeguards, this study should not threaten basic harm to the data subjects. Thus, to insist upon consent for a well-designed data infectious disease study is *prima facie* tantamount to consent worship. Yet, if the dangers of research worship are to be kept at bay, procedural safeguards will be needed to ensure that the rights are properly weighed (e.g. scrutiny procedures for individual research projects); interference with the rights of participants is minimised (e.g. anonymisation of data, particularly where the disease is one attracting social stigma); and the benefits of the research are achieved without avoidable study duplication or endangerment of public confidence (e.g. procedures to ensure that the research results are appropriately disseminated and participants are not deceived).

The contraceptive study

The contraceptive study seeks to use data from patients diagnosed with severe fertility problems and associated conditions to investigate future avenues for research into chemical contraceptives. It is thereby not designed to obtain life-saving information but to facilitate future research that could enhance the lifestyle options of those wishing to use chemical contraceptives. The generic needs tracked by this study are, therefore, less weighty (under the criterion of degrees of needfulness for action) than those protected by attempts to prevent others suffering the effects of a serious infectious disease or cancer. This is not to suggest that research into chemical contraceptives lacks moral value under the PGC. On the contrary, pregnancy can cause serious social inconvenience and can be life-threatening (though rarely in countries such as the UK and the USA), and the ability to control fertility is at least an additive good. There are, however, already many methods of contraception available, ranging from abstinence to barrier contraception and including many existing forms of chemical contraception. Thus, the interests potentially protected by this study are less significant than those protected by the infectious disease study or many instances of the cancer study.

The contraceptive study is also likely to provoke vociferous objection from some individuals and groups. A committed Catholic woman opposed to chemical contraceptives could, for example, be expected to be conscientiously opposed to the use of data associated with her irregular periods in such a study (see Beyleveld and Histed 1999, 73–74). If participation in the contraceptive study were to take place without consent, such a conscientious objector would be exposed to a very real risk of disabling anxiety or might even be placed in the invidious position of choosing between her health and her conscience. For some these harms will be basic. The Catholic woman's rights to prevent exposure to such generic harm, by preventing the use of her data in research into chemical contraception, is at least as potent as the

rights tracked by the study.

This study envisaged here is, therefore, one for which dispensing with consent would be tantamount to research worship. Dispensing with consent is not required by the possibility that the contraceptive study could yield a “consent bias”, whereby refusals will undermine the adequacy of the sample. Whatever the plausibility of a consent bias—refusals might be disproportionately tied to groups that attach significant social stigma to sub-fertility or contraceptive research—we have seen that at least some objectors will have significant generic rights supporting non-participation.

Cancer study

The cancer study seeks to use data from patients diagnosed with cancer to investigate cancer. This is the most problematic of the three hypothetical studies under consideration because it is the least specified. Cancer is potentially life-threatening; some forms more so than others. Yet, general opportunistic information gathering in the name of cancer research is so far removed from the goal of preventing and curing cancer that it cannot provide a justification for dispensing with consent without one thereby adhering to research worship. This study has particular resonance in the UK, where legislation has been enacted to allow the relevant government minister to make regulations permitting the use of confidential patient information without consent for research and wider purposes in the National Health Service and the first set of regulations passed under that provision were concerned with cancer studies.

Section 60 of the Health and Social Care Act 2001 was ostensibly intended as a temporary measure, but, some six years later, replacement provisions have yet to be enacted. It empowers the Secretary of State to pass regulations to allow the use of confidential patient information without consent, despite any obligation of confidence (s.60(2)(c)). The information must be used for “medical purposes” in the interests of improving patient care or in the public interest, where it is not “reasonably practicable” to achieve that purpose by other means. The first set of regulations made under this provision were the Health Service (Control of Patient Information) Regulations 2002. These provide for the creation of databases for medical purposes related to the diagnosis and treatment of, in effect, tumours (Reg. 2). The intention was to allow cancer patients’ information to be entered on to Cancer Registries without consent or anonymisation. Significantly, these regulations do not distinguish between patient information relating to cancer and patient information relating to patients with, or referred for, cancer. Read literally this would appear to allow any research without consent using the medical information of patients who happen to have cancer, *irrespective of the weight of the respective rights*. A very restricted interpretation is required to prevent descent into research worship. The issue is not that a cancer study could never justify dispensing with consent, but that the UK legislation is too broadly drafted to capture only those instances where a plausible case for doing so can be made out.

If we were to suggest a type of cancer study that might justify dispensing with consent, a plausible candidate would be one well-designed to test suggestive evidence—perhaps obtained from smaller, consensual data studies—of a link between a specific life-threatening cancer and a specific causal factor. Additional procedural safeguards of the type already suggested would be needed to ensure that the specifics

of the study are adequately evaluated.

Concluding remarks

Our analysis of the way in which the PGC can assist in the adjudication of conflicts of interests and rights has been confined to the conflict between medical research values and privacy. It should, however, be clear that, schematically, the analysis is equally applicable to adjudicating conflicts between privacy and other values. A structure for the adjudication is provided by the form of Article 8 ECHR, this form being that a right granted by the first part of the Article may be overridden to the extent that this is necessary to protect more weighty rights of others (as specified by the second part of the Article). What the PGC essentially does is to provide a means of determining what rights are more important than others in case of conflict. This applies when the rights to be weighed against privacy are explicitly recognised by, e.g., the ECHR. But it also applies when these rights are not explicitly recognised. Of course, the significance of this depends on the justification for deploying the PGC in the first place. It is worth noting that while all the arguments for the PGC that we mentioned are contestable, to deploy the PGC in the way in which we have done within the ECHR requires no more to be accepted than that to grant a right to something rationally requires a right to be granted to the necessary means for that right to be exercised. For, as we pointed out, from this it follows that rights to the generic conditions of action must be granted. While, as we noted, this does not automatically require the PGC itself to be accepted (because of special features that the PGC itself requires of the generic rights) our analysis of adjudication of conflicts of rights is to a large extent independent of those features. If nothing else, this indicates the significance and usefulness of the Gewirthian concept of a generic condition of action even if arguments for the PGC itself are not considered to be watertight.

Bibliography

- Beyleveld, D. 1991. *The dialectical necessity of morality: An analysis and defense of Alan Gewirth's argument to the Principle of Generic Consistency*. Chicago: Chicago University Press.
- Beyleveld, D. 2006. Conceptualising privacy in relation to medical research values. In *First do no harm: Law, ethics and healthcare*, ed. S. A. M. McLean, 151–163. Aldershot: Ashgate.
- Beyleveld, D., and R. Brownsword. 2001. *Human dignity in bioethics and biolaw*. Oxford: Oxford University Press.
- Beyleveld, D., and E. Histed. 1999. Case commentary: Anonymisation is not exoneration. *Medical Law International* 4:69–80.
- Beyleveld, D., and S. D. Pattinson. 2000. Precautionary reasoning as a link to moral action. In *Medical ethics*, ed. M. Boylan, 39–53. Upper Saddle River New Jersey: Prentice-Hall.
- Davidson, S. 1993. *Human rights*. Buckingham: Open University Press.
- Dix, A. 2000. Cancer experts call for action on GMC's confidentiality rules. *Health Service Journal* 2 November, 4.
- Gewirth, A. 1978. *Reason and morality*. Chicago: University of Chicago Press.
- Gewirth, A. 1996. *The community of rights*. Chicago: Chicago University Press.

- Hohfeld, W. N. 1964. *Fundamental legal conceptions*. New Haven: Yale University Press.
- Loucaides, L. G. 1990. Personality and privacy under the European Convention on Human Rights *British Yearbook of International Law* LXI, 175–197.
- Pattinson, S. D. 2006. *Medical law and ethics*. London: Sweet & Maxwell.
- Velu, J. 1973. The European Convention on Human Rights and the right to respect for private life, the home and communications. In *Privacy and human rights*, ed. A. H. Robertson, 12–128. Manchester: Manchester University Press.

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- ¹ Beings that take voluntary steps in pursuit of their freely chosen purposes, which they treat as reasons for their actions
- ² Gewirth (1978, 53–55) identifies, e.g., life and physical well-being (including such means to these as health, food, clothing and shelter) as basic needs, accurate information as a non-subtractive need, and further information as an additive need. However, as the generic conditions of agency figure in Gewirth’s argument for the PGC (as against in application of the PGC), such concrete specification is not necessary.
- ³ *R v Department of Health ex p. Source Informatics* [2001] Q.B. 424, reversing [1999] 4 All ER 185.
- ⁴ *Campbell v. MGN* [2004] UKHL 22.
- ⁵ See, e.g., *Z v Finland* (1998) 25 E.H.R.R. 371; and *M.S. v Sweden* (1999) 28 E.H.R.R. 313.
- ⁶ See, e.g., the so-called “Peto campaign”, reported on in, e.g., Dix 2000.
- ⁷ The text of the 2000 version is available at: <http://www.wma.net/e/policy/b3.htm>.