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An audit of informed consent in surgical patients at a university hospital
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Document 2
Rathor, Mohammad Yousuf; Abdul Rani, Mohammad Fauzi; Bin Mohammed Shah, Azarisman Shah; Bin Leman, Wan Islah; Akter, Farid Uddin; Bin Omar, Ahmad Marzuki
The principle of autonomy as related to personal decision making concerning health and research from an 'Islamic viewpoint'
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Document 3
Erbay, Hasan; Alan, Sultan; Kadioglu, Selim
A case study from the perspective of medical ethics: refusal of treatment in an ambulance
Journal of Medical Ethics 2010 November 11; 36(11): 652-655
Georgetown users check Georgetown Journal Finder for access to full text

http://jme.bmj.com/content/36/11/652.full.pdf (link may be outdated)

Document 4
Jenkins, Eric D.; Yip, Michael; Melman, Lora; Frisella, Margaret M.; Matthews, Brent D.
Informed consent: cultural and religious issues associated with the use of allogenic and xenogenic mesh products
Journal of the American College of Surgeons 2010 April; 210(4): 402-410
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**Document 5**

Krumholz, Harlan M.

**Informed consent to promote patient-centered care.**

JAMA: The Journal of the American Medical Association 2010 March 24; 303(12): 1190-1191

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**Document 6**

Volpe, Rebecca L.

**Patients' expressed and unexpressed needs for information for informed consent.**

Journal of Clinical Ethics 2010 Spring; 21(1): 45-57

**Abstract:** Informed consent is the practical application of the principle of autonomy, and two of the five core features of informed consent are related to information. Researchers have reported on patients' expressed needs for information, such as their stated desires for the quantity of and the source of information. A separate body of research has examined patients' unexpressed needs for information from the perspective of cognitive psychology, such as the emotional tone and order of information. This article suggests that the autonomy of patients is best served by meeting their expressed and unexpressed information needs for in tandem.

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**Document 7**

Pope, Thaddeus Mason

**Legal briefing: Informed consent.**

Journal of Clinical Ethics 2010 Spring; 21(1): 72-82

**Abstract:** This issue's "Legal Briefing" column covers legal developments pertaining to informed consent. Not only has this topic been the subject of recent articles in this journal, but it also been the subject of numerous public and professional discussions over the past several months. Legal developments concerning informed consent can be usefully grouped into nine categories: 1. General disclosure standards in the clinical context; 2. Shared decision making; 3. Statutorily mandated abortion disclosures; 4. Statutorily mandated end-of-life counseling; 5. Other statutorily mandated subject-specific disclosures; 6. U.S. Food and Drug Administration (FDA) labeling and federal pre-emption of state informed consent law; 7. Relaxed informed consent for HIV testing; 8. General disclosure standards in the research context; 9. Issues on the horizon.

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**Document 8**

Najafizadeh, Katayoun; Ghorbani, Fariba; Rostami, Ameneh; Ghobadi, Omid; Barbati, Esmail; Rad, Shahram Salehi; Assari, Shervin

**Seeking consent in the country of origin for transplantation from a brain-dead refugee in the host country.**

Saudi Journal of Kidney Diseases and Transplantation 2010 March; 21(2): 345-347

Georgetown users check [Georgetown Journal Finder](http://jama.ama-assn.org) for access to full text

**Document 9**


**Anaesthetists' and surgeons' attitudes towards informed consent in the UK: an observational study.**

Georgetown users check [Georgetown Journal Finder](http://jama.ama-assn.org) for access to full text
**Abstract:** BACKGROUND: The attitudes of patients' to consent have changed over the years, but there has been little systematic study of the attitudes of anaesthetists and surgeons in this process. We aimed to describe observations made on the attitudes of medical professionals working in the UK to issues surrounding informed consent. METHOD: A questionnaire made up of 35 statements addressing the process of consent for anaesthesia and surgery was distributed to randomly selected anaesthetists and surgeons in Queen's Medical Centre (Nottingham), Royal Sussex County Hospital (Brighton) and Eastbourne District General Hospital (Eastbourne) during 2007. Participants were asked to what extent they agreed with statements regarding consent. RESULTS: Of 234 questionnaires distributed, 63% were returned. Of the respondents 79% agreed that the main purpose of the consent process is to respect patient autonomy. While 55% of the examined cohort agreed that the consent process maybe inappropriate as patients do not usually remember all the information given to them. Furthermore, 84% of the participants agreed that what the procedure aims to achieve should be explained to the patient during the consent process. While of the participants, over 70% agreed that major risks of incidence greater than 1/100 should be disclosed to the patient as part of the consent process. CONCLUSIONS: The majority of respondents appear to hold attitudes in standing with current guidelines on informed consent however there was still a significant minority who held more paternalistic views to the consent process bringing into question the need for further training in the area.
Miller, Fiona A.; Hayeems, R.Z.; Carroll, J.C.; Wilson, B.; Little, J.; Allanson, J.; Bytautas, J.P.; Paynter, M.; Christensen, R.; Chakraborty, P.

**Consent for newborn screening: the attitudes of health care providers.**
Public Health Genomics 2010 February; 13(3): 181-190

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* Document 12

Egonsson, Dan

**Some comments on the substituted judgement standard.**
Medicine, Health Care, and Philosophy 2010 February; 13(1): 33-40

**Abstract:** On a traditional interpretation of the substituted judgement standard (SJS) a person who makes treatment decisions on behalf of a non-competent patient (e.g. concerning euthanasia) ought to decide as the patient would have decided had she been competent. I propose an alternative interpretation of SJS in which the surrogate is required to infer what the patient actually thought about these end-of-life decisions. In clarifying SJS it is also important to differentiate the patient's consent and preference. If SJS is part of an autonomy ideal of the sort found in Kantian ethics, consent seems more important than preference. From a utilitarian perspective a preference-based reading of SJS seems natural. I argue that the justification of SJS within a utilitarian framework will boil down to the question whether a non-competent patient can be said to have any surviving preferences. If we give a virtue-ethical justification of SJS the relative importance of consent and preferences depends on which virtue one stresses—respect or care. I argue that SJS might be an independent normative method for extending the patient's autonomy, both from a Kantian and a virtue ethical perspective.

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* Document 13

Baerøe, Kristine

**Patient autonomy, assessment of competence and surrogate decision-making: a call for reasonableness in deciding for others.**
Bioethics 2010 February; 24(2): 87-95

**Abstract:** In this paper, I address some of the shortcomings of established clinical ethics centring on personal autonomy and consent and what I label the Doctrine of Respecting Personal Autonomy in Healthcare. I discuss two implications of this doctrine: 1) the practice for treating patients who are considered to have borderline decision-making competence and 2) the practice of surrogate decision-making in general. I argue that none of these practices are currently aligned with respectful treatment of vulnerable individuals. Because of 'structural arbitrariness' in the whole process of how we assess decision-making competence, this area is open to disrespectful treatment of people. The practice of surrogate decision-making on the basis of a single person's judgment is arguably not consistent with ethical and political requirements derived from the doctrine itself. In response to the inadequacies of the doctrine, I suggest a framework for reasonableness in surrogate decision-making which might allow practice to avoid the problems above. I conclude by suggesting an extended concept of Patient Autonomy which integrates both personal autonomy and the regulative idea of morality that is required by reasonableness in deciding for non-competent others.

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[http://www3.interscience.wiley.com/journal/123226235/issue](http://www3.interscience.wiley.com/journal/123226235/issue) (link may be outdated)

* Document 14

Teaster, Pamela B.; Schmidt, Winsor C.; Wood, Erica F.; Lawrence, Susan A.; and Mendiondo, Marta S.

**PUBLIC GUARDIANSHIP: IN THE BEST INTERESTS OF INCAPACITATED PEOPLE?**

Call number: [KF553_P83 2010](#)
**Document 15**

Woo, Jennifer A.; Prager, Kenneth M.

**Substituted misjudgement**

Clinical Ethics 2009 December; 4(4): 208-210

**Abstract:** Substituted judgement is often used in the absence of advanced directives to guide decision-making when patients lack decisional capacity. We present a remarkable case of family members exercising substituted misjudgement for a 42-year-old man hospitalized with multiorgan failure on life support. Feeling that their loved one would rather die than face severe disability, they elected to withdraw life support. Although this was done, the patient remained alive and recovered enough to clearly indicate his preference for life, even with severe disability. This case suggests that in instances of unusual quality-of-life judgements where the patient's wishes cannot be known with reasonable certainty, families and physicians should be very wary using substituted judgement to refuse life support. Unless there are strong considerations based on the patient's prior statements, actions and values to decline life support, it would seem ethically appropriate to continue treatment, even with substantial disability the likely outcome.

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**Document 16**

Ezeome, Emmanuel R.; Marshall, Patricia A.

**Informed consent practices in Nigeria.**

Developing World Bioethics 2009 December; 9(3): 138-148

**Abstract:** Most writing on informed consent in Africa highlights different cultural and social attributes that influence informed consent practices, especially in research settings. This review presents a composite picture of informed consent in Nigeria using empirical studies and legal and regulatory prescriptions, as well as clinical experience. It shows that Nigeria, like most other nations in Africa, is a mixture of sociocultural entities, and, notwithstanding the multitude of factors affecting it, informed consent is evolving along a purely Western model. Empirical studies show that 70-95% of Nigerian patients report giving consent for their surgical treatments. Regulatory prescriptions and adjudicated cases in Nigeria follow the Western model of informed consent. However, adversarial legal proceedings, for a multiplicity of reasons, do not play significant roles in enforcing good medical practice in Nigeria. Gender prejudices are evident, but not a norm. Individual autonomy is recognized even when decisions are made within the family. Consent practices are influenced by the level of education, extended family system, urbanization, religious practices, and health care financing options available. All limitations notwithstanding, consent discussions improved with increasing level of education of the patients, suggesting that improved physician's knowledge and increasing awareness and education of patients can override other influences. Nigerian medical schools should restructure their teaching of medical ethics to improve the knowledge and practices of physicians. More research is needed on the preferences of the Nigerian people regarding informed consent so as to adequately train physicians and positively influence physicians' behaviors.

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**Document 17**

Hanson, Janice Lynn

**Quandaries of informed consent: comment on "patient comprehension of an interactive, computer-based information program for cardiac catheterization" [commentary]**

Archives of Internal Medicine 2009 November 9; 169(20): 1914-1915

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Document 18
Granero-Molina, José; Fernández-Sola, Cayetano; Aguilera-Manrique, Gabriel

Applying a sociolinguistic model to the analysis of informed consent documents.
Nursing Ethics 2009 November; 16(6): 797-812

Abstract: Information on the risks and benefits related to surgical procedures is essential for patients in order to obtain their informed consent. Some disciplines, such as sociolinguistics, offer insights that are helpful for patient-professional communication in both written and oral consent. Communication difficulties become more acute when patients make decisions through an informed consent document because they may sign this with a lack of understanding and information, and consequently feel deprived of their freedom to make their choice about different treatments or surgery. This article discusses findings from documentary analysis using the sociolinguistic SPEAKING model, which was applied to the general and specific informed consent documents required for laparoscopic surgery of the bile duct at Torrecárdenas Hospital, Almeria, Spain. The objective of this procedure was to identify flaws when information was provided, together with its readability, its voluntary basis, and patients' consent. The results suggest potential linguistic communication difficulties, different languages being used, cultural clashes, asymmetry of communication between professionals and patients, assignment of rights on the part of patients, and overprotection of professionals and institutions.

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Document 19
Dreyer, A.; Forde, R.; Nortvedt, P.

Autonomy at the end of life: life-prolonging treatment in nursing homes—relatives' role in the decision-making process.
Journal of Medical Ethics 2009 November; 35(11): 672-677

Abstract: BACKGROUND: The increasing number of elderly people in nursing homes with failing competence to give consent represents a great challenge to healthcare staff's protection of patient autonomy in the issues of life-prolonging treatment, hydration, nutrition and hospitalisation. The lack of national guidelines and internal routines can threaten the protection of patient autonomy. OBJECTIVES: To place focus on protecting patient autonomy in the decision-making process by studying how relatives experience their role as substitute decision-makers. DESIGN: A qualitative descriptive design with analysis of the contents of transcribed in-depth interviews with relatives. PARTICIPANTS: Fifteen relatives of 20 patients in 10 nursing homes in Norway. RESULTS AND INTERPRETATIONS: The main findings reveal deficient procedures for including relatives in decision-making processes. Relatives have poor knowledge about the end of life, and there is little discussion about their role as substitute decision-makers for patients who are not competent to give consent. Few relatives understand the concept of patient autonomy. In Norway the treating physician is responsible for patient treatment. When relatives are included in discussions on treatment, they perceive themselves as responsible for the decision, which is a burden for them afterwards. This qualitative study describes relatives' experiences, thus providing important information on the improvement potential with the main objective of safeguarding patient autonomy and caring for relatives. CONCLUSION: The study reveals failing procedures and thus a great potential for improvement. Both ethical and legal aspects must be addressed when considering patient autonomy.

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Document 20
McLean, Sheila A.M.

Live and let die.
British Medical Journal 2009 October 10; 339(7725): 837

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http://www.bmj.com (link may be outdated)
**Document 21**

Badger, James M.; Ladd, Rosalind Ekman; Adler, Paul

*Respecting patient autonomy versus protecting the patient's health*

JONA's Healthcare Law, Ethics, and Regulation 2009 October-December; 11(4): 120-126

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**Document 22**

Badger, James M.; Ladd, Rosalind Ekman; Adler, Paul

*Respecting patient autonomy versus protecting the patient's health: a dilemma for healthcare providers.*

JONA'S Healthcare Law, Ethics and Regulation 2009 October-December; 11(4): 120-126

**Abstract:** A 74-year-old man with multiple chronic medical problems was hospitalized for respiratory distress. He experienced recurrent aspiration and required frequent suctioning and endotracheal intubation on several occasions. The patient was deemed competent and steadfastly refused feeding tube placement. The patient demanded that he be allowed to eat a normal diet despite being told that it could lead to his death. The patient wanted to go home, but there was no one there to care for him. Additionally, neither a nursing home nor hospice would accept him in his present condition. The case is especially interesting because of the symbolic value of food and the plight of the patient who has no alternative to hospitalization. The hospital staff experienced considerable stress at having to care for him. They were uncertain whether their obligation was to respect his autonomy and continue to provide food or to protect his health by avoiding aspiration, pneumonia, and possible death by denying him food. This ethical dilemma posed by the professionals' duty to do what is in the patient's best interest versus the patient's right to decide treatment serves as the focus for this case study. Ethical, legal, and healthcare practitioners' considerations are explored. The case study concludes with specific recommendations for treatment.

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**Document 23**

Szmukler, G.

"Personality disorder" and capacity to make treatment decisions.

Journal of Medical Ethics 2009 October; 35(10): 647-650

**Abstract:** Whether treatment decision-making capacity can be meaningfully applied to patients with a diagnosis of "personality disorder" is examined. Patients presenting to a psychiatric emergency clinic with threats of self-harm are considered, two having been assessed and reviewed in detail. It was found that capacity can be meaningfully assessed in such patients, although the process is more complex than in patients with diagnoses of a more conventional kind. The process of assessing capacity in such patients is very time-consuming and may become, in itself, a therapeutic intervention.

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[http://jme.bmj.com/content/35/10.toc](http://jme.bmj.com/content/35/10.toc) (link may be outdated)

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**Document 24**

Lemmens, Christophe

End-of-life decisions and minors: do minors have the right to refuse life preserving medical treatment? A comparative study


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Document 25
Hendriks, Aart
Personal autonomy, good care, informed consent and human dignity - some reflections from a European perspective
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Document 26
Runels, Sarah
Informed consent laws and the constitution: balancing state interests with a physician's First Amendment rights and a woman's due process rights
Journal of Contemporary Health Law and Policy 2009 Fall; 26(1): 185-211
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Document 27
Broström, Linus; Johansson, Mats
Surrogates have not been shown to make inaccurate substituted judgments.
Journal of Clinical Ethics 2009 Fall; 20(3): 266-273
Georgetown users check Georgetown Journal Finder for access to full text

Document 28
White, Douglas B.; Evans, Leah R.; Bautista, Christopher A.; Luce, John M.; Lo, Bernard
Are physicians' recommendations to limit life support beneficial or burdensome? Bringing empirical data to the debate.
American Journal of Respiratory and Critical Care Medicine 2009 August 15; 180(4): 320-325
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Document 29
Ohto, Hitoshi; Yonemura, Yuji; Takeda, Junzo; Inada, Eiichi; Hanada, Ryoji; Hayakawa, Satoshi; Miyano, Takeshi; Kai, Katsunori; Iwashi, Waichiro; Muto, Kaori; Asai, Fumikazu;
Guidelines for managing conscientious objection to blood transfusion.
Transfusion Medicine Reviews 2009 July; 23(3): 221-228
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Document 30
Shimoda, Motomu
Rationality of refusing treatment: Clinical Ethics Conference at the Department of Emergency Medicine
Formosan Journal of Medical Humanities 2009 June; 10(1-2): 99-104
Georgetown users check Georgetown Journal Finder for access to full text
Document 33
Macharia, E.; Milanovic, D.
Obtaining consent from minors with parental responsibility
Clinical Ethics 2009 June; 4(2): 102-105
Abstract: Britain has the highest rate of pregnancies in Europe among young women aged 15–19 years. In girls under 16, the rates of pregnancy are rising: in 2006, there were 7.8 conceptions per 1000 girls; in 2007, there were 8.3 conceptions per 1000 girls. Where babies are born with conditions requiring treatment, the clinician may be faced with the task of obtaining consent from a parent who is also a minor. These situations present potential pitfalls. Guidance from legislative acts and case law is sparse. For example, the Children Act 1989 does not specify age limits for the assumption of parental responsibility. Legal precedents for assessing competence and capacity may not apply to minors. The Gillick principle for assessing competence does not extend to the competence of minors to take decisions as responsible parents. The Mental Capacity Act 2005 prescribes the limits of capacity but only in those aged over 16 years. Lastly, although a minor's parents will bear responsibility for the minor, this responsibility does not extend to the minor's child. This article explores these controversies through four case scenarios. These scenarios are loosely based on the authors' prior experiences as paediatric surgeons. In light of current statutory guidance, and the paucity of legal precedent, there are few answers to be offered. However, exploring the issues, enabling them to be thoughtfully considered by health professionals, is in itself valuable.

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Document 34
Berger, Jeffrey T.
Patients' concerns for family burden: a nonconforming preference in standards for surrogate decision making.
Journal of Clinical Ethics 2009 Summer; 20(2): 158-161

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Document 35
Nelson, James Lindemann
Berger on burdens.
**Document 36**
Levine, Carol
*Commentary on "Patients' concerns for family burden".*
Journal of Clinical Ethics 2009 Summer; 20(2): 165-167
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DeRenzo, Evan G.
*Commentary on Berger's "Patients' concerns for family burden".*
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Derse, Arthur R.
*When I lay my burden down: commentary on Berger.*
Journal of Clinical Ethics 2009 Summer; 20(2): 172-174
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**Document 39**
Eskew, Stewart; Meyers, Christopher
*Religious belief and surrogate medical decision making.*
Journal of Clinical Ethics 2009 Summer; 20(2): 192-200
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**Document 40**
Walters, Thomas Paul
*The Mental Capacity Act--a balance between protection and liberty.*
British Journal of Nursing 2009 May 14-27; 18(9): 555-558
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**Document 41**
*Informed patient consent for defaulter tracing: should we obtain it?*
International Journal of Tuberculosis and Lung Disease 2009 May; 13(5): 551-555
**Document 42**

*Response to 'Informed patient consent for defaulter tracing: should we obtain it?'.*
International Journal of Tuberculosis and Lung Disease 2009 May; 13(5): 556-557

**Document 43**


*Under what conditions do patients want to be informed about their risk of a complication? A vignette study.*
Journal of Medical Ethics 2009 May; 35(5): 276-282

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Childers, Ryan; Lipsett, Pamela A.; Pawlik, Timothy M.

*Informed consent and the surgeon.*
Journal of the American College of Surgeons 2009 April; 208(4): 627-634

**Document 45**

Brosnam, Terenia; Perry, Michael

*"Informed" consent in adult patients: can we achieve a gold standard?*
British Journal of Oral and Maxillofacial Surgery 2009 April; 47(3): 186-190
Document 46
Miola, José
Informed consent and the rise of autonomy.
British Journal of Nursing 2009 April 23-May 13; 18(8): 504, 506
Georgetown users check Georgetown Journal Finder for access to full text

Document 47
Berg, Stacey L.
When too much is just enough: what do oncologists tell parents?
Pediatric Blood & Cancer 2009 April; 52(4): 437-438
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Ramirez, Lisa Ysela; Huestis, Samantha E.; Yap, Tsiao Yi; Zyzanski, Stephen; Drotar, Dennis; Kodish, Eric
Potential chemotherapy side effects: what do oncologists tell parents?
Pediatric Blood and Cancer 2009 April; 52(4): 497-502
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Document 49
Bruce, Courtenay R.; Berg, Stacey L.; McGuire, Amy L.
Please don't call my mom: pediatric consent and confidentiality.
Clinical Pediatrics 2009 April; 48(3): 243-246
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Document 50
Irabor, David O.; Omonzejele, Peter
Local attitudes, moral obligation, customary obedience and other cultural practices: their influence on the process of gaining informed consent for surgery in a tertiary institution in a developing country.
Developing World Bioethics 2009 April; 9(1): 34-42
Abstract: The process of obtaining informed consent in a teaching hospital in a developing country (e.g. Nigeria) is shaped by factors which, to the Western world, may be seen to be anti-autonomous: autonomy being one of the pillars of an ideal informed consent. However, the mix of cultural bioethics and local moral obligation in the face of communal tradition ensures a mutually acceptable informed consent process. Paternalism is indeed encouraged by the patients who prefer to see the doctor as all-powerful and all-knowing, and this is buttressed by the cultural practice of customary obedience to those 'above you': either in age or social rank. The local moral obligation reassures the patients that those in authority will always look after others placed in their care without recourse to lengthy discussions or signed documentation, while the communal traditions ensure that the designated head of a family unit has the honor and sole responsibility of assenting and consenting to an operation to be carried out on a younger, or female, member of the family. Indeed it is to only a few educated patients that the informed consent process is deemed a shield against litigation by the doctors. This paper later addresses the need for physicians to update their knowledge on the process of informed consent through the attendance of biomedical ethics courses, which should highlight socio-cultural practices that may make this process different from the Western concept, but perfectly acceptable in this setting.
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Jørgensen, K.J.; Brodersen, J.; Hartling, O.J.; Nielsen, M.; Gøtzsche, P.C.
Informed choice requires information about both benefits and harms.
Journal of Medical Ethics 2009 April; 35(4): 268-269

Abstract: A study found that women participating in mammography screening were content with the programme and the paternalistic invitations that directly encourage participation and include a pre-specified time of appointment. We argue that this merely reflects that the information presented to the invited women is seriously biased in favour of participation. Women are not informed about the major harms of screening, and the decision to attend has already been made for them by a public authority. This short-circuits informed decision-making and the legislation on informed consent, and violates the autonomy of the women. Screening invitations must present both benefits and harms in a balanced fashion, and should offer, not encourage, participation. It should be stated clearly that the choice not to participate is as sensible as the choice to do so. To allow this to happen, the responsibility for the screening programmes must be separated from the responsibility for the information material.

http://jme.bmj.com (link may be outdated)

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Davis, Dena
Fathers, foreskins and family law
Medical Ethics Newsletter [Lahey Clinic] 2009 Spring; 16(2): 4, 7

http://www.lahey.org/Ethics/ (link may be outdated)

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Opala, Justice Marian P.; Sanbar, S. Sandy
Informed consent and informed refusal in Oklahoma.
Journal of the Oklahoma State Medical Association 2009 March; 102(3): 86-91

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Robinson, Richard; Makin, Erica; Wheeler, Robert
Consent for non-therapeutic male circumcision on religious grounds.
Annals of the Royal College of Surgeons of England 2009 March; 91(2): 152-154

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Varelius, Jukka
Collective informed consent and decision power

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Document 56
Pattinson, Shaun D.

Consent and informational responsibility
Journal of Medical Ethics 2009 March; 35(3): 176-179

Abstract: The notion of "consent" is frequently referred to as "informed consent" to emphasise the informational component of a valid consent. This article considers aspects of that informational component. One misuse of the language of informed consent is highlighted. Attention is then directed to some features of the situation in which consent would not have been offered had certain information been disclosed. It is argued that whether or not such consent is treated as sufficiently informed must, from a moral point of view, take account of four conditions. When these are applied to the operation of consent in relation to criminal responsibility for HIV transmission, the approach in some recent cases is shown to be morally questionable.

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Document 57
Dresser, Rebecca

Substituting authenticity for autonomy.
Hastings Center Report 2009 March-April; 39(2): 3

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Document 58
Farrell, Ruth M.

True north.
Hastings Center Report 2009 March-April; 39(2): 9-10

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Schonfeld, Toby L.; Galich, Kristine

Case study. Waiting it out. [case study and commentary]
Hastings Center Report 2009 March-April; 39(2): 16-17

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Document 60
Kern, Steven I.

When religious beliefs collide with medicine.
Medical Economics 2009 February 20; 86(4): 44

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**Document 61**

Salmon, Daniel A.; Sotir, Mark J.; Pan, William K.; Berg, Jeffrey L.; Omer, Saad B.; Stokley, Shannon; Hopfensperger, Daniel J.; Davis, Jeffrey P.; Halsey, Neal A.

*Parental vaccine refusal in Wisconsin: a case-control study.*

WMJ 2009 February; 108(1): 17-23

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**Document 62**

Iijima, Yoshihiko

*Risk disclosure in securities exchange and medical treatment contracts.*

Nagoya Journal of Medical Science 2009 February; 71(1-2): 63-69

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**Document 63**

Berger, O.; Grønberg, B.H.; Sand, K.; Kaasa, S.; Loge, J.H.

*The length of consent documents in oncological trials is doubled in twenty years.*


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**Document 64**

Hall, Mark A.; Schneider, Carl E.

*When patients say no (to save money): an essay on the tectonics of health law*


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**Document 65**

Escher, M.; Perneger, Thomas V.; Heidegger, Claudia P.; Chevrolet, Jean-Claude

*Admission of incompetent patients to intensive care: doctors’ responsiveness to family wishes.*

Critical Care Medicine 2009 February; 37(2): 528-532

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**Document 66**

Davidson, Judy E.; Palmer, Beth

*Is responsiveness to family wishes an expression of professional transcendence?*

Critical Care Medicine 2009 February; 37(2): 760

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**Document 67**
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Informed consent for epidural analgesia in labour: a survey of UK practice.
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Disclosure and rationality: comparative risk information and decision-making about prevention
Theoretical Medicine and Bioethics 2009; 30(3): 199-213
Abstract: With the growing focus on prevention in medicine, studies of how to describe risk have become increasing important. Recently, some researchers have argued against giving patients "comparative risk information," such as data about whether their baseline risk of developing a particular disease is above or below average. The concern is that giving patients this information will interfere with their consideration of more relevant data, such as the specific chance of getting the disease (the "personal risk"), the risk reduction the treatment provides, and any possible side effects. I explore this view and the theories of rationality that ground it, and I argue instead that comparative risk information can play a positive role in decision-making. The criticism of disclosing this sort of information to patients, I conclude, rests on a mistakenly narrow account of the goals of prevention and the nature of rational choice in medicine.
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Chell, Byron
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Little, Miles
**The role of regret in informed consent**
**Abstract:** Informed consent to medical procedures tends to be construed in terms of principle-based ethics and one or other form of expected utility theory. These constructions leave problems created by imperfect communication; subjective distress and other emotions; imperfect knowledge and incomplete understanding; complexity, and previous experience or the lack of it. There is evidence that people giving consent to therapy or to research participation act intuitively and assess consequences holistically, being influenced more by the magnitude of outcomes than their probability. People avoid decisions they may regret, but modern regret theory has received little attention in discussions of informed consent. This essay suggests ways in which regret may be acknowledged in the consent process and in the assessment of the information that is an intrinsic part of it.

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**Can I decide please? the state of children's consent in the UK.**
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Goldsmith, Lesley; Skirton, Heather; Webb, Christine
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Journal of Advanced Nursing 2008 December; 64(6): 549-563
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Chen, Donna T.
Why surrogate consent is important: a role for data in refining ethics policy and practice.
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Bhangu, A.; Hood, E.; Datta, A.; Mangaleshkar, S.
Is informed consent effective in trauma patients?
Journal of Medical Ethics 2008 November; 34(11): 780-782
Abstract: BACKGROUND: Informed consent in the modern era is a common and important topic both for the well-informed patient and to prevent unnecessary litigation. However, the effectiveness of informed consent in trauma patients is an under-researched area. This paper aims to assess the differences in patient recall of the consent process and desire for information by performing a comparative analysis between orthopaedic trauma and elective
methods: Information from 41 consecutive elective operations and 40 consecutive trauma operations was collected on the first post-operative day. Results: 100% of elective patients and 90% of trauma patients knew what operation they had received (p = 0.06). Overall recall of complications was poor, but was significantly lower in trauma patients compared with elective patients (62% vs 22%, p<0.001). 30% of trauma patients desired more information about their operation compared to 12% of elective patients (p = 0.049), although only 35% of trauma patients wanted written as well as verbal explanations, compared to 85% of elective patients p<0.001. Overall 100% of elective and 90% of trauma patients were happy with the consent process (p = 0.06). Subset analysis of neck of femur compared to other trauma patients showed that the above factors were not significantly different between the two groups. Conclusions: Recall of complications in the trauma patients is significantly lower than in elective patients, although both groups scored poorly overall. Repeated verbal explanations should be reinforced with the option of additional information leaflets for trauma operations. Further research into the usefulness of DVDs for commonly performed operations is warranted, although official internet resources may be more cost-effective.

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Winburn, E.; Mullen, R.
**Personality disorder and competence to refuse treatment**
Journal of Medical Ethics 2008 October; 34(10): 715-716

**Abstract:** The traditional view that having a personality disorder, unlike other mental disorders, is not usually reason enough to consider a person incompetent to make healthcare decisions is challenged. The example of a case in which a woman was treated for a physical disorder without her consent illustrates that personality disorder can render a person incompetent to refuse essential treatment, particularly because it can affect the doctor-patient relationship within which consent is given.

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Oberklaid, Frank
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**Gaining consent for publication in difficult cases involving children**
BMJ: British Medical Journal 2008 September 13; 337(7670): 608-609

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**The view of the BMJ's ethics committee [commentary]**
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**Medicine vs. prayer: the case of Kara Neumann.**
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Substituted judgment: the limitations of autonomy in surrogate decision making.
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* Article Document 107
Weisleder, P.

Physicians as healthcare surrogate for terminally ill children

Abstract: The parents of some terminally ill children have reported that being asked to authorise removal of life-sustaining measures is akin to being requested to sign a "death warrant". This dilemma leaves families not only enduring the grief of losing a loved one, but also with feelings of ambivalence, anxiety and guilt. A straightforward method by which the parents of terminally ill children can entrust the role of healthcare surrogate to the treating physician is presented. The cornerstone of this paradigm is parental awareness that the physician will act in the child's best interest, even if that means discontinuing life-sustaining measures. The goal is to mitigate parental guilt and fear of misperception, by self and others, of having given up on their child. From a moral standpoint this concept is an appealing option as it conforms to the four basic principles of medical ethics. While laws in the USA and several European nations prevent members of the medical team from taking on the responsibilities of healthcare surrogate for terminally ill patients, formal and informal precedence for this option already exists in France, The Netherlands, Norway, Sweden, Switzerland, and the Canadian province of Manitoba.

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* Article Document 108
Delany, C.

Making a difference: incorporating theories of autonomy into models of informed consent

Abstract: Background: Obtaining patients' informed consent is an ethical and legal obligation in healthcare practice. Whilst the law provides prescriptive rules and guidelines, ethical theories of autonomy provide moral foundations. Models of practice of consent, have been developed in the bioethical literature to assist in understanding and integrating the ethical theory of autonomy and legal obligations into the clinical process of obtaining a patient's informed consent to treatment. Aims: To review four models of consent and analyse the way each model incorporates the ethical meaning of autonomy and how, as a consequence, they might change the actual communicative process of obtaining informed consent within clinical contexts. Methods: An iceberg framework of consent is used to conceptualise how ethical theories of autonomy are positioned and underpin the above surface, and visible clinical communication, including associated legal guidelines and ethical rules. Each model of consent is critically reviewed from the perspective of how it might shape the process of informed consent. Results and discussion: All four models would alter the process of obtaining consent. Two models provide structure and guidelines for the content and timing of obtaining patients' consent. The two other models rely on an attitudinal shift in clinicians. They provide ideas for consent by focusing on underlying values, attitudes and meaning associated with the ethical meaning of autonomy. Conclusions: The paper concludes that models of practice that explicitly incorporate the underlying ethical meaning of autonomy as their basis, provide less prescriptive, but more theoretically rich guidance for healthcare communicative practices.

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*Document 109
Maclean, Alasdair

**Keyholders and flak jackets: the method in the madness of mixed metaphors**
Clinical Ethics 2008 September; 3(3): 121-126

**Abstract:** The law in England allows that both parents and competent minors concurrently have the right to consent to medical treatment of the minor. This means that while competent minors may consent to treatment their refusal of consent does not act as an effective veto of treatment and treatment remains lawful if given with parental consent. This approach has been heavily criticized as inconsistent with the House of Lords decision in the Gillick case and damned as 'palpable nonsense'. In this article, I examine these criticisms and conclude that, far from being illogical, it is entirely consistent with the essential asymmetry between consent to treatment and refusal of treatment. I examine the two metaphors of keyholders and flak jackets used to explain this approach and I suggest that both have value but only when used in combination. I also explain why, contrary to the criticism, it is consistent with Gillick.

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*Document 110
Duhan, Gary; Moazam, Farhat

**An uncomfortable refusal [case study and commentary]**

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*Document 111
Walter, T.

**To see for myself: informed consent and the culture of openness**
Journal of Medical Ethics 2008 September; 34(9): 675-678

**Abstract:** Informed consent needs to be practised within a culture of openness if it is to enhance public trust in medical procedures around death. Openness should entail patients not just receiving information from doctors, but also having the right to see certain medical procedures. This article proposes in particular that it would be desirable for the public to be allowed to attend an autopsy of a person they do not know. Evidence from the UK, where members of the public may go backstage to witness the process of cremation, the other technical process in which dead bodies are violently but legitimately assaulted, suggests benefits from a policy of openness. When a family consents to cremation in Britain, their consent is only minimally informed, but the system has nothing to hide, and trust is high. This suggests that the opportunity for lay people also to witness certain medical procedures might do more to restore public trust in medical procedures around death than a narrow interpretation of informed consent in which information is controlled by the profession.

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Huxtable, Richard

**Whatever you want? Beyond the point in medical law**

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Best interests: puzzles and plausible solutions at the end of life
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"Reader, I detained him under the Mental Health Act": a literary response to Professor Fennell's Best interests and treatment for mental disorder
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Best interests in the MCA 2005 – what can healthcare law learn from family law?
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Best interests, the power of the medical profession, and the power of the judiciary
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Best interests, public interest, and the power of the medical profession
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Holm, Søren; Edgar, Andrew
Best interest: a philosophical critique
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Best interests: a reappraisal
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Audrey, Suzanne; Abel, Julian; Blazeby, Jane M.; Falk, Stephen; Campbell, Rona
What oncologists tell patients about survival benefits of palliative chemotherapy and implications for informed consent: qualitative study
BMJ: British Medical Journal 2008 August 30; 337(7668): 492-496
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Sokol, Daniel K.
Clarifying best interests. What should doctors consider when determining what's best for their patients?
BMJ: British Medical Journal 2008 August 2; 337(7664): 264
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Little, M.; Jordens, C.F.C.; McGrath, C.; Montgomery, K.; Lipworth, W.; Kerridge, I.
**Informed consent and medical ordeal: a qualitative study.**
Internal Medicine Journal 2008 August; 38(8): 624-628
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**When a patient refuses assistance**
American Journal of Nursing 2008 August; 108(8): 36-38
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Zier, Lucas S.; Burack, Jeffrey H.; Micco, Guy; Chipman, Anne K.; Frank, James A.; Luce, John M.; White, Douglas B.
**Doubt and belief in physicians' ability to prognosticate during critical illness: the perspective of surrogate decision makers.**
Critical Care Medicine 2008 August; 36(8): 2341-2347
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Goodyear, P.W.A.; Anderson, A.R.; Kelly, G.
**How informed is consent in a modern ENT department.**
European Archives of Oto-Rhino-Laryngology 2008 August; 265(8): 957-961
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Prabhu, Apama; Lockie, Jane
**Children refusing general anaesthesia: to postpone or proceed?**
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Marks, Melissa A.Z.; Arkes, Hal R.
**Patient and surrogate disagreement in end-of-life decisions: can surrogates accurately predict patients' preferences?**
Medical Decision Making 2008 July-August; 28(4): 524-531
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Berman, Loren; Curry, Leslie; Gusberg, Richard; Dardik, Alan; Fraenkel, Liana
Informed consent for abdominal aortic aneurysm repair: The patient's perspective.
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Raymundo, M.M.; Goldim, J.R.
Moral-psychological development related to the capacity of adolescents and elderly patients to consent
Journal of Medical Ethics 2008 August; 34(8): 602-605
Abstract: Objective: To evaluate moral development as an indicator of the capacity to consent among two groups of patients from the Hospital de Clínicas in Porto Alegre, RS, Brazil. Method: Fifty-nine adolescents and 60 patients over 60 years of age participated in a cross-sectional study to assess moral development using Loevinger's model of ego stages. Results: Age and moral development showed no association, with most participants in the two groups being in the conscientious phase. Conclusions: Age is probably not an adequate variable to measure decision-making capacity, because questions of medical consent relate to participants' own personal health. Decision-making capacity should be viewed as a continuous function. While the age of the person whose consent is needed should be considered, age alone, from a moral perspective, is not the main determinant of this capacity.
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Owen, Gareth S.; Richardson, Genevra; David, Anthony S.; Szmukler, George; Hayward, Peter; Hotopf, Matthew
Mental capacity to make decisions on treatment in people admitted to psychiatric hospitals: cross sectional study
BMJ: British Medical Journal 2008 July 5; 337(7660): 40-42
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Berger, Jeffrey T.; DeRenzo, Evan G.; Schwartz, Jack
Surrogate decision making: reconciling ethical theory and clinical practice
Annals of Internal Medicine 2008 July 1; 149(1): 48-53
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Osime, C.O.
Jehovah's Witnesses and refusal of blood transfusion: the medico-legal challenges.
West African Journal of Medicine 2008 July; 27(3): 186-190
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Moazam, Farhat
Comment on "Consent to treatment: practice vis-à-vis principle" by B.K. Bastia
Indian Journal of Medical Ethics 2008 July-September; 5(3): 115-116

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Bastia, Binaya Kumar
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Downie, Jocelyn; Rajotte, Chantelle; Shea, Alison
Pre-mortem transplantation optimizing interventions: the legal status of consent.

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Steven, Mairi; Broadis, Emily; Carachi, Robert; Brindley, Nicola
Sign on the dotted line: parental consent
Pediatric Surgery International 2008 July; 24(7): 847-849

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General Medical Council [GMC] (Great Britain)
Consent: patients and doctors making decisions together

Call number: citation only

http://www.gmc-uk.org/guidance/ethical_guidance/consent_guidance/Consent_guidance.pdf (link may be outdated)

Document 141
Hui, Edwin
Parental refusal of life-saving treatments for adolescents: Chinese familism in medical decision-making re-
**Abstract:** This paper reports two cases in Hong Kong involving two native Chinese adolescent cancer patients (APs) who were denied their rights to consent to necessary treatments refused by their parents, resulting in serious harm. We argue that the dynamics of the 'AP-physician-family-relationship' and the dominant role Chinese families play in medical decision-making (MDM) are best understood in terms of the tendency to hierarchy and parental authoritarianism in traditional Confucianism. This ethic has been confirmed and endorsed by various Chinese writers from Mainland China and Hong Kong. Rather than giving an unqualified endorsement to this ethic, based more on cultural sentimentalism than rational moral reasoning, we warn that a strong familism in MDM, which deprives ‘weak’ family members of rights, represents the less desirable elements of this tradition, against which healthcare professionals working in this cultural milieu need to safeguard. Specifically for APs, we suggest that parental authority and family integrity should be re-interpreted in terms of parental responsibility and the enhancement of children's interests respectively, as done in the West. This implies that when parents refuse to consent to necessary treatment and deny their adolescent children's right to consent, doctors, as the only remaining advocates of the APs' interest, have the duty to inform the state, which can override parental refusal to enable the doctors to fulfill their professional and moral obligations. In so doing the state exercises its 'parens patriae' power to defend the defenseless in society and the integrity of the medical profession.

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autonomy of legally minor Jehovah's Witnesses; autonomy in cosmetic surgery; inappropriate treatment; autonomy and human medical research, and euthanasia and other end-of-life options. The discussion is within a South African framework with reference to other jurisdictions and decisions where appropriate. I conclude that whilst some unusual instances of limitation of bioethical informed consent might be ethically justifiable, the arguments presented point to the opposite: the unfounded limitation of informed consent.

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Rubíños López, Emilio; Rodríguez Vázquez, Luis Miguel; Varela Centelles, Aimudena; Varela Otero, Flor; Blanco Otero, Ana Isabel; Fernández Fraga, Carlos; Varela Centelles, Pablo

**Impact of the systematic use of the informed consent form at public dental care units in Galicia (Spain).**

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Schwartz, Peter H.; Meslin, Eric M.

**The ethics of information: absolute risk reduction and patient understanding of screening**
JGIM: Journal of General Internal Medicine 2008 June; 23(6): 867-870

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* Document 147
Torke, Alexia M.; Simmerling, Mary; Siegler, Mark; Kaya, Danit; Alexander, G. Caleb

**Rethinking the ethical framework for surrogate decision making: a qualitative study of physicians**

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Rodríguez del Pozo; Pablo; Fins, Joseph J.

**Islam and informed consent: notes from Doha**
CQ: Cambridge Quarterly of Healthcare Ethics 2008 Summer; 17(3): 273-279

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* Document 149
Lucas, Tracey

**Implementing the Mental Capacity Act and the code of practice -- a developing scenario**
Clinical Ethics 2008 June; 3(2): 63-68

**Abstract:** This article sets out a scenario highlighting some of the issues to be faced by NHS hospitals when dealing with patients who may require treatment under the Mental Capacity Act 2005. The article sets out matters to consider when dealing with patients in A&E, assessments of best interests, emergency treatment, lasting powers of attorney and transferring patients to nursing homes. All of these matters come under the remit of the Act.

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**Document 150**

Franchitto, Nicolas; Gavarri, Laurent; Dédouit, Fabrice; Telmon, Norbert; Rougé, Daniel

Photography, patient consent and scientific publications: medicolegal aspects in France.

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**Document 151**

Milliez, Jacques;

Guidelines regarding informed consent.
International Journal of Gynaecology and Obstetrics 2008 May; 101(2): 219-220

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**Document 152**

Asghari, Fariba; Mirzazadeh, A.; Fotouhi, A.

Patients' preferences for receiving clinical information and participating in decision-making in Iran
Journal of Medical Ethics 2008 May; 34(5): 348-352

Abstract: INTRODUCTION: This study, the first of its kind in Iran, was to assess Iranian patients' preferences for receiving information and participating in decision-making and to evaluate their satisfaction with how medical information is given to them and with their participation in decision-making at present. METHOD AND MATERIALS: 299 of 312 eligible patients admitted to general internal medicine or surgery wards from May to December 2006 were interviewed according to a structured questionnaire. The questionnaire contained questions about patients' preferences regarding four domains of information and their participation in decision-making. Patients' responses were measured on a visual analogue scale graded from 1 to 10. RESULTS: The mean (SD) score for desire to receive information was 8.88 out of 10 (1.5) and for participation in medical decision-making was 7.75 out of 10 (3). The desire to receive information was greater in women than men (9.0 (1.5) vs 7.8 (1.4), p = 0.025). It was also correlated with their education (r = 0.2, p = 0.001) and their estimation of the severity of their own disease (r = 0.13, p = 0.027). The score for preference to participate in decision-making was higher in women than in men (7.95 (2.8) and 7.0 (3.2), respectively; beta = 0.8, p = 0.022) and was negatively correlated with education (r = -0.14, p = 0.015).

DISCUSSION: This study shows that Iranian patients are highly interested in receiving information about their condition and participating in clinical decision-making. No predictive variable for such attitudes was found; therefore, the only way for the physician to recognise patients' desire is to ask them explicitly.

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**Document 153**


An assessment of the process of informed consent at the University Hospital of the West Indies
Journal of Medical Ethics 2008 May; 34(5): 344-347

Abstract: OBJECTIVE: To assess the adequacy of the process of informed consent for surgical patients at the University Hospital of the West Indies. Method: The study is a prospective, cross-sectional, descriptive study. 210 patients at the University Hospital of the West Indies were interviewed using a standardised investigator-administered questionnaire, developed by the authors, after obtaining witnessed, informed consent for participation in the study. Data were analysed using SPSS V.12 for Windows. RESULTS: Of the patients, 39.4% were male. Of the surgical procedures, 68.6% were scheduled, 7.6% urgent and 23.8% emergency, 35.2% were minor and 64.8% major. Information imparted/received was acceptable in 40% of cases, good in 24% and inadequate (unacceptable) in 36% of cases. Almost all (97.6%) patients stated that they understood why an operation was planned and 93.3% thought that they had given informed consent. Most (95.2%) thought that they had free choice and made up their
own mind. A quarter (25.2%) of all patients were told that it was mandatory for them to sign the form. There was a
discussion of possible side effects and complications in 56.7% of patients. CONCLUSIONS: This study clearly
indicates that surgical patients at the University Hospital of the West Indies feel that they have given informed
consent. However, it also suggests that more information should be given to patients for consent to be truly
informed.

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http://www.jmedethics.com (link may be outdated)
"Above these badlands": delusions, autonomy, and individual beliefs in right to refuse psychotropic medication cases
Webb, Lindsay J.

Abstract: This paper reviews the claim that matters of truth can be arbitrated through general consensus or agreement. Philosopher William James proposed two methods for establishing truth: First, we may be able to directly verify the truth of ideas by checking our hypotheses against the world. Second, when verification is not possible, truth can be approached through the utilization of consensus. There are some contexts in which a general consensus of truth will suffice. However, a mere consensus of truth is inadequate when reliance on such an agreement may result in the preservation or minimization of individual autonomy. Mental disability jurisprudence is often concerned with the preservation of individual autonomy. Yet, often, individual autonomy is cast aside in lieu of professional agreements. This is especially the case in right to refuse psychotropic medication cases.

Can "presumed consent" justify the duty to treat infectious diseases? An analysis.
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BMC Infectious Diseases 2008 March 6; 8: 29; 11 p.

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Mulnix, Jennifer Wilson
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Case one: interests and medical paternalism.
Mulnix, Jennifer Wilson
Clinical Laboratory Science 2008 Spring; 21(2): 116-117

Benefits and challenges of informed consent.
Murphy, Joshua B.
Mayo Clinic Proceedings 2008 March; 83(3): 272-273
Paterick, Timothy J.; Carson, Geoff V.; Allen, Marjorie C.; Paterick, Timothy E.
**Medical informed consent: general considerations for physicians.**
Mayo Clinic Proceedings 2008 March; 83(3): 313-319
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**Reconceptualizing the informed consent process at eight innovative hospitals.**
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**Relational autonomy or undue pressure? Family's role in medical decision-making.**
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**A strategy for learning principles and elements of informed consent.**
Nurse Educator 2008 March-April; 33(2): 75-78
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Lipman, Hannah I.
**Surrogate decision making.**
American Journal of Geriatric Cardiology 2008 March-April; 17(2): 120-122
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Lenselink, Charlotte H.; Gerrits, Marloes M.J.G.; Melchers, Willem J.G.; Massuger, Leon F.A.G.; van Hamont, Dennis; Bekkers, Ruud L.M.
**Parental acceptance of Human Papillomavirus vaccines.**
European journal of Obstetrics, Gynecology, and Reproductive Biology 2008 March; 137(1): 103-107
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Maid, Gustavo; Guerchicoff, Marianna; Falconi, Mariano; de Arenaza, Diego Perez

Written consent to use the drug in children: the problem of off-label drugs.
Current Pharmaceutical Design 2008 March; 14(8): 776-781

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Clark, Randall Baldwin

Bleedings, purges, and vomits: Dr. Benjamin Rush's republican medicine, the bilious remitting yellow-fever epidemic of 1793, and the non-origin of the law of informed consent

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Document 171

Dunn, Michael C.; Clare, Isabel C.H.; Holland, Anthony J.

Substitute decision-making for adults with intellectual disabilities living in residential care: learning through experience

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Document 172

Kihlbom, U.

Autonomy and negatively informed consent
Journal of Medical Ethics 2008 March; 34(3): 146-149

Abstract: The requirement of informed consent (IC) to medical treatments is almost invariably justified with appeal to patient autonomy. Indeed, it is common to assume that there is a conceptual link between the principle of respect for autonomy and the requirement of IC, as in the influential work of Beauchamp and Childress. In this paper I will argue that the possible relation between the norm of respecting (or promoting) patient autonomy and IC is much weaker than conventionally conceived. One consequence of this is that it is possible to exercise your autonomy without having the amount of and the kind of information that are assumed in the standard requirement of IC to medical treatments. In particular, I will argue that with a plausible conception of patient autonomy, the respect for and the promotion of patient autonomy are in certain circumstances better protected by giving patients the right to give their negatively informed consent to medical treatments.

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Liseckiene, I.; Liubarskiene; Z.; Jacobsen, R.; Valius, L.; Norup, M.

Do family practitioners in Lithuania inform their patients about adverse effects of common medications?
Journal of Medical Ethics 2008 March; 34(3): 137-140

Abstract: OBJECTIVES: (1) To investigate the extent to which family physicians (GPs) in Lithuania inform their patients about possible side-effects when a common treatment is proposed. (2) To examine the relation between physicians' estimation of the severity and frequency of these side-effects and their willingness to inform patients. (3) To identify the reasons for informing or not informing the patients. METHODS: A questionnaire, presenting three
hypothetical cases involving decisions about ordinary medical treatments and a series of general questions about information about side-effects, was distributed to 500 Lithuanian GPs. The response rate was 42%. RESULTS: The respondents differed considerably with regard to their willingness to inform patients about side-effects, but they informed their patients significantly more if the side effect was considered to be common and serious, than in cases when it was considered to be rare and trivial. The majority of the respondents informed their patients primarily to enable them to react appropriately to the side-effects in question. The major reason for not informing was that the side-effects were considered too rare to be relevant to the patient's decision-making. CONCLUSION: Information, given to patients about side-effects by Lithuanian GPs, is not in accordance with the principle of respect for patients' autonomy and requirements of Lithuanian legislation.

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Favre, Romain; Moutel, Grégoire; Duchange, Nathalie; Vayssière, Christophe; Kohler, Monique; Bouffet, Nicole; Hunsinger, Marie-Christine; Kohler, Anne; Mager, Cécile; Neumann, Muriel; Vayssière, Christine; Viville, Brigitte; Hervé, Christian; Nisand, Israel
What about informed consent in first-trimester ultrasound screening for Down syndrome?
Fetal Diagnosis and Therapy 2008 February; 23(3): 173-184

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Informed consent in shoulder surgery.
La Chirurgia degli Organi di Movimento 2008 February; 91(2): 103-107

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Liégeois, A.; Eneman, M.
Ethics of deliberation, consent and coercion in psychiatry
Journal of Medical Ethics 2008 February; 34(2): 73-76

Abstract: In psychiatry, caregivers try to get free and informed consent of patients, but often feel required to restrict freedom and to use coercion. The present article develops ethical advice given by an Ethics Committee for Mental Health Care. The advice recommends an ethical ideal of shared deliberation, consisting of information, motivation, consensus and evaluation. For the exceptional use of coercion, the advice develops three criteria, namely incapacity to deliberate, threat of serious harm and proportionality between harm and coercion. The article also discusses the viewpoints of the ethical advice and of the European Convention on Human Rights and Biomedicine: is the advice in agreement with the Convention and can the advice refine the guidelines of the Convention for the particular context of psychiatry? Although the Convention emphasises the autonomy of the individual patient, whereas the advice focuses on the relationships between the partners involved, the advice enjoys a complementary and supportive function in the application of the Convention.

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Arnold, Suzanne V.; Rich, Michael W.
Informed consent in older patients with acute coronary syndromes offered invasive management
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Dimond, Bridgit

**The Mental Capacity Act 2005 and decision-making: Code of Practice**
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Mackenzie, Catriona

**Relational autonomy, normative authority and perfectionism**

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**Legal basis of consent for health care and vaccination for adolescents.**
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**Adolescent's refusal of treatment: principles in conflict.**

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Prenatal HIV testing: women’s experiences of informed consent in Toronto, Ontario

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Journal of Hospital Medicine (Online) 2008 January; 3(1): 1-3

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Informed consent: good medicine, dangerous side effects

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Nagasawa, Yujin
Proxy consent and counterfactuals
Bioethics 2008 January; 22(1): 16-24
Abstract: When patients are in vegetative states and their lives are maintained by medical devices, their surrogates might offer proxy consents on their behalf in order to terminate the use of the devices. The so-called 'substituted judgment thesis' has been adopted by the courts regularly in order to determine the validity of such proxy consents. The thesis purports to evaluate proxy consents by appealing to putative counterfactual truths about what the patients would choose, were they to be competent. The aim of this paper is to reveal a significant limitation of the thesis, which has hitherto been recognised only vaguely and intuitively. By appealing to the metaphysics of counterfactuals I explain how the thesis fails to determine the validity of proxy consents in a number of actual cases.

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Jones, James W.; McCullough, Laurence B.
The shifting sands of senility: canceled consent

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Ford, M.E.; Kallen, M.; Richardson, P.; Matthiesen, E.; Cox, V.; Teng, E.J.; Cook, K.F.; Petersen, N.J.
Effect of social support on informed consent in older adults with Parkinson disease and their caregivers
Journal of Medical Ethics 2008 January; 34(1): 41-47

Abstract: PURPOSE: To evaluate the effects of social support on comprehension and recall of consent form information in a study of Parkinson disease patients and their caregivers. DESIGN and METHODS: Comparison of comprehension and recall outcomes among participants who read and signed the consent form accompanied by a family member/friend versus those of participants who read and signed the consent form unaccompanied. Comprehension and recall of consent form information were measured at one week and one month respectively, using Part A of the Quality of Informed Consent Questionnaire (QuIC). RESULTS: The mean age of the sample of 143 participants was 71 years (SD = 8.6 years). Analysis of covariance was used to compare QuIC scores between the intervention group (n = 70) and control group (n = 73). In the 1-week model, no statistically significant intervention effect was found (p = 0.860). However, the intervention status by patient status interaction was statistically significant (p = 0.012). In the 1-month model, no statistically significant intervention effect was found (p = 0.480). Again, however, the intervention status by patient status interaction was statistically significant (p = 0.040). At both time periods, intervention group patients scored higher (better) on the QuIC than did intervention group caregivers, and control group patients scored lower (worse) on the QuIC than did control group caregivers. IMPLICATIONS: Social support played a significant role in enhancing comprehension and recall of consent form information among patients.

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de Lusignan, Simon

**Using routinely collected patient data with and without consent: trust and professionalism.**
Informatics in Primary Care 2008; 16(4): 251-254

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Ledray, Linda E.

**Consent to photograph: how far should disclosure go?**

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Vars, Fredrick E.

**Illusory consent: when an incapacitated patient agrees to treatment**
Oregon Law Review 2008; 87(2): 353-400

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Kluge, Eike-Henner W.

**Incompetent patients, substitute decision making, and quality of life: some ethical considerations.**
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Informed consent and the law—an English legal perspective.
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Kotzampassi, Katerina; Shrewsbury, Anne D.
Intragastric balloon: ethics, medical need and cosmetics.
Digestive Diseases 2008; 26(1): 45-48
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Papatheodoridis, George V.
Ethics related to liver biopsies and antiviral therapies in chronic viral hepatitis.
Digestive Diseases 2008; 26(1): 59-65
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*  Document 209
Banic, Marko; Kardum, Dusko; Plesko, Sanja; Petrovecki, Marko; Urek, Marija; Babic, Zarko; Kujundzic, Milan; Rotkvic, Ivo
Informed consent for gastrointestinal endoscopy: a view of endoscopists in Croatia.
Digestive Diseases 2008; 26(1): 66-70
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*  Document 210
Archard, David
Informed consent: autonomy and self-ownership
**Abstract:** Using the example of an unconsented mouth swab I criticise the view that an action of this kind taken in itself is wrongful in respect of its being a violation of autonomy. This is so much inasmuch as autonomy merits respect only with regard to 'critical life choices'. I consider the view that such an action is nevertheless harmful or risks serious harm. I also respond to two possible suggestions: that the action is of a kind that violates autonomy; and, that the class of such actions violates autonomy. I suggest that the action is wrongful in as much as it is a bodily trespass. I consider, and criticise, two ways of understanding how morally I stand to my own body: as owner
and as sovereign. In respect of the latter I consider Arthur Ripstein's recent defence of a sovereignty principle. Finally I criticise an attempt by Joel Feinberg to explain bodily trespass in terms of personal autonomy.

* Document 211

Humayun, Ayesha; Fatima, Noor; Naqqash, Shahid; Hussain, Salwa; Rasheed, Almas; Imtiaz, Huma; Imam, Sardar Zakariya

**Patients' perception and actual practice of informed consent, privacy and confidentiality in general medicine outpatient departments of two tertiary car hospitals of Lahore**


**Abstract:** Background: The principles of informed consent, confidentiality and privacy are often neglected during patient care in developing countries. We assessed the degree to which doctors in Lahore adhere to these principles during outpatient consultations. Material and Method: The study was conducted at medical out-patient departments (OPDs) of two tertiary care hospitals (one public and one private hospital) of Lahore, selected using multi-stage sampling. 93 patients were selected from each hospital. Doctors’ adherence to the principles of informed consent, privacy and confidentiality was observed through client flow analysis performed by trained personnel. Overall patient perception was also assessed regarding these practices and was compared with the assessment made by our data collectors. Results: Some degree of informed consent was obtained from only 9.7% patients in the public hospital and 47.8% in the private hospital. 81.4% of patients in the public hospital and 88.4% in the private hospital were accorded at least some degree of privacy. Complete informational confidentiality was maintained only in 10.8% and 35.5% of cases in public & private hospitals respectively. Informed consent and confidentiality were better practiced in the private compared to the public hospital (two-sample t-test > 2, p value < 0.05). There was marked disparity between the patients' perspective of these ethical practices and the assessment of our trained data collectors. Conclusion: Observance of medical ethics is inadequate in hospitals of Lahore. Doctors should be imparted formal training in medical ethics and national legislation on medical ethics is needed. Patients should be made aware of their rights to medical ethics.

* Document 212

Greene, Mark; Smith, Suzanne M.

**Consenting to uncertainty: challenges for informed consent to disease screening-a case study.**


**Abstract:** This paper uses chronic beryllium disease as a case study to explore some of the challenges for decision-making and some of the problems for obtaining meaningful informed consent when the interpretation of screening results is complicated by their probabilistic nature and is clouded by empirical uncertainty. Although avoidance of further beryllium exposure might seem prudent for any individual whose test results suggest heightened disease risk, we will argue that such a clinical precautionary approach is likely to be a mistake. Instead, advice on the interpretation of screening results must focus not on risk per se, but on avoidable risk, and must be carefully tailored to the individual. These points are of importance for individual decision-making, for informed consent, and for occupational health.

* Document 213

Stanger, Kim C.; Gustavson, Michelle; Hamilton, Gabriel

**Consent for healthcare under Idaho law: a primer**

Document 214
Rolon, Yamilka M.; Jones, Joshua C.W.
**Right to refuse treatment**

Document 215
Houchin, Timothy; Ciccone, J. Richard
**Consent in incompetent patients**

Document 216
McGrath, Pam; Phillips, Emma
**Western notions of informed consent and indigenous cultures: Australian findings at the interface**

**Abstract:** Despite the extensive consideration the notion of informed consent has heralded in recent decades, the unique considerations pertaining to the giving of informed consent by and on behalf of Indigenous Australians have not been comprehensively explored; to the contrary, these issues have been scarcely considered in the literature to date. This deficit is concerning, given that a fundamental premise of the doctrine of informed consent is that of individual autonomy, which, while privileged as a core value of non-Indigenous Australian culture, is displaced in Indigenous cultures by the honouring of the family unit and community group, rather than the individual, as being at the core of important decision-making processes relating to the person. To address the hiatus in the bioethical literature on issues relating to informed consent for Aboriginal peoples, the following article provides findings from a two-year research project, funded by Australia’s National Health and Medical Research Council (NHMRC), conducted in the Northern Territory. The findings, situated in the context of the literature on cultural safety, highlight the difference between the Aboriginal and biomedical perspectives on informed consent.

Document 217
Johansson, Mats; Broström, Linus
**Turning failures into successes: a methodological shortcoming in empirical research on surrogate accuracy**
Theoretical Medicine and Bioethics 2008; 29(1): 17-26

**Abstract:** Decision making for incompetent patients is a much-discussed topic in bioethics. According to one influential decision making standard, the substituted judgment standard, a surrogate decision maker ought to make the decision that the incompetent patient would have made, had he or she been competent. Empirical research has been conducted in order to find out whether surrogate decision makers are sufficiently good at doing their job, as this is defined by the substituted judgment standard. This research investigates to what extent surrogates are able to predict what the patient would have preferred in the relevant circumstances. In this paper we address a methodological shortcoming evident in a significant number of studies. The mistake consists in categorizing responses that only express uncertainty as predictions that the patient would be positive to treatment, on the grounds that the clinical default is to provide treatment unless it is refused. We argue that this practice is based on confusion and that it risks damaging the research on surrogate accuracy.
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