EthxWeb Search Results

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Document 1
Bahus, Marianne K; Førde, Reidun
Parents as decision-makers--do the attitudes of Norwegian doctors conform to law?
European journal of health law 2011 Dec; 18(5): 531-47
Abstract: This article studies whether the attitudes of Norwegian doctors regarding surrogate decision power in end-of-life care conform to legal rules, particularly as they apply to the protection of children. The article is based on a hypothetical scenario concerning a critically ill child, believed to be dying, presented to 406 doctors. The study indicates that doctors may permit parental/surrogate decision-making to a greater extent than justified by law, sometimes in contravention of the child's best interests, which should be a fundamental guideline in all decisions that concern children. This article suggests a need to improve knowledge of doctors concerning parents'/surrogates' right to participate in life-or-death decisions. We conclude that Norway needs a precedent decision from the Supreme Court that confirms the right of judicial review of end-of-life decisions, and which applies the principle of the child's best interests as a fundamental guideline in the final decision.
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Document 2
Miller, Victoria A; Ittenbach, Richard F; Harris, Diana; Reynolds, William W; Beauchamp, Tom L; Luce, Mary Frances; Nelson, Robert M
The decision making control instrument to assess voluntary consent.
Medical decision making: an international journal of the Society for Medical Decision Making 2011 Sep-Oct; 31(5): 730-41
Abstract: The decision to participate in a research intervention or to undergo medical treatment should be both informed and voluntary.
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Document 3
Meller, Simon; Barclay, Sarah
Mediation: an approach to intractable disputes between parents and paediatricians.
Archives of disease in childhood 2011 Jul; 96(7): 619-21
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Document 4
Peiró, Ana M
[The mature minor's decisions' in health]. = El menor maduro ante las decisiones sanitarias.
Medicina clínica 2011 Jun 25; 137(3): 140-1
Georgetown users check Georgetown Journal Finder for access to full text
**Document 5**

Diekema, Douglas S

**Revisiting the best interest standard: uses and misuses.**
The Journal of clinical ethics 2011 Summer; 22(2): 128-33

**Abstract:** The best interest standard is the threshold most frequently employed by physicians and ethics consultants in challenging a parent's refusal to provide consent for a child's medical care. In this article, I will argue that the best interest standard has evolved to serve two different functions, and that these functions differ sufficiently that they require separate standards. While the best interest standard is appropriate for choosing among alternative treatment options for children, making recommendations to parents, and making decisions on behalf of a child when the legal decision makers are either unable to make a decision or are in dispute, a different standard is required for deciding when to seek state interference with parental decision-making authority. I will suggest that the harm principle provides a more appropriate threshold for determining when to seek state intervention than the best interest standard.

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**Document 6**

Pope, Thaddeus Mason

**The best interest standard: both guide and limit to medical decision making on behalf of incapacitated patients.**
The Journal of clinical ethics 2011 Summer; 22(2): 134-8

**Abstract:** In this issue of JCE, Douglas Diekema argues that the best interest standard (BIS) has been misemployed to serve two materially different functions. On the one hand, clinicians and parents use the BIS to recommend and to make treatment decisions on behalf of children. On the other hand, clinicians and state authorities use the BIS to determine when the government should interfere with parental decision-making authority. Diekema concedes that the BIS is appropriately used to "guide" parents in making medical treatment decisions for their children. But he argues that the BIS is inappropriately used as a "limiting" standard to determine when to override those decisions. Specifically, Diekema contends that the BIS "does not represent the best means for determining when one must turn to the state to limit parental action." He argues that this limiting function should be served by the harm principle instead of by the BIS. I contend that we should not reassign the BIS's limiting function to the harm principle. In this article I make two arguments to support my position. First, the BIS has effectively served, and can serve, both guiding and limiting functions. Second, the harm principle would be an inadequate substitute. It cannot serve the limiting function as well as the more robust BIS.

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**Document 7**

Deneyer, M; Clybouw, C; De Groot, E; De Backer, A; Van den Brande, P; Vandenplas, Y

**The surgeon and the law on patient's rights for minors.**

**Abstract:** The law of August 22nd, 2002 concerning patients' rights (LPR) gave a new dimension to the relationship between the physician and the patient. According to this law, it is up to the physician to judge if a patient is able to exercise his own rights or if the patient needs assistance from a representative. In the particular case of the patient being a minor, this often leads to a difficult situation because of the absence of validated criteria to evaluate the capacity of judgment of a minor patient. The triangular relationship physician-patient-parents might be hampered when the parents are involved in a divorce. In daily practice, there are many questions concerning the physicians' attitude towards the rights of the minor patient, particularly in cases of medical intervention. By means of case histories, we describe several problematic situations: the right of free choice of the physician, the right of the minor to obtain informational privacy, obtaining consent for a medical intervention. In cases where there is a divorce, the situation is even more difficult. Solutions are provided to act as effectively as possible in the minors' interests and to offer support to the physician.

Note: According to article 388 of the Belgian Civil Code a minor is a person, either male or female, who has not attained the age of 18 years.

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**Document 8**

Friedlander, Joel A; Loeben, Greg S; Finnegan, Patricia K; Puma, Anita E; Zhang, Xuemei; de Zoeten, Edwin F; Piccoli,
A novel method to enhance informed consent: a prospective and randomised trial of form-based versus electronic assisted informed consent in paediatric endoscopy.


Abstract: To evaluate the adequacy of paediatric informed consent and its augmentation by a supplemental computer-based module in paediatric endoscopy.

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Document 9

Tait, Alan R; Voepel-Lewis, Terri; Gauger, Virginia

Parental recall of anesthesia information: informing the practice of informed consent.

Anesthesia and analgesia 2011 Apr; 112(4): 918-23

Abstract: Informed consent is a process of sharing information that facilitates the individual patient's right to self-determination. Despite its importance in anesthesia practice, the process of informed consent is rarely audited or examined. As such, there are only limited data with respect to anesthesia consent practices, particularly within the pediatric setting. We designed this study, therefore, to examine the information that parents seek regarding their child's anesthesia, what they are told, who told them, and how much of the information they recall.

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Document 10

Lim, Sok Bee

Handling request for non-disclosure of clinical information in paediatrics.

Annals of the Academy of Medicine, Singapore 2011 Jan; 40(1): 56-3

Abstract: Non-disclosure in Paediatric Practice is a controversial issue. There was a time when the care of children was solely the responsibility of parents and any decision with respect to treatment or non-treatment would have been the joint responsibility of the parents and of the attending medical professionals. This practice, viewed as adopting a more paternalistic approach, has been challenged in many parts of the world. In essence what is being challenged is the notion that the sole responsibility of decision-making rests with parents.

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Document 11

Guttman, Nurit; Lotan, Tsippy

Spying or steering? Views of parents of young novice drivers on the use and ethics of driver-monitoring technologies.

Accident; analysis and prevention 2011 Jan; 43(1): 412-20

Abstract: In-vehicle technologies that document driving practices have the potential to enhance the driving safety of young drivers, but their installation depends largely on their parents' willingness and raises ethical dilemmas. This study investigated, using closed and open-ended questions, the views of 906 parents of young drivers in Israel regarding their willingness to install such a technology, and their conceptions of social norms and ethical issues associated with the technology and of factors that would encourage or discourage parents to adopt it. Most believed parents should feel morally obligated to install it. When cost was not a consideration, most said they would, and believed other parents would be willing to install the technology. Fewer (about half) expressed willingness to install it after being told about its estimated cost. Monetary cost was rated as a barrier to install it by about half. Environmental considerations were viewed as an incentive. Parents who supported the installation believed it would serve as a trigger for parent-young driver communication but those who did not thought it would erode trust in the parent-young driver relationship. Most said parents should have access to the monitoring data. Policy implications regarding issues of privacy and resources for parents are discussed.

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Dignity and informed consent in the treatment of mature minors.


Abstract: In today's world, as evinced in various human rights provisions, emphasis is placed on the assertion and protection of the entrenched rights of every human and particularly the dignity of humans and respect of human autonomy. Medical/health workers are concerned about protecting every patient's right to the dignity of his or her person. This led to the formulation of the concept of self-determination and informed consent in medical diagnosis and treatments. However, serious concern is placed on these principles especially as it affects mature minors, a group of individuals who by conduct demand a level of respect but may at the same time be viewed as not capable of making the "best" informed decisions, especially about health. The following issues may arise as a result of the aforementioned concerns: --are mature young ones entitled to right of self-determination and informed consent despite the alleged fear that they may lack capacity to make informed decisions? --if no, who should decide on their behalf--their parents, their medical/health provider or the society/government (especially since the 3 (three) interested groups may have different and conflicting stands on what is best for the child); --if the answer to the initial question is yes, to what extent should mature minors be informed of their medical choices and be allowed to exercise their right of self-determination? --should they be guided? --and who should so guide them? In resolving the above issue, due consideration has been given not only to legal and bio-ethical provisions of some countries but also to international conventions which several countries are party to. Thereafter, it became clear that most authorities are of the view that mature minors should be fully informed and be allowed to have a say in health decisions, coaching them with few exceptions. Ultimately, because of the importance of respect for human dignity, autonomy and self-determination along with medical disclosure in today's world, it will be recommended that laws in a number of jurisdictions need to be reviewed to reflect the current international trend and amended or replaced as the need might be.

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[Prerequisites and limits of preoperation discussion by telephone: Federal High Court decision on consent for minor patients]. = Voraussetzungen und Grenzen der telefonischen Aufklärung: BGH-Urteil zur Aufklärung bei Minderjährigen.

Der Anaesthesist 2010 Dec; 59(12): 1133-4

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Consent by proxy for nonurgent pediatric care.

Pediatrics 2010 Nov; 126(5): 1022-31

Abstract: Minor-aged patients are often brought to the pediatrician for nonurgent acute medical care, physical examinations, or health supervision visits by someone other than their legally authorized representative, which, in most situations, is a parent. These surrogates or proxies can be members of the child's extended family, such as a grandparent, adult sibling, or aunt/uncle; a noncustodial parent or stepparent in cases of divorce and remarriage; an adult who lives in the home but is not biologically or legally related to the child; or even a child care professional (eg, au pair, nanny). This report identifies common situations in which pediatricians may encounter "consent by proxy" for nonurgent medical care for minors, including physical examinations, and explains the potential for liability exposure associated with these circumstances. The report suggests practical steps that balance the need to minimize the physician's liability exposure with the patient's access to health care. Key issues to be considered when creating or updating office policies for obtaining and documenting consent by proxy are offered.

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**Birchley, Giles**  
**What limits, if any, should be placed on a parent's right to consent and/or refuse to consent to medical treatment for their child?**

_Nursing philosophy : an international journal for healthcare professionals 2010 Oct; 11(4): 280-5_

**Abstract:** Abstract There is an overwhelming consensus that parent's rights to consent must be limited to decisions that are in the child's best interests, yet best interests are difficult to determine. I reflect on the case of severely developmentally delayed children, and suggest that the interests of parent and child are difficult to separate. In such cases there is a strong argument for the use of substituted judgement by a parent. Although there are coherent conceptions of the limitations of parental rights, these are based on the eventual autonomy of the child, a state that children with severe developmental delay will never achieve. Legal treatments of best interests fail to explicitly take account of such nuances, and are open to accusations of judicial subjectivity. Increased clarity could be gained by setting out the relative weight of medical, parental, and child views of best interests.

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**Illits, Ana S**  
**Toward a coherent account of pediatric decision making.**  

**Abstract:** Within and among societies, there are competing understandings of the status of children, including debates over whether they can bear rights and, if so, which rights they bear and against whom, and their capacity to make decisions and be held responsible and accountable for actions. There also are different understandings of what constitutes a family; what authority parents have over and regarding their children; and what should happen to children who are without parents because of death, desertion, or imprisonment. These and other related debates reflect deep differences in worldviews, in how one understands the legitimate role of the state, in how one come to know the proper way to raise children, and so on. The United Nations Convention on the Rights of the Child purports to reflect international convergence on the rights of children, on how decisions concerning children should be made, and on how children ought to be treated by the state and by their parents. This paper examines whether the Convention's framework for decision making concerning children is an appropriate framework for pediatric bioethics. Questions about how to make health care decisions for children ultimately are questions of who is in authority to make and judge such decisions. Establishing who is in authority, determining whether there are any limits to that authority and, if so, defining those limits should be the focus of efforts to develop and implement a pediatric decision-making framework.

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**Cherry, Mark J**  
**Parental authority and pediatric bioethical decision making.**  

**Abstract:** In this paper, I offer a view beyond that which would narrowly reduce the role of parents in medical decision making to acting as custodians of the best interests of children and toward an account of family authority and family autonomy. As a fundamental social unit, the good of the family is usually appreciated, at least in part, in terms of its ability successfully to instantiate its core moral and cultural understandings as well as to pass on such commitments to future generations. The putative rights of children to expression, information, freedom of thought, conscience, religion, and to freedom of association with others are, in this essay, assessed from the perspective of those conditions necessary for the family to function as a moral community. In so doing, I respond to the move to liberate children from parental authority and to effect the transformation of the family as implied by the United Nations' "Convention on the Rights of the Child" and the pediatric bioethics it supports.

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**Engelhardt, H Tristram Jr.**  
**Beyond the best interests of children: four views of the family and of foundational disagreements regarding pediatric decision making.**  
Abstract: This paper presents four different understandings of the family and their concomitant views of the authority of the family in pediatric medical decision making. These different views are grounded in robustly developed, and conflicting, worldviews supported by disparate basic premises about the nature of morality. The traditional worldviews are often found within religious communities that embrace foundational metaphysical premises at odds with the commitments of the liberal account of the family dominant in the secular culture of the West. These disputes are substantial and ultimately irresolvable by sound rational argument because of the failure to share common foundational premises and rules of evidence. It is in light of these fundamental disagreements that there is a need to evaluate critically the claims and agenda advanced by the Convention on the Rights of the Child.

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Document 19

Stewart, Mary W
Research News: Parental understanding of informed consent.

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Document 20

Gillam, Lynn
Children's bioethics and the zone of parental discretion.
Monash bioethics review 2010 Sep; 20(2): 09.1-3

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Document 21

Chantry, Caroline J; Byrd, Robert S; Sage, Allyson C; Calvert, Emma E
Video versus traditional informed consent for neonatal circumcision.
Acta paediatrica (Oslo, Norway : 1992) 2010 Sep; 99(9): 1418-24
Abstract: To determine if videotapes about newborn circumcision would be superior to traditional physician 'informed consent' discussion for maternal knowledge, satisfaction and perception of provider bias.

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Document 22

Hazen, Rebecca A; Eder, Michelle; Drotar, Dennis; Zyzanski, Steve; Reynolds, Amy E; Reynolds, C Patrick; Kodish, Eric; Noll, Robert B
A feasibility trial of a video intervention to improve informed consent for parents of children with leukemia.
Pediatric blood & cancer 2010 Jul 15; 55(1): 113-8
Abstract: BACKGROUND: Research on parental understanding of informed consent for pediatric randomized clinical trials (RCTs) has highlighted weaknesses in understanding of key aspects of informed consent. The goals of the current study were to assess the feasibility of and parental satisfaction with a video intervention to improve informed consent for pediatric leukemia RCTs and to compare parental question asking during informed consent conferences (ICCs) for parents in the current study with historical control data. PROCEDURE: A 20-min video was produced. Utilizing the principles of anticipatory guidance, it included information delivered by nurses and physicians about leukemia and key aspects of informed consent. Parents were encouraged to be active participants in ICCs. Participants included 12 parents of children newly diagnosed with pediatric leukemia. The video was viewed by local pediatric oncologists prior to utilization with families. RESULTS: Ninety-two percent of parents reported that the video made it easier to understand information that their child's physician later provided; 83% of parents reported that it helped them to think of questions to ask the physician; and 67% of parents indicated that the video made them feel more comfortable with asking questions of the physician. Results of a t-test comparing question asking during ICCs revealed that parents who participated in the intervention asked a higher rate of questions than parents from a historical control sample (t = 1.95, P = 0.05).
DISCUSSION: Our study supports the feasibility and potential efficacy of a brief video intervention employing anticipatory guidance to prepare parents for future discussions about RCTs.

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**Document 23**

Long, Kristin A  
Informed consent in pediatric cancer clinical trials: giving adolescents a voice.  

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**Document 24**

Ott, Mary A; Rosenberger, Joshua G; Fortenberry, J Dennis  
Parental permission and perceived research benefits in adolescent STI research.  
Journal of empirical research on human research ethics : JERHRE 2010 Jun ; 5(2): 57-64

**Abstract:** An understanding of why parents provide consent for adolescent participation in research on sensitive topics can inform and improve the ethical conduct and review of such research. As part of a longitudinal study of sexually transmitted infections (STIs) in lower-income adolescents, we asked 134 parents why they permitted their daughter to participate, analyzing responses using qualitative methods. Over half described participation benefits, providing reasons such as the study being generally good for their daughters, sex education, someone to talk to, and STI testing. Other reasons included positive interactions and familiarity with research and clinical staff, friend or family member participation, and adolescent autonomy in making the decision to participate. If parents perceived their daughter to be "at risk" in some way, such as for STI or pregnancy, they were more likely to cite participation benefits. These data can be used to make such research more sensitive to family and community needs.

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**Document 25**

Dute, Joseph  
European Court of Human Rights. ECHR 2010/10 Case of M.A.K and R.K. v. The United Kingdom, 23 March 2010, no. 45901/05 and 40146/06 (Fourth section).  

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**Document 26**

Strode, Ann; Slack, Catherine; Essack, Zaynab  
Child consent in South African law: implications for researchers, service providers and policy-makers.  
South African medical journal = Suid-Afrikaanse tydskrif vir geneeskunde 2010 Apr ; 100(4): 247-9

**Abstract:** Children under 18 are legal minors who, in South African law, are not fully capable of acting independently without assistance from parents/legal guardians. However, in recognition of the evolving capacity of children, there are exceptional circumstances where the law has granted minors the capacity to act independently. We describe legal norms for child consent to health-related interventions in South Africa, and argue that the South African parliament has taken an inconsistent approach to: the capacity of children to consent; the persons able to consent when children do not have capacity; and restrictions on the autonomy of children or their proxies to consent. In addition, the rationale for the differing age limitations, capacity requirements and public policy restrictions has not been specified. These inconsistencies make it difficult for stakeholders interacting with children to ensure that they act lawfully.

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Macdougall, D Robert

**Rawls and the refusal of medical treatment to children.**
The Journal of medicine and philosophy 2010 Apr; 35(2): 130­53

**Abstract:** That Jehovah's Witnesses cannot refuse life-saving blood transfusions on behalf of their children has acquired the status of virtual "consensus" among bioethicists. However strong the consensus may be on this matter, this article explores whether this view can be plausibly defended on liberal principles by examining it in light of one particularly well worked-out liberal political theory, that of Rawls. It concludes that because of the extremely high priority Rawls attributes to "freedom of conscience," and the implication from the original position that parents must act paternalistically toward their children as their protectors, Jehovah's Witnesses cannot legitimately be barred from making decisions on behalf of their children, even when the consequences of such decisions are serious and irremediable.

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Geisheker, John V

**Where is the voice of the man the child will become?**
The Journal of clinical ethics 2010 Spring; 21(1): 86­8

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Harty­Golder, Barbara

**Custodial issues can interfere with minor child's medical care.**
MLO: medical laboratory observer 2010 Apr ; 42(4): 52

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Bérard, E

**[The child between medical decision and parental wish] = L'enfant entre décision médicale et désir parental.**
Archives de pédiatrie : organe officiel de la Société française de pédiatrie 2010 Feb ; 17 Suppl 1(): S1-2

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Miller, Fiona A.; Hayeems, R.Z.; Carroll, J.C.; Wilson, B.; Little, J.; Allanson, J.; Bytautas, J.P.; Paynter, M.; Christensen, R.; Chaktraborty, P.

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

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Melamed, Yuval; Yaron-Melamed, Lili; Heinik, Jeremia

**Guardianship appointment: current status in Israel.**
The Israel journal of psychiatry and related sciences 2010; 47(4): 260-8

**Abstract:** The appointment of a guardian is an important complex process that significantly infringes upon the individuals liberty and autonomy; however it is a necessary paternalistic intervention when called for. The law does not provide
precise criteria for the appointment of a guardian, though physicians have tried to determine criteria for the initiation of the process. The authors present a review of the various aspects of the assessment of the need for guardianship and the appointment process for guardians for adults in Israel. The medical document that will ultimately determine the need for the appointment of a guardian for an elderly person should be the product of a comprehensive medical, psychiatric and cognitive evaluation and an accurate evaluation of competence.

**Document 33**

Tarini, B.A.; Goldenberg, A.; Singer, D.; Clark, S.J.; Butchart, A.; Davis, M.M.

**Not without my permission: parents' willingness to permit use of newborn screening samples for research.**

Public Health Genomics 2010; 13(3): 125-130

**Abstract:** BACKGROUND: State newborn screening (NBS) programs are considering the storage and use of NBS blood samples for research. However, no systematic assessment of parents' attitudes exists. METHODS: We conducted an Internet-based survey of a nationally representative parent sample. We examined parents' willingness (1) to permit use of their children's NBS samples for research with/without their permission and (2) to allow NBS sample storage. Using bivariate and multinomial logistic regression, we examined the association of parent and child characteristics with parents' willingness to permit NBS sample storage and use for research, respectively. RESULTS: The response rate was 49.5%. If permission is obtained, 76.2% of parents were 'very or somewhat willing' to permit use of the NBS sample for research. If permission is not obtained, only 28.2% of parents were 'very or somewhat willing'. Of parents surveyed, 78% would permit storage of their children's NBS sample. Parents who refused NBS sample storage were also less willing to permit use of the NBS sample for research. CONCLUSIONS: Three-quarters of parents would permit use of their children's NBS samples for research - if their permission is obtained. Parents not in favor of storing NBS samples often opposed the use of NBS samples for research.

**Document 34**

Miller, F.A.; Hayeems, R.Z.; Carroll, J.C.; Wilson, B.; Little, J.; Allanson, J.; Bytautas, J.P.; Paynter, M.; Christensen, R.; Chaktraborty, P.

**Consent for newborn screening: the attitudes of health care providers.**

Public Health Genomics 2010; 13(3): 181-190

**Abstract:** BACKGROUND: As newborn screening (NBS) expands to meet a broader definition of benefit, the scope of parental consent warrants reconsideration. METHODS: We conducted a mixed methods study of health care provider attitudes toward consent for NBS, including a survey (n = 1,615) and semi-structured interviews (n = 36). RESULTS: Consent practices and attitudes varied by provider but the majority supported mandatory screening (63.4%) and only 36.6% supported some form of parental discretion. Few health care providers (18.6%) supported seeking explicit consent for screening condition-by-condition, but a larger minority (39.6%) supported seeking consent for the disclosure of incidentally generated sickle cell carrier results. Qualitative findings illuminate these preferences: respondents who favored consent emphasized its ease while dissenters saw consent as highly complex. CONCLUSION: Few providers supported explicit consent for NBS. Further, those who supported consent viewed it as a simple process. Arguably, these attitudes reflect the public health emergency NBS once was, rather than the public health service it has become. The complexity of NBS panels may have to be aligned with providers' capacity to implement screening appropriately, or providers will need sufficient resources to engage in a more nuanced approach to consent for expanded NBS.

**Document 35**

Fitzsimmons, Emma Graves

**Wisconsin couple sentenced in death of their sick child**

New York Times 2009 October 8; p. A16

[http://www.nytimes.com](http://www.nytimes.com) (link may be outdated)
**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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**Prospective parental consent for autopsy research following sudden unexpected childhood deaths: a successful model.**

Archives of Disease in Childhood 2009 May; 94(5): 354-358

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**When too much is just enough: what do oncologists tell parents?**

Pediatric Blood & Cancer 2009 April; 52(4): 437-438

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**Potential chemotherapy side effects: what do oncologists tell parents?**

Pediatric Blood and Cancer 2009 April; 52(4): 497-502

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**Please don't call my mom: pediatric consent and confidentiality.**

Clinical Pediatrics 2009 April; 48(3): 243-246

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Document 41

Davis, Dena

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

Georgetown users check [Georgetown Journal Finder](http://www.lahey.org/Ethics/) for access to full text

Document 42

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

Georgetown users check [Georgetown Journal Finder](http://www.lahey.org/Ethics/) for access to full text

Document 43

Farrell, Ruth M.

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

Georgetown users check [Georgetown Journal Finder](http://www.lahey.org/Ethics/) for access to full text

Document 44

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

Georgetown users check [Georgetown Journal Finder](http://www.lahey.org/Ethics/) for access to full text

Document 45

Hagger, Lynn

**Children in research**
Call number: [KD3405 .C48 H34 2009](http://www.lahey.org/Ethics/)

Document 46

Hagger, Lynn

**Confidentiality and children**
Call number: [KD3405 .C48 H34 2009](http://www.lahey.org/Ethics/)

Document 47

Hagger, Lynn

**Parental responsibility and children's health care treatment**
**Document 48**

Hagger, Lynn

The law and children's autonomy


Call number: KD3405 .C48 H34 2009

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**Document 49**

Perera, Anthony

Can I decide please? the state of children's consent in the UK.


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**Document 50**

Minor consent laws are imperative for adolescents but accidental breaches in privacy still occur.

School Nurse News 2008 November; 25(5): 7-8

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**Document 51**

King, Cheryl A.; Kramer, Anne C.

Intervention research with youths at elevated risk for suicide: meeting the ethical and regulatory challenges of informed consent and assent.

Suicide and Life-threatening Behavior 2008 October; 38(5): 486-497

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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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analyse the parental consent process in NBS. RESULTS: The parental consent procedures in NBS and the quality of the information provided before obtaining consent vary widely. Because the traditional NBS was incorporated into routine paediatric practices in most clinics/hospitals, the most frequently encountered consent model is "informed dissent" (60.9%) and "no informed/consent" (30.4%); while an "informed consent" model (45.5%) is the frequent model for screening rare metabolic/genetic disorders. CONCLUSIONS: Specific guidelines to regulate the parental consent process for NBS are essential. Further studies should investigate parental responses to NBS, taking these as the basis on which to establish an informed consent model in Taiwan.

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Written parental consent in school-based HIV/AIDS prevention research
American Journal of Public Health 2005 July; 95(7): 1266-1269
Abstract: OBJECTIVES: We examined the process of obtaining "active," written parental consent for a school-based HIV/AIDS prevention project in a South African high school by investigating (1) parental consent form return rates, (2) parents' recall and knowledge of the research, and (3) the extent to which this consent procedure represented parents' wishes about their child's involvement in the research. METHODS: This cross-sectional descriptive study comprised interviews with parents of children in grades eight and nine in a poor, periurban settlement in Cape Town. RESULTS: Within 2 weeks, 94% of 258 parents responded to a letter requesting written consent and of those, 93% consented, but subsequent interviews showed that 65% remembered seeing the consent form. At the end of the interview, 99% consented to their child's participation. CONCLUSIONS: These findings challenge many of the assumptions underlying active written parental consent. However, they should not be used to deny adolescents at high risk of HIV infection the opportunity to participate in prevention trials. Rather, researchers together with the communities in which the research is undertaken need to decide on appropriate informed consent strategies.
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Pace, Christine; Talisuna, Ambrose; Wendler, David; Maiso, Faustin; Wabwire-Mangen, Fred; Bakyaita, Nathan; Okiria, Edith; Garrett-Mayer, Elizabeth S.; Emanuel, Ezekiel; Grady, Christine
Quality of parental consent in Ugandan malaria study
American Journal of Public Health 2005 July; 95(7): 1184-1189
Abstract: OBJECTIVES: We surveyed Ugandan parents who enrolled their children in a randomized pediatric malaria treatment trial to evaluate the parents’ levels of understanding about the treatment trial and the quality of the parents’ consents to allow their children to participate in the study. METHODS: We conducted 347 interviews immediately following enrollment at 4 Ugandan sites. RESULTS: A majority (78%) of the parents, most of whom where mothers (86%) had at most a primary school education. Of the participating mothers, a substantial percentage reported that they remembered being told about the study's purpose (77%), the required number of visits (88%), the risks involved (61%), treatment allocation (84%), and their ability to discontinue their children's participation (64%). In addition, most reported knowing the trial's purpose (80%) and the required number of visits (78%); however, only 18% could name possible side effects from the drugs being administered, and only 19% knew that children would not all be administered identical treatments. Ninety-four percent reported that they made the enrollment decision themselves, but 58% said they felt pressure to participate because of their child's illness, and 15% said they felt some type of pressure to participate from others; 41% reported knowing that they did not have to participate. CONCLUSIONS: The consent Ugandan parents provided to allow their children to participate in the malaria study was of mixed quality. Parents understood many of the study details, but they were not very aware of the risks involved or of randomization. Many parents felt that they could not have refused to participate because their child was sick and they either did not know or did not believe that their child would receive treatment outside of the study. Our results indicate that further debate is needed about informed consent in treatment studies of emergent illnesses in children.

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Incomprehensible consent forms -- child friendly consent forms lead the way [letter]
BMJ: British Medical Journal 2005 June 18; 330(7505): 1450

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Asking adolescents: does a mature minor have a right to participate in health care decisions?
Hastings Women's Law Journal 2005 Summer; 16(2): 221-249

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Beh, Hazel; Diamond, Milton
Ethical concerns related to treating gender noncomformity in childhood and adolescence: lessons from the family court of Australia

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Pretzlaff, Robert K.
Should age be a deciding factor in ethical decision-making?
Abstract: The question of age as a factor in ethical decision-making takes two forms. The first form considers age as a factor at the societal, or policy, level, and the second as a factor in determining the capacity of the individual patient to make decisions regarding their own care. This article satisfies itself with a consideration of only the latter question. The
issue of whether age is contributing factor in medical decision-making is frequently posited when one considers ethically charged instances of medical decision making at the end of life. Few would argue that the person who has the capacity for decision-making should be denied the ability to exercise that facility and so, it is when a person has lost their ability for making those choices that the question of age as a contributing factor in ethical decision making is raised. The question therefore becomes one of capacity more then age, with age as a useful, but inexact, gauge of that capacity. The inexactitude of age as a surrogate of capacity is a contributing factor to the problem posed in this series of articles. Therefore, to define the relative contribution of age to the capacity for ethical decision-making this article will focus not on the loss of that ability, but rather on the factors that define the realization of that faculty. To do this it will be necessary to define how that faculty is to be to be measured and what are the characteristics of an ethical decision that define it apart from other decisions. Since at the beginning of life, if age is the only variable (adjusting for other co-morbid states) then the issue of surrogacy is a temporary one and is unlike the adult where the presumption is that the person is unlikely to regain decision-making capacity as they slip further into their morbid state.

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Issues of patient consent: a study of paediatric high-dependency care
British Journal of Nursing 2005 May 12-25; 14(9): 519-523

*  Document 158
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The right of minors to confidentiality and informed consent [letter and reply]
Journal of Child Neurology 2005 May; 20(5): 460-461

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Ward, Frances R.
Parents and professionals in the NICU: communication within the context of ethical decision making -- an integrative review
Neonatal Network 2005 May-June; 24(3): 25-33

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Dickens, B.M.; Cook, R.J.
Adolescents and consent to treatment
International Journal of Gynecology and Obstetrics 2005 May; 89(2): 179-184

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Hallstrom, Inger; Elander, Gunnel
Decision making in paediatric care: an overview with reference to nursing care
Nursing Ethics 2005 May; 12(3): 223-238
Abstract: The purpose of this overview of published articles on decision making in paediatric care was to identify important aspects of its possible use in clinical practice and to obtain a base for future research. A literature review was undertaken utilizing snowball sampling to identify articles because of the diversity present within the area of decision

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making in paediatric care. The databases PubMed and CINAHL were used. The search was limited to articles published in English during the period 1994–2004. The analysis entailed a series of comparisons across articles, focusing on major areas of enquiry and patterns of results. Various levels of decision making are described because these seem to form a basis for how decisions are made. Concepts found to be of importance for decision making are described under the following headings: competence, the child's best interests, knowledge, values and attitudes, roles and partnership, power, and economy. Further research is suggested.

McKinney, Patricia A.; Jones, Samantha; Parslow, Roger; Davey, Nicola; Darowski, Mark; Chaudhry, Bill; Stack, Charles; Parry, Gareth; Draper, Elizabeth S.
A feasibility study of signed consent for the collection of patient identifiable information for a national paediatric clinical audit database
BMJ: British Medical Journal 2005 April 16; 330(7496): 877-879
Abstract: OBJECTIVES: To investigate the feasibility of obtaining signed consent for submission of patient identifiable data to a national clinical audit database and to identify factors influencing the consent process and its success. DESIGN: Feasibility study. SETTING: Seven paediatric intensive care units in England. PARTICIPANTS: Parents/guardians of patients, or patients aged 12-16 years old, approached consecutively over three months for signed consent for submission of patient identifiable data to the national clinical audit database the Paediatric Intensive Care Audit Network (PICANet). MAIN OUTCOME MEASURES: The numbers and proportions of admissions for which signed consent was given, refused, or not obtained (form not returned or form partially completed but not signed), by age, sex, level of deprivation, ethnicity (South Asian or not), paediatric index of mortality score, length of hospital stay (days in paediatric intensive care). RESULTS: One unit did not start and one did not fully implement the protocol, so analysis excluded these two units. Consent was obtained for 182 of 422 admissions (43%) (range by unit 9% to 84%). Most (101/182; 55%) consents were taken by staff nurses. One refusal (0.2%) was received. Consent rates were significantly better for children who were more severely ill on admission and for hospital stays of six days or more, and significantly poorer for children aged 10-14 years. Long hospital stays and children aged 10-14 years remained significant in a stepwise regression model of the factors that were significant in the univariate model. CONCLUSION: Systematically obtaining individual signed consent for sharing patient identifiable information with an externally located clinical audit database is difficult. Obtaining such consent is unlikely to be successful unless additional resources are specifically allocated to training, staff time, and administrative support.

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Proxy consent in neonatal care – goal-directed or procedure-specific?
Abstract: The prescription of practice guidelines for consent in neonatal care that are appropriate for all interventions faces substantial problems. Current practice varies widely. Consent in neonatal care is compromised by postnatal constraints on information sharing and decision-making. Empirical research shows marked individual and cultural variation in the degree to which parents want to contribute to decision-making on behalf of their infants. Conflict between the parents' wishes and the infant's best interests could arise if consent for a recommended intervention were refused, and parental refusal of consent may have to be overridden. Consent to an appropriate package of care (such as special, intensive or palliative care) may be morally preferable to a universal requirement to seek consent for all individual interventions entailed by that package.

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Consent, competence, and confidentiality
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**A general paediatrician's practice in children's rights**
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**Good practice in consent**
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Jacob, Marie-Andree
**Frail connections: legal and psychiatric knowledge practices in U.S. adjudication over organ donations by children and incompetent adults**

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Freeman, Michael
**Rethinking Gillick**
Ethical issues in pediatrics

Call number: R724 .L59 2005

Ethical and legal aspects of using an identical twin as a skin transplant donor for a severely burned minor


Who knows best?


Capacity and competence in child and adolescent psychiatry


Abstract: Capacity and competence in the field of child and adolescent psychiatry are complex issues, because of the many different influences that are involved in how children and adolescents make treatment decisions within the setting of mental health. This article will examine some of the influences which must be considered, namely: developmental aspects, the paradoxical relationship between the need for autonomy and participation and the capacity of children, family psychiatry, and the duty of care towards children and adolescents. The legal frameworks relevant to consideration of consent and competence will be briefly considered, as well as some studies of children's consent, participation and competence. A case vignette will be used as a focus to consider the complexity of the issue of competence in child and adolescent psychiatry, in the particular mental disorder of anorexia nervosa.

In Nigeria, talking up two drops of vaccine: polio eradication efforts get back on track after hostility to treatment reignited disease

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Abstract: In Spain, any person under the age of 18 is a minor. Generally, minors lack the legal capacity to take legally binding actions because they are deemed incapable of legally binding consent. Spanish civil law recognises, however, that the child, in accordance with the law and being sufficiently mature, may act for himself. It stands, then, that consent, as expressed by the "sufficiently mature" minor, should be legally valid.

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