School of Law

UNIVERSITY OF LEEDS

YOUNG PEOPLE WHO REFUSE LIFE SUSTAINING TREATMENT

A Briefing Paper on Current Law and the Need for Reform

Introduction

This paper is aimed at health policy makers and healthcare professionals working with young people.

The common law (case law that it is accepted as legal) allows parents to override competent decisions to refuse treatment made by under 18 year olds. In 2009 the Department of Health issued guidance which questioned whether this was compatible with the Human Rights Act 1998.[i]

In other countries, human rights developments have led to proposals for law reform. The Law Reform Commission in Ireland proposed a draft Bill in 2011.[ii] Scotland (though this has yet to be tested in a court of law) protects competent young people's rights to consent and refuse treatment from the age of 16.[iii]

In England and Wales, the legal ambiguity is unresolved. This issue adds to an already complicated and inconsistent legal framework in which there are different competency tests for 18 year olds, 16/17 year olds and under 16 year olds. Furthermore, the timing, content and relevance of the test for competence is unclear.

The Medical Practitioners, Adolescents and Informed Consent project 2011-2013

The project sought to explore how legal ambiguity surrounding child consent affects clinicians (and young people and their families), and to debate the potential impact of various proposals for reform of the law on adolescent consent.

The project took place at the School of Law, University of Leeds and was funded by the Nuffield Foundation. The PI (Emma Cave) was guided by a team of project advisors, each an expert in their field, and assisted by a Research Assistant, Dr Zenon Stavrinides. At four workshops legal, ethical and social science experts joined healthcare professionals from a range of specialties. Participants included paediatric surgeons, registrars, nurses and anaesthetists; GPs; psychiatrists and ethics committee members. The specialisms included general paediatrics, oncology, intensive care, psychiatry, adolescent medicine and eating disorders.

Summary

- The law on adolescent treatment refusals lacks coherence and aspects of it may conflict with the Human Rights Act 1998. The court has not considered a treatment refusal case since 2003 and has never considered the human rights implications of current law.
- Where under 16 year olds' refusals of treatment are contrary to their best interests, the law states that doctors may rely on parental consent.
- However the DH has advised that, where young people are competent, this aspect of the law may conflict with their human rights and advised that clinicians do not treat without court authorisation.
- There are procedural and substantive issues which reduce the viability of court authorisation for Trusts.
- On the other hand, the lack of legal guidance may result in clinicians accepting refusals which a court would overrule. This raises potential liability issues.
- A court case would provide guidance on whether treatment can go ahead. Furthermore it might 'test' the law on treatment refusals and judges might modify the law or provide additional guidance to help clinicians work out when a minor is competent and what factors are relevant to determining the patients' best interests.

Structure of Briefing Paper

This paper will focus on the following questions

1. What is the law on adolescent consent?
2. Evolving children's rights
3. Why hasn't there been a court case in 10 years?
4. Why do healthcare professionals need legal clarification?
5. How might judges resolve the legal ambiguities?
6. Conclusions

What is the law on adolescent consent?

There is evidence that healthcare professionals find the law on adolescent consent confusing and incoherent.[iv] This section articulates the legal principles and highlights areas of uncertainty. Consent provides a defence to battery: Whilst in some countries, doctors have the authority to issue life saving treatment to a minor without consent, in England and Wales such powers are limited to emergency situations. Consent provides a justification to what would otherwise be a battery. Depending on the circumstances it can be obtained from the minor, their legal Guardian or the court. Minors (u 18) cannot give a legally valid consent to treatment, subject to the following exceptions:

- 16/17 year olds are assumed competent to consent to medical treatment. (Family Law Reform Act 1969, s. 8; Mental Capacity Act 2005, s. 1).
- Under 16s can consent to medical treatment in their best interests[v] if they are Gillick[vi] competent: ie if the minor has 'sufficient understanding and intelligence to enable him or her to understand fully what is proposed'.

The House of Lords decision in Gillick [1986] established that competent minors could provide the necessary consent to contraceptive advice and treatment. The impact of the case in other areas of medicine was left to judges and doctors to develop.[vii]

Treatment refusals: Minors frequently refuse treatment, but where the treatment is life sustaining, the decision may be challenged either on the basis that it is not competent or because, though competent, the law allows the decision to be overruled:

Competence: Under 16 year olds are assumed not to be competent. The graver the potential outcome is, the higher the standard of proof. In some treatment refusal cases which reached the courts,[viii] the threshold for competence was arguably unachievable.

Authority: Competence does not confer adult status on minors. In the 1990s Court of Appeal cases, Re R and Re W,[ix] Lord Donaldson asserted (though this was not strictly relevant to the outcome of the cases) that where a competent minor refuses to give consent to treatment in his best interests, a parent or the court can do so. This applies even if the minor is 16/17.

Faced with a refusal of treatment, clinicians have a number of choices:

Accept refusal	Persuade
Refusal is in the minor's best interests	Time permitting, minors might change their minds.
Court	**Treat**
Potential arbiter in face of dissention regarding competence / best interests	On basis of parental consent.

Evolving children's rights

There are grounds to challenge current law (which allows parents to veto competent refusals by young people).[x] On the other hand, there are also strong reasons to limit minors' autonomy rights in order to protect their welfare.[xi]

The leading cases on adolescent treatment refusal were heard prior to the enactment of the Human Right Act 1998 (HRA). Since then, the courts have placed increased emphasis on minors' human rights. Competent minors have been recognised as having a right to contribute to or make certain decisions.

Participatory rights: Judges and policy makers seek to comply with the UN Convention on the Rights of the Child (UNCRC), though it is not legally binding. On the basis of Article 12 of the UNCRC, minors (whether competent or not) have a right to participate in decisions made about them.

Limitation of parental powers: The HRA gives further legal effect in the UK to the fundamental rights and freedoms contained in the European Convention on Human Rights. One such right is the Article 8(1) right to respect for private and family life. This is a 'qualified' right in that it need not be upheld where breach is 'necessary' and 'proportionate' according to Article 8(2).

Overruling a competent young person's decision might breach Article 8(1). Arguably it is neither necessary nor proportionate to veto a competent decision in reliance on parental consent.[xii]

Autonomy rights: Minors' views must be given serious consideration corresponding with their maturity and understanding. This does not necessarily mean that the courts would respect competent refusals of treatment, particularly if treatment would sustain life.[xiii] The UNCRC demands a careful balancing of minors' best interests (Article 3) and their evolving capacities to make decisions on their own (Article 12). The balancing exercise is particularly difficult when young people's interpretations of their best interests clash with medical assessments.

Call for a test case: The GMC advises doctors: *'You should seek legal advice if you think treatment is in the best interests of a competent young person who refuses' (0-18 (2007), para 32).* Similarly, the Department of Health 2009 guidance states: *'The courts have, in the past, also found that parents can consent to their competent child being treated even where the child/young person is refusing treatment. However, there is no post-Human Rights Act 1998 authority for this proposition, and it would therefore be prudent to obtain a court declaration or decision if faced with a competent child or young person who is refusing to consent to treatment, to determine whether it is lawful to treat the child.'* [xiv]

Why hasn't there been a court case on adolescent treatment refusals for 10 years?

The fact that the decisions are generally made behind closed doors does not mean that they are made consistently across different treatment settings and different specialties. Nor does it mean that the law is always understood or properly applied. More research is needed to determine how these decisions are made.

The last court case was in 2003. It is unlikely that children have stopped refusing treatment. Indeed the media occasionally report cases where treatment refusals have been respected.[xv] There are procedural and substantive reasons for the lack of court cases:

Procedural:

1. The costs are prohibitive.
2. The court is arguably an inappropriately adversarial forum for resolving this kind of dispute.
3. Sometimes mediation is preferable for families, children and physicians, even if the minor ends up with sub-optimal treatment.

Substantive:

1. The decision is often a practical one where the law plays only a minor part.
2. Professional guidance fills some of the gaps left or created by law.
3. There is a growing reluctance to subject patients (even young ones) to coercive treatment.
4. There is arguably greater respect for competent young people's views than there was 10 years ago.

Why do healthcare professionals need legal clarification?

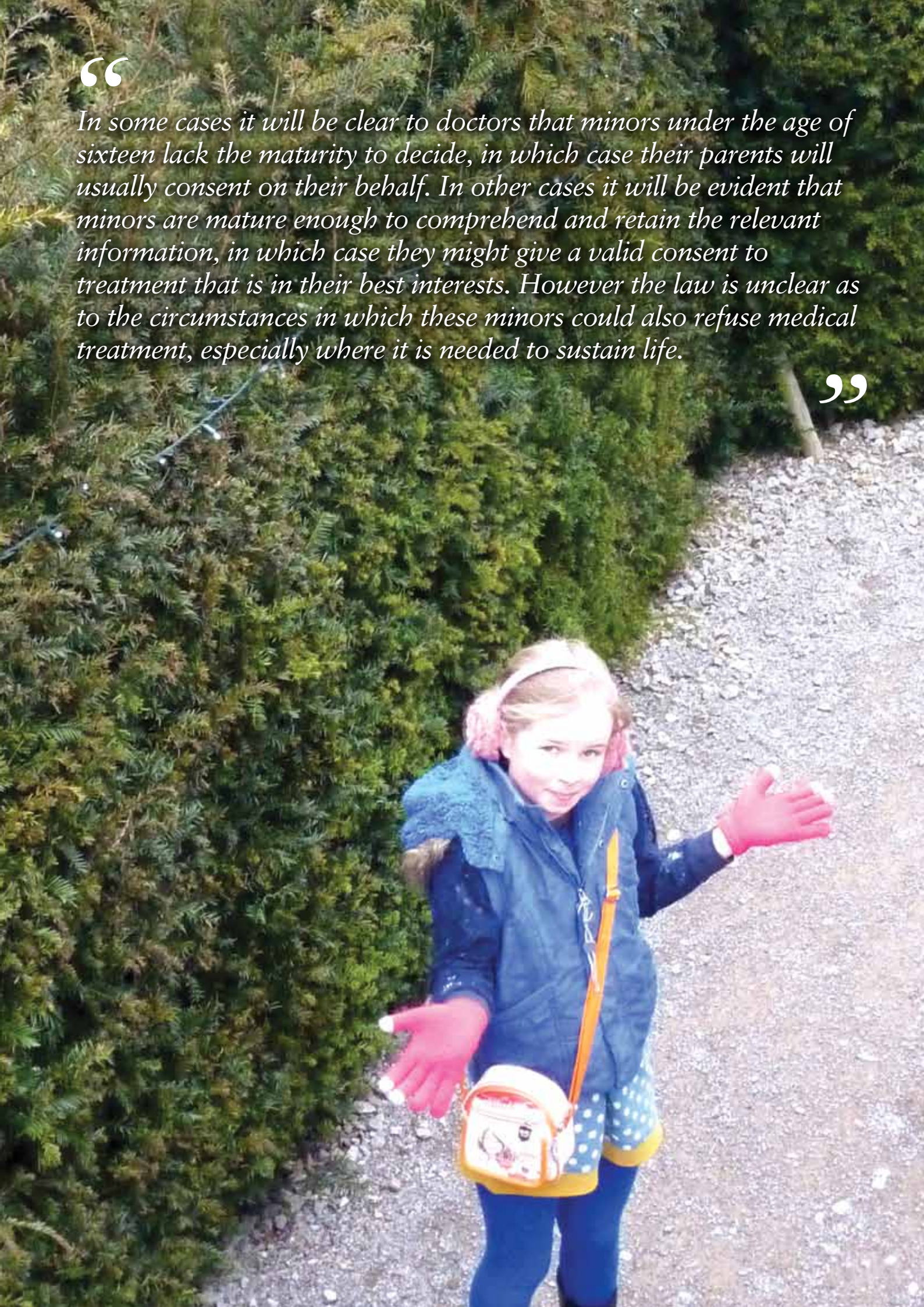
In addition to questions over who can provide the necessary consent to life-sustaining treatment of minors, the current legal position raises the following issues:

1. Doctors are required (where practicable) to facilitate competent decision-making in adults (Mental Capacity Act 2005, s 1(3)). It is unclear if this duty extends to under 16 year olds, or if doctors are simply required to assess competence. Empirical evidence of even young children's abilities[xvi] and recent developments in human rights laws suggest that the same duty should apply to minors, but this duty is not clearly defined in law or professional guidance.[xvii]

Example: A 14 year old is having difficulty understanding the long term consequences of his preference to refuse surgery. He is incompetent so treatment can proceed with parental consent, but how far are doctors required to improve his understanding in order to facilitate a competent consent or refusal?

2. It is unclear how 'competence' is defined; when it should be assessed; and its role in determining whether or not to accept minors' treatment refusals.[xviii]

The GMC 0-18 guidance (para 24) supplements the sparse legal test for competence with the recommendation that part of the adult test for capacity, is also applied to minors. Para 25 differentiates



In some cases it will be clear to doctors that minors under the age of sixteen lack the maturity to decide, in which case their parents will usually consent on their behalf. In other cases it will be evident that minors are mature enough to comprehend and retain the relevant information, in which case they might give a valid consent to treatment that is in their best interests. However the law is unclear as to the circumstances in which these minors could also refuse medical treatment, especially where it is needed to sustain life.

between over 16s (who are presumed to have capacity) and under 16s (who are assumed not to have capacity). Whilst this provides a practical solution to the definitional gap, the adult test was not designed for use in this context and may set the threshold for competence too high.

3. The test for best interests is unclear. The GMC provides useful practical guidance (0-18, para 32) but there is legal ambiguity regarding how far consideration of best interests incorporates minors' views. In a recent Canadian case,[xix] it was held that competent views are especially relevant when determining best interests, but it is unclear how far this is the case in England and Wales.

Example: A 16 year old Jehovah's Witness refuses a life-sustaining blood transfusion. He fully understands and accepts the implications. Might it be said that the high level of competence makes it contrary to his best interests to administer the transfusion?

4. Judges have shown willing to coerce patients to protect their best interests.[xx] Clinicians who accept a minor's refusal of life-sustaining treatment may, in some circumstances, be allowing minors to make decision which a court would not support. There is potential for this to result in a legal challenge.

Example: Doctors respect a 13 year old girl's decision to refuse a lung transplant. A year later she changes her mind but the operation is no longer viable and she is likely to die within a year. The minor and her family seek legal remedy.

How might judges resolve the ambiguities?

If a treatment refusals case were brought before the court, judges would have at least 3 options:

The court might take a narrow view and apply existing law. It could authorise treatment on the basis that the minor lacks competence, thereby avoiding the question of whether a competent decision can be vetoed by a parent or the court.[xxi]

The court may revisit and challenge judicial statements in Re R and Re W. The court might rule that parents cannot veto a competent decision by a minor.[xxii] It might go further still and decide that the court itself lacks the jurisdiction to overrule competent refusals (but this is unlikely given the strong human rights arguments in favour of protecting minors' lives and health).

The court might provide advice for lawyers, families and healthcare professionals on how to assess competence and best interests.[xxiii]

Conclusions

1. More research is needed on how decisions about minors who refuse medical treatment are made at a clinical level.

2. Parents can consent on behalf of a young person who lacks competence. The test for competence is vague and the threshold depends on the likely outcome of the decision.

3. The parental power to overrule a young person's competent decision is subject to legal challenge.

4. The court can provide authority to treat a competent young person in order to protect life (Art 2 HRA) and health (Art 8(2) HRA).

5. A test case is needed, not only as a practical solution when doctors consider it to be in the best interests of young people to receive treatment they refuse, but also to resolve legal ambiguities concerning the tests for competence and best interests.

6. In the mean time, clinicians should be wary of:

   - Using the possibility of court authorisation as leverage (to persuade a young person to agree to treatment) - because this may undermine the young person's autonomy interests.
   - Accepting refusals which the court might overrule - because this may not adequately protect children's welfare. Also this may result in complaints at a later date if the decision adversely affected the young person's quality or longevity of life.
   - Relying too heavily on part of the Mental Capacity Act 2005 definition of capacity to assess the capacity of under 16 year olds. This is only one part of a two part test that was not designed to be used in isolation or in this context. Its use sets a high threshold for competence which might mean that some young people are viewed incompetent to consent, or that different tests are used for consent and refusal.

Further information

Medical Practitioners, Adolescents and Informed Consent project: **http://www.law.leeds.ac.uk/research/projects/medical-practitioners-adolescents-and-informed-consent.php**

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This Briefing Paper summarises arguments developed in the following academic articles:

- Emma Cave, 'Goodbye Gillick? Identifying and Resolving Problems with the Concept of Child Competence' Legal Studies, advance online publication (2013). DOI: 10.1111/lest.12009
- Emma Cave, Adolescent Consent to Medical Treatment. In Heather Montgomery (Ed), Oxford Bibliographies in Childhood Studies. (New York: Oxford University Press, 2013). doi: 10.1093/OBO/9780199791231-0138
- Emma Cave, 'Competence and Authority: Adolescent Treatment Refusals for Physical and Mental Health Conditions' (2013) 8(2) Contemporary Social Science, forthcoming. doi:10.1080/1582041.2012.751502
- Emma Cave, Julie Wallbank, 'Minors' Capacity to Refuse Treatment: A Reply to Gilmore and Herring' (2012) 20(3) Medical Law Review, 423-449. doi: 10.1093/medlaw/fws003
- Emma Cave, 'Maximisation of a Minors' Capacity' (2011) 4 Child and Family Law Quarterly, 429-450.
- Emma Cave, 'Seen but not Heard: Children in Clinical Trials' (2010) 18(1) Medical Law Review, 1-27. doi:10.1093/medlaw fwp024
- Emma Cave 'Adolescent Consent and Confidentiality in the UK' (2009) 16(4) European Journal of Healthcare Law, 309-331. Doi: 10.1163/092902709X12506817652775.

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[i] Department of Health. 2009. Reference Guide to Consent for Examination or Treatment, 2nd ed, Ch 3, para 15

[ii] LRC 103-2011.

[iii] S Elliston, The Best Interests of the Child in Healthcare (Abingdon, New York: Routledge Cavendish, 2007), p 112.

[iv] See for example C.S. Ashteka, A. Hande, E. Stallard and D. Tuthill. 2007. How Much do Junior Staff Know about Common Legal Situations in Paediatrics? Child Care Health Development 35(5); 631-634.

[v] Special rules apply in situations where the treatment may not be in the minor's best interests eg clinical trials, organ donation etc.

[vi] Gillick v West Norfolk Area Health Authority [1986] AC 112.

[vii] See J. Fortin. 2011. The Gillick Decision – Not Just a High-Water Mark. In S. Gilmore, J. Herring, R. Probert (Eds), Landmark Cases in Family Law. Hart.

[viii] Eg Re L (Medical Treatment: Gillick Competency) [1998] 2 FLR 810; Re E (A Minor) (1990) 9 BMLR 1.

[ix] Re R (A Minor) (Wardship: Consent to Medical Treatment) [1992] Fam 11; Re W (A Minor) (Medical Treatment: Court's Jurisdiction) [1993] Fam 64.

[x] R. Taylor. 2007. Reversing the Retreat from Gillick? R (Axon) v Secretary of State for Health. Child and Family Law Quarterly. 19(1), 81-97.

[xi] Eg see Children Act 1989 s 3(1).

[xii] See E. Cave. 2009. Adolescent Consent and Confidentiality in the UK. European Journal of Healthcare Law, 16(4); 309-331.

[xiii] D. Archard, M. Skivenes. 2009. Balancing a Child's Best Interests and a Child's Views. The International Journal of Children's Rights. 17(1), 1-21.

[xiv] Department of Health. 2009. Reference Guide to Consent for Examination or Treatment, 2nd ed, Ch 3, para 15.

[xv] See, for example, E. Grice. 2008. Hannah Jones: "I Have Been in Hospital too Much". The Telegraph. November 12; L. Roberts. 2010. Teenage Jehovah's Witness Refuses Blood Transfusion and Dies. The Telegraph. May 18.

[xvi] P. Alderson. 2007. Competent Children? Minors' Consent to Health Care Treatment and Research. Social Science and Medicine 65; 2272-2283

[xvii] See E. Cave. 2011. Maximising Minors' Capacity. Child and Family Law Quarterly 4; 429-450

[xviii] E. Cave. 2013. Goodbye Gillick? Identifying and Resolving Problems with the Concept of Child Competence. Legal Studies, advance online publication.

[xix] AC v Manitoba (Director of Child and Family Service) 2009 SCC 30.

[xx] See for example A Local Authority v E [2012] EWHC 1639 (COP), involving an adult lacking mental capacity.

[xxi] A. McFarlane. 2011. Mental Capacity: One Standard for All Ages. Family Law 41; 479-558.

[xxii] R. Taylor. 2007. Reversing the Retreat from Gillick? R (Axon) v Secretary of State for Health. Child and Family Law Quarterly. 19(1), 81-97.

[xxiii] As in the Canadian case of AC v Manitoba (Director of Child and Family Service) 2009 SCC 30.

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