

Zenon Stavrinides

## Medical Practitioners, Adolescents and Informed Consent. Final Report

# Emma Cave, School of Law, University of Leeds Zenon Stavrinides, School of Law, University of Leeds April 2013

## Funded by the Nuffield Foundation

This report and related documents are available at <a href="http://www.law.leeds.ac.uk/research/projects/medical-practitioners-adolescents-and-informed-consent.php">http://www.law.leeds.ac.uk/research/projects/medical-practitioners-adolescents-and-informed-consent.php</a>

**Citation:** This report should be cited as follows: E. Cave, Z. Stavrinides. April 2013. *Medical Practitioners, Adolescents and Informed Consent Project Final Report.* University of Leeds.

## Contents

i Acknowledgements	4
ii Executive Summary	5
1. Introduction	7
1.1 Background	7
<u>1.2 Remit</u>	7
1.3 Method	8
1.4 Dialogue with healthcare professionals	10
2. The law in England and Wales	11
2.1 Consent and refusal	11
2.2 What are the legal ambiguities?	16
2.3 Asymmetry between consent and refusal	
<u>3 Human rights developments</u>	20
3.1 The European Convention on Human Rights	21
3.2 The UN Convention on the Rights of the Child	23
3.3 Prioritising best interests	25
3.4 Protecting autonomy interests	28
4. International Comparisons	33
4.1 Scotland	33
4.2 Ireland	35
4.3 Canada	36
5. Reform- Challenging Current Law	40
5.1 Why hasn't there been a test case on adolescent treatment refusals?	40
5.2. How might judges resolve the ambiguities?	41
Appendix. Project Publications	45

## i Acknowledgements

We are indebted to the project advisors and the workshop speakers and participants.

We are grateful for the financial support from the Nuffield Foundation. The Nuffield Foundation is an endowed charitable trust that aims to improve social well-being in the widest sense. It funds research and innovation in education and social policy and also works to build capacity in education, science and social science research. The Nuffield Foundation has funded this project, but the views expressed are those of the authors and not necessarily those of the Foundation. More information is available at www.nuffieldfoundation.org

### ii Executive Summary

The Medical Practitioners, Adolescents and Informed Consent 2011-2013 project set out to clarify the current legal position as to when a young person can consent to and refuse medical treatment, and to suggest ways forward. Desk-based research was complemented by four inter-disciplinary one-day workshops predominated by clinicians but also including legal, ethical and social science experts. The outputs included: a short Briefing Paper aimed at healthcare professionals and policy makers; an annotated international bibliography; and six academic articles published in peer reviewed journals.

We found that refusals of life-sustaining treatment by minors do still occur, but because doctors and family seldom involve lawyers or the media, they rarely reach the public eye. There has not been an application for court-authorised treatment for ten years. More research is needed to determine how frequently minors refuse treatment and variations in practice across different contexts and medical specialties.

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 urging doctors to seek court authorisation before relying on parental consent to treat a competent minor who refuses treatment. This was based on the potential incompatibility of current law with the Human Rights Act 1998.

However, it is apparent that there are practical, legal and ethical reasons why NHS Trusts are slow to bring a court case when a minor refuses treatment. Amongst them is the perception that the courts are inappropriately adversarial for this situation, the fact that court authorisation is costly, and the effect it may have on the relationship between family and healthcare professionals.

Inconsistent and incoherent laws leave clinicians, families and young people uncertain of their respective rights, powers and duties. There may be value in bringing a court case to determine the appropriate outcome when a minor refuses treatment. Without it, clinicians might accept a refusal of treatment which a court would overrule, or apply undue pressure to persuade a minor to agree to treatment. In some circumstances, either position might later be challenged by the minor or family.

The legal uncertainty extends beyond questions of who can authorise medical treatment. It also covers the tests for competence and best interests. A 'test case' would enable the courts to provide additional guidance. The test set down in *Gillick* is vague. It may be that aspects of the Mental Capacity Act 2005 (which applies to over 16 year olds) might be utilised to supplement the common law test. However, this approach does not offer a panacea. When this adult-centred test is applied to minors in conjunction with the requirement that minors bear the burden of providing competence in law, the threshold is raised considerably.

More radical reform might seek to address the problems inherent with the vague *Gillick* competence test, whilst protecting minors' best interests. This could be achieved by extending the presumption of capacity to minors, but developing a new common law test to apply in conjunction with the Mental Capacity Act test in order to identify those who lack capacity on the basis of immaturity or undue influence in order that a decision can be made in their best interests.

## 1. Introduction

#### 1.1 Background

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, in 2009 the Department of Health 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.<sup>1</sup>

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.<sup>2</sup> Scotland protects competent young people's rights to consent and refuse treatment from the age of 16 (though this has yet to be tested in a court of law).<sup>3</sup>

In England and Wales, the legal ambiguity is unresolved. The court has not considered a treatment refusal case since 2003 and has never considered the human rights implications of current law. This issue adds to an already complicated and inconsistent legal framework in which there are different competency tests for over 18 year olds, 16/17 year olds and under 16 year olds. Furthermore, the timing, content and relevance of the test for competence are unclear. The Department of Health, along with other professional bodies such as the General Medical Council,<sup>45</sup> and the British Medical Association offer helpful advice.<sup>6</sup> However, stymied by the law, significant areas of confusion remain.

#### 1.2 Remit

The *Medical Practitioners, Adolescents and Informed Consent* project sought to explore how legal ambiguity surrounding child consent affects clinicians, young people and their families, and to debate the potential impact of various proposals for

<sup>&</sup>lt;sup>1</sup> Department of Health. 2009. *Reference Guide to Consent for Examination or Treatment*, 2nd ed, Ch 3, para 15.

<sup>&</sup>lt;sup>2</sup> LRC 103-2011.

<sup>&</sup>lt;sup>3</sup> S Elliston. 2007. *The Best Interests of the Child in Healthcare,* Abingdon, New York: Routledge Cavendish, p 112.

<sup>&</sup>lt;sup>4</sup> General Medical Council. 2007. *0-18: Guidance for all Doctors*, London: GMC.

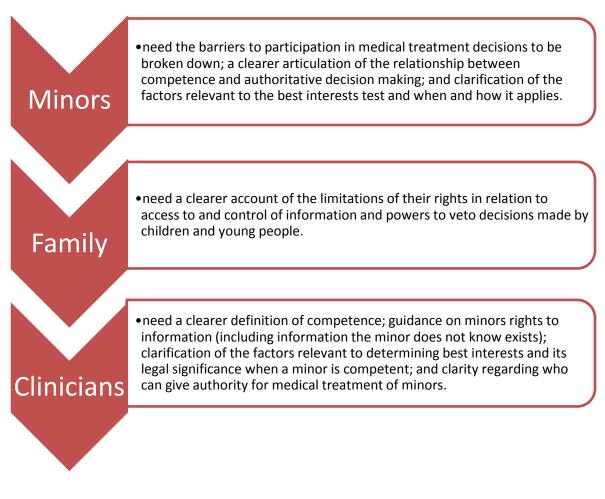
<sup>&</sup>lt;sup>5</sup> Department of Health. 2009. *Reference Guide to Consent for Examination or Treatment.* 

<sup>&</sup>lt;sup>6</sup> BMA. 2007. Consent, Rights and Choices in Health Care for Children and Young People; 2011. Children and Young Person Toolkit.

reform of the law on adolescent consent, taking into account international comparisons.

Ambiguities in the law on child consent are well documented.<sup>7</sup> What has received less attention are their effects in clinical practice. In this project, a series of interdisciplinary workshops focused on the views and experiences of healthcare practitioners with regard to the law on consent and options for reform.

The legal ambiguities affect clinicians, minors and their family:



#### 1.3 Method

The *Medical Practitioners, Adolescents and Informed Consent* project took place at the School of Law, University of Leeds and was funded by the **Nuffield Foundation**. The PI (Dr 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.

<sup>&</sup>lt;sup>7</sup> Summarised in S. Gilmore and J. Herring. 2011. 'No' is the hardest word: consent and children's autonomy *Child and Family Law Quarterly*, 23;3, p. 4.

Desk-based research (incorporating legal, medical, ethical and social science literature) culminated in an annotated international bibliography published with Oxford University Press. This review of legal, medical, ethical and social science literature<sup>8</sup> was complemented by a series of four workshops predominated by clinicians but also attended by participants from multiple disciplines including law, ethics and social science. The health care professionals emanated from a wide range of specialties including general paediatrics, oncology, intensive care, psychiatry, adolescent medicine and eating disorders. Participants included paediatric surgeons, registrars, nurses and anaesthetists; GPs; psychiatrists; and ethics committee members.

The first workshop looked at the role of human rights in understanding informed consent of young people. In recent years the concept of informed consent and its relationship with individual autonomy have been put under intense scrutiny.<sup>9</sup> In relation to *clinical* consent, emphasis on relational autonomy and family may be more relevant than individual autonomy and transferral of responsibility. Having considered the shortcomings of consent as a method of promoting individual interests, in workshop 2 we considered the potential conflicts between the minors' interests in welfare and autonomy. Workshop 3 looked at models from other countries, focusing (after consideration of various options) on statutory and common law reforms in Canada, proposals for a new Bill in Ireland and interpretation of existing statute in Scotland. Finally, we considered 'ways forward' in Workshop 4, highlighting the potential of the law to make things worse by accentuating the chasm between legal and clinical consent and failing to address the ambiguities which are apparent at a practical level.

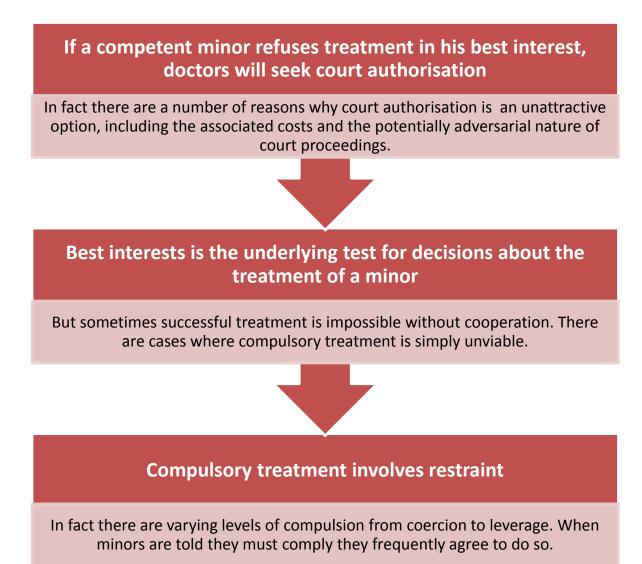
The research resulted in a series of academic papers and a short Briefing Paper aimed at healthcare professionals and policy makers.<sup>10</sup>

 <sup>&</sup>lt;sup>8</sup> E. Cave. Adolescent Consent to Medical Treatment. In H. Montgomery (Ed). 2013. Oxford Bibliographies in Childhood Studies. New York: Oxford University Press, forthcoming.
<sup>9</sup> S. Maclean. 2009. Autonomy, Consent and the Law Routledge-Cavendish; D. Beyleveld and R. Brownsword. 2007. Consent in the Law Oxford: Hart Publishing; A. Maclean. 2009. Autonomy, Informed Consent and Medical Law: A Relational Challenge, CUP.

<sup>&</sup>lt;sup>10</sup> See section 6 'Project Publications'.

#### **1.4 Dialogue with healthcare professionals**

An integral element of the project was dialogue with healthcare professionals who made up at least half the participants at each of the workshops. The workshops challenged a number of common preconceptions:



10

## 2. The law in England and Wales

#### 2.1 Consent and refusal

Medical treatment is rarely, if ever, pleasant and frequently it is unpleasant and painful. In all cases it is expensive to the patient or the NHS. So, if a certain form of treatment is indicated or recommended for a patient, it must be because it is regarded in some sense good for the patient, despite the downside; it is in the patient's best interests to receive it. The restoration, or - failing that - the improvement, of the patient's health constitutes his best interests, and uncontroversially so. However, what is usually the case is not always the case. There are circumstances where doctors may disagree as to which treatment would make the patient better. At other times doctors may agree that a given treatment is recommended, or even that it is imperative, for the good of the patient, but the patient refuses the treatment, because he finds it too drastic (e.g. amputation), or too painful (chemotherapy), or too dangerous (open heart surgery), or against one's religious convictions (as e.g. blood transfusion for many Jehovah's Witnesses). If the patient is a competent adult, the law generally requires that medical practitioners must obtain his informed consent for any treatment they provide to him, and if he refuses the treatment because he judges that it is not 'good' for him, doctors normally have to abide by his decision.

Consent provides a defence to what might otherwise constitute a battery. Other defences are set down in statute – for example if treatment without consent will protect public health<sup>11</sup> or (more controversially<sup>12</sup>) is needed because the patient has a particular mental health condition<sup>13</sup>.

Under the Mental Capacity Act 2005, adults are assumed to have capacity to give consent – an assumption that can be rebutted only where, on the balance of probabilities, the individual is 'unable to make a decision for himself in relation to the

<sup>&</sup>lt;sup>11</sup> Public Health (Control of Disease) Act 1984, section 37 and 38.

<sup>&</sup>lt;sup>12</sup> L. Scott-Moncrieff. (2004) Capacity, Choice and Compulsion. *Journal of Mental Health Law*, Sep. 142.

<sup>&</sup>lt;sup>13</sup> Mental Health Act 1983, s. 83 states: '... consent of a patient shall not be required for any medical treatment given to him for the mental disorder from which he is suffering, not being a form of treatment to which sections 57, 58 or 58A applies, if the treatment if given by or under the direction of the responsible medical officer'.

matter because of an impairment of, or a disturbance in the functioning of, the mind or brain' (s. 2(1)), and lacks the requisite understanding to the extent that the patient is unable to make a decision (s. 3). Where this is the case, the Act sets down ways in which the patient's best interests might be determined.

The Mental Capacity Act applies, in a large part, to 16 and 17 year olds. 16/17 year olds are also assumed to be competent to consent to medical treatment, including any associated procedures such as administering anaesthetic and blood transfusion, according to the Family Law Reform Act 1969, section 8. If either the presumption of capacity or the presumption of competence is rebutted, then others can consent on their behalf to treatment which is in their best interests.

Minors under the age of 16 can consent to treatment which is in their best interests, provided they are *Gillick*<sup>14</sup> 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 v. West Norfolk and Wisbech Area Health Authority*<sup>15</sup> introduced a test<sup>16</sup> according to which 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.<sup>17</sup>

Where a minor refuses treatment recommended by doctors, the situation is complicated by virtue of the fact that the law generally regards minors, in varying degrees depending on their age and level of maturity, as incapable of forming a sound and responsible judgment on where their best interests lie and of finding the means of securing their own protection. The view that minors need special protection by the state is held very widely all over the world. Representatives of world governments met in 1989 under the auspices of UNICEF and adopted the United Nations Convention on the Rights of the Child.<sup>18</sup> The Convention is a legally binding

<sup>&</sup>lt;sup>14</sup> Gillick v. West Norfolk and Wisbech Area Health Authority [1986] AC 112.

<sup>&</sup>lt;sup>15</sup> *Gillick*, ibid..

<sup>&</sup>lt;sup>16</sup> *Gillick*, ibid, 188-189 per Lord Scarman: 'It will be a question of fact whether a child seeking advice has sufficient understanding of what is involved to give a consent valid in law.'

<sup>&</sup>lt;sup>17</sup> 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.

<sup>&</sup>lt;sup>18</sup> Adopted and opened for signature, ratification and accession by General Assembly resolution 44/25 of 20 November 1989.

instrument which obligates state parties to recognise and protect a range of rights for children within their jurisdictions. Article 3(1) states:

In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.

Article 3 places great responsibility on parents and public officials to protect the health and welfare interests of children. The writers of the Convention must have wanted to secure the best conditions possible for minors, but in doing so, they recognised that minors, like adults, have an interest in participating in decisions made about them and even in making relevant decisions for themselves. Doing so can plainly constitute an important aspect of one's best interests. There is empirical evidence that even young children can demonstrate or develop the understanding needed to make medical treatment decisions<sup>19</sup>. Thus, Article 12 states:

1. States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.

2. For this purpose, the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative or an appropriate body, in a manner consistent with the procedural rules of national law.

The law in the UK attempts to accommodate both Articles. The Children Act 1989 (which is broadly concerned with a child's upbringing and the administration of his property) brings the two, potentially conflicting trends, together in the opening section. This Act lays down that in determining any question, "the child's welfare shall be the court's paramount consideration." The same section also says that "a court shall have regard in particular to ... the ascertainable wishes and feelings of the child concerned (considered in the light of his age and understanding)".

<sup>&</sup>lt;sup>19</sup> P. Alderson. 1993. *Children's Consent to Surgery*. Open University Press; P. Alderson. 2000. *Young Children's Rights: Exploring Beliefs, Principles and Practice*. Jessica Kingsley Publishers.

One way this can be achieved is by attaching a high threshold of understanding to decisions which will have a long term impact on the minors' health. The graver the potential outcome, the higher the standard of proof required to demonstrate competence. In some treatment refusal cases which reached the courts,<sup>20</sup> the threshold for competence was arguably unachievable.

Another way to protect the minor's best interests is to limit the authority which is conferred by virtue of a refusal being labelled competent. Lord Donaldson in the Court of Appeal, stated:

[The court has the] right and, in appropriate cases, duty to override the decision of the parents or other guardians. If it can override such consents, as it undoubtedly can, I see no reason why it would not be able, and in an appropriate case, willing, to override decisions by 'Gillick competent' children...<sup>21</sup>

Children, even if competent are still subject to the best interest test. Their competence does not confer on them the authority to make medical treatment decisions which are contrary to their best interests.

Similar reasoning applies to 16/17 year olds. In accordance with Section 8 of the Family Law Reform Act 1969, 16 and 17 year olds are presumed to be capable of consenting to their own treatment. However, if an adolescent in this age range refuses treatment in circumstances that, in all probability, will lead to his death or permanent injury, and an alternative source of valid consent can be found, the treatment can proceed. The leading case is Re W (A Minor) (Medical Treatment: *Court's Jurisdiction*).<sup>22</sup> This case concerned W, a sixteen-year-old young woman suffering from anorexia nervosa, who was in the care of the local authority. The local authority sought leave to move W to a treatment centre where she would be subject to compulsory feeding. Lord Donaldson opined that, whether or not W was competent, her wishes could be overridden if someone with parental responsibility gave consent (in this case, the local authority). Lord Donaldson stated:

<sup>&</sup>lt;sup>20</sup> Eg Re L (Medical Treatment: Gillick Competency) [1998] 2 FLR 810; Re E (A Minor) (1990) 9 BMLR 1. <sup>21</sup> Re R (A Minor) (Wardship: Consent to Medical Treatment) [1992] Fam 11, [25] per Lord Donaldson

MR.

<sup>&</sup>lt;sup>22</sup> Re W (A Minor) (Medical Treatment: Court's Jurisdiction) [1993] Fam 64, [1993] 1 FLR 1.

It will normally be in the best interests of a child of sufficient age and understanding to make an informed decision that the court should respect its integrity as a human being and not lightly override its decision on such a personal matter as medical treatment, all the more so if that treatment is invasive.... Nevertheless, if the court's powers are to be meaningful, there must come a point at which the court, while not disregarding the child's wishes, can override them in the child's own best interests, objectively considered. Clearly such a point will have come if the child is seeking to refuse treatment in circumstances which will in all probability lead to the death of the child or to severe permanent injury.<sup>23</sup>

W's views were more relevant to 'clinical consent' – to the practicalities of providing treatment - than to legal consent. The doctor could get his legal 'flak jacket' from the minor, the court, or the minor's parent.

The views of academic writers and commentators on the matter of adolescent consent and refusal of treatment fall on different points in a spectrum. At one end of the spectrum there are writers whose thinking basically agrees with Lord Donaldson in that they consider a minor as someone who has not yet attained 'the age of reason', and although his wishes should always be heard and considered seriously, when he cannot judge his healthcare needs properly and make the correct decision, he has to be placed under the benevolent protection of his parents, legal guardians or a court of law who can in principle override his wishes in his own best interests.<sup>24</sup> At the opposite end of the spectrum, there is a very different view which sees the child as a full person whose wishes and opinions should carry increasing weight as he grows in age and maturity, and when he is able to *fully understand* the treatment proposed to him he should be recognised as having full rights to autonomy in personal matters, including the right to consent to or refuse this treatment without undue influence from others.<sup>25</sup>

<sup>&</sup>lt;sup>23</sup> [1992] All ER 627,[4].

<sup>&</sup>lt;sup>24</sup> Among such writers are W.G. Brooks Jr., L. Bahar-Posey, L.S. Weathers, W. Pardue.1994. Children's Consent to Treatment. *British Medical Journal* 309:807.

<sup>&</sup>lt;sup>25</sup> See P. Alderson and J. Montgomery. 1996. *Health Care Choices: Making Decisions with Children.* London: Institute for Public Policy Research, Chapter 5 and passim.

#### 2.2 What are the legal ambiguities?

There is evidence that healthcare professionals find the law on adolescent consent confusing and incoherent.<sup>26</sup>

It is apparent from the last section that whilst there is relative clarity on when minors can consent to treatment, the circumstances in which a minor can refuse medical treatment are unclear. Of course, children do refuse treatment all the time, and many of those refusals are respected, whether because coercion would be impracticable (eg where cooperation is essential for successful treatment); or where the benefits of treatment are outweighed by the risks of refusal; or where alternative (and acceptable) treatment is possible. Nonetheless, there remain areas of confusion for clinicians, which flow from *Gillick* and its interpretation in the 1990s 'refusal cases'. These issues are the subject of the outputs listed at the end of this report. In brief, they include the following:

#### a) The test for competence is unclear

The *Gillick* case did not firmly establish at what stage competence should be assessed or what is meant by the malleable phrase 'full understanding'. In addition, there is uncertainty surrounding:

Legal sources for competency test: 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 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.

<u>The level of understanding required</u>: It is probable that a higher level of understanding is required of young people than of adults, but also that the level varies from case to case. Despite dicta to the contrary, the competence test itself is arguably dependent upon outcome as opposed to being purely functional.

<sup>&</sup>lt;sup>26</sup> 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.

<u>Duties to facilitate understanding</u>: 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 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 some of the relevant professional guidelines.

<u>Whether understanding must relate exclusively to the proposed 'treatment'</u>: The focus (in the competency test set down in *Gillick*) on minors' understanding of the proposed treatment has practical application provided patients consent, but is more difficult to apply (at least in clinical practice<sup>27</sup>) when they refuse treatment.<sup>28</sup> Clinicians tend to focus on understanding of the implications of a *decision* rather than the understanding of a *particular treatment* in isolation. For example, the minor's competence might be assessed in relation to his ability to choose between whether to have chemotherapy or radiotherapy, or whether to accept aggressive treatment or move to palliative care. This can be at odds with the legal approach.

#### b) The relevance of competence is uncertain:

Even where minors are deemed to have made competent decisions, those decisions can be vetoed by others who have concurrent powers to consent (in minors' best interests).

It is unclear how the broad principles articulated in the 'refusals cases' should be adapted to take into consideration variation in age, medical condition, illnessexperience, life-experience, and family environment.

Whilst the 'refusals cases' have sanctioned life-sustaining treatment against the minor's will, it is unclear whether the young person must be at risk of 'grave or permanent harm'<sup>29</sup> or if a lesser risk will suffice.

 <sup>&</sup>lt;sup>27</sup> S. Gilmore and J. Herring. 2011. 'No' is the Hardest Word: Consent and Children's Autonomy *Child and Family Law Quarterly* 23;3 convincingly argue that it has value when applied in a court setting to minors who refuse treatment.
<sup>28</sup> E. Cave and J. Wallbank. 2012. Minors' Capacity to Refuse Treatment: A Reply to Gilmore and

<sup>&</sup>lt;sup>28</sup> E. Cave and J. Wallbank. 2012. Minors' Capacity to Refuse Treatment: A Reply to Gilmore and Herring' *Medical Law Review* 20(3); 423.

<sup>&</sup>lt;sup>29</sup> Department of Health. 2009. *Reference Guide to Consent for Examination or Treatment*, para 8.1.

#### c) 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,<sup>30</sup> 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.

#### d) Confidentiality

The ambiguities surrounding the definition of competence and the authority it confers on minors with respect to their ability to refuse consent also has implications for their right to confidentiality. In *Axon*<sup>31</sup> the rights of competent children to confidentiality were outlined, but Silber J stressed that the purpose of this is to protect welfare. If competent refusals can be overridden by parents to protect minors' welfare, then so too might their confidentiality rights. Minors usually make decisions with their parents but sometimes request that doctors respect their confidentiality. The privacy right protected by virtue of Article 8(1) of the European Convention on Human Rights is qualified by virtue of Article 8(2) which includes protection of health. But any breach of Article 8(1) must be proportional and necessary, so a balancing exercise is required. The more urgent or necessary the treatment, the more likely it is that parental consent would be required and with it (should the minor request that parents are not informed) a justifiable breach of confidentiality.<sup>32</sup>

#### 2.3 Asymmetry between consent and refusal of treatment

At the heart of the matter are two types of asymmetry which have emerged between consent and refusal.

- between the levels of understanding required to consent and refuse treatment.
- between the authority conferred on the minor by virtue of making a competent consent or refusal.

<sup>&</sup>lt;sup>30</sup> AC v Manitoba (Director of Child and Family Service) 2009 SCC 30.

<sup>&</sup>lt;sup>31</sup> R (Axon) v Secretary of State for Health [2006] QB 539.

<sup>&</sup>lt;sup>32</sup> J. Loughrey. 2012. The Adolescent's Legal Rights to Privacy and Confidentiality. Medical Practitioners, Adolescents and Informed Consent, Workshop 2.

If the standard of competence varies according to risk, and the risk of refusal is much greater than the risk of consenting, then arguably it is logical to distinguish between the two outcomes in law.<sup>33</sup> There is already asymmetry between a parent's powers to consent to and refuse treatment on behalf of an incompetent minor - they can consent to treatment in the best interests of the child but the court can override their refusal. This results, in part at least, from the view that treatment will not be offered unless it is in the child's best interests.<sup>34</sup> Refusal may be contrary to the minor's best interests in which case it is arguably subject to override until young people are considered old or mature enough to take responsibility for defining their own best interests.

On the other hand, this makes the overly simplistic assumption that consent is good and refusal is bad. The converse may also be true. Refusal of treatment when treatment would be futile or would merely postpone inevitable death for a short time and with painful consequences, may be the option which corresponds most appropriately with an objective assessment of the child's best interests.

Critiques of the asymmetry which flows from the decisions in Re R and Re W have been made by many commentators, among them Taylor,<sup>35</sup> Hall<sup>36</sup> and Fortin.<sup>37</sup> The asymmetry results in the unusual situation in which greater protection is given to the positive autonomy right (to consent) than to the negative autonomy right (to refuse).

Judges have shown willing to coerce patients to protect their best interests.<sup>38</sup> 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. Consider the following example:

<sup>&</sup>lt;sup>33</sup> N. Manson. 2011. The Asymmetry of Consent and Refusal. Medical Practitioners, Adolescents and Informed Consent Project. Workshop 1.

<sup>&</sup>lt;sup>34</sup> Ibid.

<sup>&</sup>lt;sup>35</sup> R. Taylor. 2007. Reversing the Retreat from Gillick? R (Axon) v Secretary of State for Health. *Child* and Family Law Quarterly 19(1);81.

<sup>&</sup>lt;sup>36</sup> A. Hall, [2006] Children's Rights, Parents' Wishes and the State: The Medical Treatment of Children Fam Law 317.

<sup>&</sup>lt;sup>37</sup> J. Fortin. 2006. Children's Rights – Substance or Spin? *Family Law* 36; 757.

<sup>&</sup>lt;sup>38</sup> For example, see A Local Authority v E [2012] EWHC 1639 (COP), involving an adult lacking mental capacity.

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.

There is a chance that the much awaited test case will come from a Trust seeking advice on whether or not to treat a minor who withholds consent. In light of the continued reluctance to make such an application and thereby give the courts the opportunity to clarify the law, it is also possible that a case might emanate from a minor or family member who challenges a previous decision by clinicians to respect a minor's refusal. The minor might regret their earlier reticence and argue that they should have been compelled to accept the treatment in their best interests.

## 3. Human rights developments

The most recent case on treatment refusals was reported in 2003.<sup>39</sup> In Re P and previous cases, the human rights of the young person were not considered. Since that time, however, there have been two significant human rights developments. First, the law on informed consent has developed to take greater account of human rights,<sup>40</sup> and second, there has been greater articulation of children's rights.

The result was that, nearly 20 years after Re W, criticism of the case on the basis that it may not give due deference to minors' participation rights (broadly emanating from Article 12 of the UN Convention on the Rights of the Child) and autonomy rights (broadly emanating from Article 8 of the European Convention on Human Rights),<sup>41</sup> resulted in the Department of Health advising that, contrary to dicta in Re R and Re W, doctors should not rely on parental consent to veto a competent refusal by a minor and should instead seek court authorisation if treatment is in the minor's best interests.42

The apparent conflict between a minor's wishes and opinions and his best interests as determined by others - which can result in the authorised treatment - has attracted the interests of lawyers, specialists in children's studies, social workers,

<sup>&</sup>lt;sup>39</sup> Re P (Medical Treatment: Best Interests) [2003] EWHC 2327 (Fam).

<sup>&</sup>lt;sup>40</sup> Chester v Afshar [2004] UKHL 41, [24], per Lord Steyn.

<sup>&</sup>lt;sup>41</sup> See, Re Roddy (A Child) (Identification: Restriction on Publication) [2003] EWHC 2927 (Fam); Mabon v Mabon [2005] EWCA Civ 634; and R (Axon) v Secretary of State for Health [2006] EWHC 37 (Admin).

Department of Health. 2009. Reference Guide to Consent for Examination or Treatment, para 15

ethicists and other scholars. The accumulated scholarly literature is rich and it contains a considerable variety of positions.<sup>43</sup> The landscape is evolving.

There are grounds upon which to challenge current law (which allows parents to veto competent refusals by young people).<sup>44</sup> On the other hand, there are also strong reasons to limit minors' autonomy rights in order to protect their welfare.<sup>45</sup>

#### **3.1 European Convention on Human Rights**

The leading cases on adolescent treatment refusal were heard prior to the enactment of the Human Right Act 1998 (HRA). The Act (broadly speaking) incorporates into UK law the Articles of the European Convention on Human Rights 1950. It does not specifically refer to children, but to all people, including children. Amongst the relevant articles are Article 8 - a qualified right, protecting private and family life (including infringements of integrity); Article 9 - also qualified, protecting religious freedoms; Article 5 protecting against restraint; and Article 3 which protects from inhuman and degrading treatment.

Compulsory treatment has potential to breach Articles 3 and 5. However, compulsion comes in many forms. It is a contextual concept. Those subject to compulsory treatment might require restraint and coercion in order to deliver the relevant treatment. On the other hand, some patients will comply with the compulsory treatment and make choices within the boundaries set by doctors or the court. Compulsory treatment can degrade and demean, but it can also bring certainty to a situation where choices are, in reality, severely constrained. In some situations, it might even be viewed by the patient and their family (either at the time or with hindsight) as supportive.<sup>46</sup> Conversely, seemingly consensual treatment might be the subject of choice limitation by doctors or of persuasion or leverage ('Sign here or I will seek court authorisation to treatment you because treatment is in your best interests').

<sup>&</sup>lt;sup>43</sup> See Michael Freeman (ed.). 2006. *Children's Health and Children's Rights*, Martinus Nijhoff Publishers.

<sup>&</sup>lt;sup>44</sup> R. Taylor. 2007. Reversing the Retreat from Gillick? R (Axon) v Secretary of State for Health. *Child* and *Family Law Quarterly*. 19(1); 81.

<sup>&</sup>lt;sup>45</sup> Eg see Children Act 1989 s 3(1).

<sup>&</sup>lt;sup>46</sup> A. Stewart. 2012. Approaches to Treatment Decision Making in Adolescent Mental Health. Medical Practitioners, Adolescents and Informed Consent Project, Workshop 3.

Since the HRA came into force, 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. In Re Roddy<sup>47</sup> - a case on freedom of information - for example, Munby J recognised the relevance of competent minors' views. In Axon,<sup>48</sup> minors rights to confidentiality and to consent to treatment were recognised. Parliament has mirrored these concerns. For example, s. 43 of the Mental Health Act 2007 places limitations on the rights of parents and the clinical team to override the competent decision of a young person refusing to be admitted to hospital. In 2012, following recommendations by the independent Children and Young People's Health Outcomes Forum, the NHS Constitution was revised to so as to be applicable to children, young people and their families. This approach reflects jurisprudence in the European Court of Human Rights. In YF v Turkey<sup>49</sup>, for example, protections against compulsory medical treatment were recognised - even if the patient is a minor.

Professional guidance encourages the clinical team to support a relational autonomy approach whereby decisions are taken within the family setting.<sup>50</sup> However, it is possible following R (Axon) v Secretary of State for Health<sup>51</sup> that the parental power to veto a competent child's consent may be subjected to legal challenge. The decision in Axon turned upon an application of Article 8 of the Human Rights Act 1998, taking into consideration European jurisprudence: in particular Article 12 of the UN Convention on the Rights of the Child 1989 and the European Court of Human Rights jurisprudence on Article 8 of the European Convention. Silber J., contended that parental rights to veto medical treatment under Article 8(1) cease when the child is 'Gillick competent' to make his own decisions.

On the other hand the court has a strong duty to protect minors. Article 8(1) is qualified by Article 8(2) where it is necessary and proportionate to protect health, and

<sup>&</sup>lt;sup>47</sup> Re Roddy (a child)(identification: restriction on publication) [2003] EWHC 2927 (Fam) [2004] 2 FLR 949

<sup>&</sup>lt;sup>48</sup> [2006] EWHC 37 (Admin). <sup>49</sup> (2004) 39 EHRR 34.

<sup>&</sup>lt;sup>50</sup> Department of Health. 2009. *Reference Guide to Consent for Examination or Treatment,* para 9.

<sup>&</sup>lt;sup>51</sup> [2006] EWHC 37 (Admin).

by the Article 2 right to life.<sup>52</sup> The result of this balancing exercise is that the parental veto of competent decisions is subject to challenge, but the court's powers of veto are more readily justifiable.

Some clinicians view the Department of Health's advice that court authorisation is needed to justify treatment against the wishes of a competent child as a suggestion that competent decisions should be respected. This is compounded by the NHS Constitution (as amended March 2012) which has a section on 'respect, consent and confidentiality' which states: there is a 'right to accept and refuse treatment that is offered to you'. The Handbook (at p 42) explains:

For children who are unable to consent to or refuse treatment because they lack sufficient understanding (i.e. they are not 'Gillick competent') parents may consent or refuse treatment where this would be in the child's best interests. Again in some difficult cases the courts will be asked to determine what is in a child's best interests.

The implication is that those who *are* competent have the right to accept and refuse treatment. In fact, given the opportunity, the court might contest the minor's competence or overrule a competent decision if it is clearly in the minor's best interests to do so. Court authorisation of medical treatment in the best interests of the child remains very much a relevant option.

#### **3.2 UN Convention on the Rights of the Child (UNCRC)**

The UNCRC, which is not legally binding, recognises that in addition to the protections children receive by virtue of their relationship with adults, they also have their own intrinsic rights.

The UNCRC supports children's participatory rights (the right of a child 'who is capable of forming his or her own views ... to express those views freely ...' Article 12 UNCRC<sup>53</sup>). Participation can be an affirmation, but it is important to recognise that

<sup>&</sup>lt;sup>52</sup> J. Fortin. 2011. Adolescent Autonomy and Human Rights – The Developing Law in a Health Context. Medical Practitioners, Adolescents and Informed Consent Project, Workshop 1.

<sup>&</sup>lt;sup>53</sup> Article 12(1): States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.

in some contexts it can also be a burden.<sup>54</sup> Respecting children's rights to participate requires a careful consideration of the individual needs of the minor and his / her family.

There are degrees of participation. Roger Hart describes a 'ladder of participation', with manipulation and tokenism at the bottom, graduating to more meaningful roles and culminating in shared decision making at the top of the ladder. The ability of a child to participate is very much dependent on context. The medical context will determine the minor's familiarity with the medical setting and their illness. Any disabilities or perceived vulnerabilities they or members of their family have will also be relevant. The family context will determine the input of family members to the decision making process. The socio-economic context informs minors' identity and their approach to participation.<sup>55</sup>

There remain significant barriers to participation of children in the consent process. In addition to the legal barriers (such as the prevalence of the best interests test as indicated in the sections above) there are also practical barriers including inaccessible language, parental attitudes and clinicians' lack of time, training or resources.56

In addition to participatory rights, children also have autonomy rights (children's views should be '... given due weight in accordance with ... age and maturity' (Article 12). On the other hand, it also recognises their need and right to protection (encompassing a right to 'primary consideration' of children's 'best interests' (Article 3<sup>57</sup>) and a 'right to life' (Article 6)). One challenge is to accommodate Articles 3 and

<sup>&</sup>lt;sup>54</sup> E. Clavering. 2012. Locating Spaces of Connection and Disconnection between Child and Adult: Reflections from Ethnographic Research. Medical Practitioners, Adolescents and Informed Consent Project. Workshop 4. <sup>55</sup> J. McLaughlin. 2012. Reflections on consenting processes in social research with young people.

Medical Practitioners, Adolescents and Informed Consent Project. Workshop 4.

<sup>&</sup>lt;sup>56</sup> M. Donnelly. 2012. Barriers to Participation: The Scope of Participation Rights in the ECHR and the CRC. Adolescents and Informed Consent Project. Workshop 3.

Article 3(1): In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.

12 within a rights-based framework.<sup>58</sup> As we shall see in the next sections, Eekelaar has shown that the two Articles are not incompatible.<sup>59</sup>

The debate surrounding the reconciliation of Articles 3 and 12 can be divided into two sub-debates. The first concerns best interests. The law recognises that, in relation to children, they should be prioritised, but can they be objectively defined and if so, how relevant are the minors' views? The second concerns autonomy. How is it manifested and what version of autonomy requires what type of legal recognition and protection?

#### **3.3 Prioritising best interests – the changing landscape**

The position taken in *Re R* and *Re W* 'Bolamises'<sup>60</sup> the decision on child competence. That is, it puts the decision into the hands of doctors. As Brazier and Miola recognise:

The 'reasonable doctor' determines whether or not to override the adolescent's refusal of treatment, regardless of whether or not the young person is *Gillick* competent. ... [The refusals cases] grant the power to decide disputes about the treatment of a minor to the medical profession.<sup>61</sup>

This reduces the relevance of human rights. <sup>62</sup> The decision in *Bolitho*<sup>63</sup> ushered in a new era of reduced judicial deference to doctors. This has had an effect on the application of the best interests test. An enlarged conception of a young patient's best interests has been embraced, which includes physical, intellectual and emotional health, and other elements that have to be assessed in the context of the minor's relations with family and friends. On this view, any treatment recommended by doctors and refused by a minor or his parents will need to be evaluated in terms of a wide range of considerations, such as the nature of the young patient's

 <sup>&</sup>lt;sup>58</sup> J. Fortin. 2006. Accommodating Children's Rights in a Post-Human Rights Act Era. *Modern Law Review* 69; 299
<sup>59</sup> J. Eekelaar. 1994. 'The Interests of the Child and the Child's Wishes: The Role of Dynamic Self-

<sup>&</sup>lt;sup>59</sup> J. Eekelaar. 1994. 'The Interests of the Child and the Child's Wishes: The Role of Dynamic Self-Determinism *International Journal of Law and the Family* 8;42.

<sup>&</sup>lt;sup>60</sup> Bolam v Friern Hospital Management Committee [1957] 1 WLR 582.

<sup>&</sup>lt;sup>61</sup> M. Brazier and J. Miola. 2000. 'Bye-bye Bolam: A Medical Litigation Revolution? *Medical Law Review* 8;85, p 94.

<sup>&</sup>lt;sup>62</sup> Ibid., p 95.

<sup>&</sup>lt;sup>63</sup> Bolitho v City and Hackney Health Authority [1997] 4 All ER 771.

condition, his maturity and sophistication and the stability of his beliefs and wishes, the risks and anticipated benefits of the treatment and others.

One effect of the potential legal challenge to the acceptability of doctors accepting parental consent when a competent minor refuses treatment, is that it makes them reliant on the courts (where mediation fails) to adjudicate disputes about competence and best interests. In the next section, we will see that the most recent decision in the Commonwealth - the 2009 decision of the Canadian Supreme Court in *AC v Manitoba (Director of Child and Family Service)*<sup>64</sup> empowers the court to determine best interests of competent minors by incorporating within the test the minor's competent view as a relevant factor. If the courts in England and Wales followed a similar route, they would retain their inherent jurisdiction to overrule competent decisions whilst respecting children's participatory and autonomy rights by recognising the *relevance* of the minor's view.

In AC, Binnie J listed some of the factors relevant to a determination of best interests. They included

What is the nature, purpose and utility of the recommended medical treatment? What are the risks and benefits?

Does the [minor] demonstrate the intellectual capacity and sophistication to understand the information relevant to making the decision and to appreciate the potential consequences?

Is there reason to believe that the [minor's] views are stable and a true reflection of his or her core values and beliefs?

What is the potential impact of the [minor's] lifestyle, family relationships and broader social affiliations on his or her ability to exercise independent judgment?

Are there any existing emotional or psychiatric vulnerabilities?

Does the [minor's] illness or condition impact on his or her decision-making ability?

<sup>&</sup>lt;sup>64</sup> 2009 SCC 30.

Is there any relevant information from adults who know the [minor], like teachers or doctors?

The list is not intended to be exhaustive. Its inherent adaptability can be seen as both a strength and weakness. Hall and Edgar are critical of the legal conception of best interests as an objective concept.<sup>65</sup> Furthermore, they deny that a court is always or even often in a good position to decide what is in the patient's best interests. Lyons takes a similar line, arguing that an examination of case law reveals the subjective and value-laden nature of the test.<sup>66</sup> Courts must make decisions in contested cases, but there is no reason to hold that a judge is in the best position to divine the best interests of a critically ill child.

In a same vein, Baines attacks the assumption that there are objective tests for determining a person's best interests.<sup>67</sup> It is not always possible to separate the interests of individuals within an intimate family. Parents have a very strong interest in the well-being of their child. For most parents, that their child or children should do well is among the most important of the parents' interests. The child's interests are irretrievably intertwined not only with that of the parents, but also other family members.<sup>68</sup>

Bridgeman replies that that there will always be desperately difficult cases presenting complex aspects and needs. The best interests principle offers the scope to allow an approach to the treatment of a child which is specific to the facts of the case, sensitive to the context, and focused on the rights and needs of the child as a separate individual, were the decision will have to take account of the views of all those involved in the treatment, including parents and other family, doctors, nurses and community health teams, deliberating together.<sup>69</sup>

The continued legal authority of Lord Donaldson's comments that parents or the court can veto a competent refusal reveals resistance to change in relation to

<sup>&</sup>lt;sup>65</sup> 2008. Best Interest: A Philosophical Critique. *Health Care Analysis* Sep;16(3):197.

<sup>&</sup>lt;sup>66</sup> B. Lyons. 2010. Children, Best Interests and the Courts: A Response to Bridgeman. *Clinical Ethics* 5(4); 188.

<sup>&</sup>lt;sup>67</sup> P. Baines. 2008. Death and Best Interests. *Clinical Ethics* 3;171. For response see J. Bridgeman. 2009. A Response to Death and Best Interests. *Clinical Ethics*, 4;15.

<sup>&</sup>lt;sup>68</sup> P. Baines. 2010. Death and Best Interests: A Response to the Legal Challenge. *Clinical Ethics* 5(4);195.

<sup>&</sup>lt;sup>69</sup> J. Bridgeman. 2010. Editorial: Critically III Children and Best Interests. *Clinical Ethics* 5(4);184.

adolescent consent. Arguably, deference to minors' human rights demands a closer relationship between capacity to decide and authority to decide. It is to this debate that we now turn.

#### **3.4 Protecting autonomy interests**

In their highly influential textbook *Principles of Biomedical Ethics*,<sup>70</sup> Beauchamp and Childress argued that 'informed consent' have two entrenched meanings. In the first sense,

[I]nformed consent is analysable in terms of autonomous choice by patients and subjects [of medical experiments]: an informed consent is an autonomous authorization of a medical intervention or involvement in research by individual persons. This first sense of informed consent requires that a patient or a subject ... must actively authorize the proposal in the act of consent."71

In the second sense:

[I]nformed consent is analysable in terms of the social rules of informed *consent* in those institutional context in which it is necessary to obtain legally valid consent from potential patients or subjects before proceeding with therapeutic procedures or research. Informed consents are not always autonomous acts in those settings and are not necessarily even meaningful authorisations. This second sense of consent may be understood in terms of institutional rules of consent, because informed consent here refers to the institutionally or legally effective authorization from a patient or a subject. An authorization is effective if obtained through procedures that satisfy the rules that government specific institutional practices of consent.<sup>72</sup>

Consent in the first sense operates not merely as a legal defence to battery, but also protects the autonomy interests of the patient. The law takes a particular approach to authorisation which does not inevitably mirror an individual's current or potential autonomy. The various tests for capacity and competence are legal tools designed to increase certainty and practicality rather than conduct exact measurements of

<sup>&</sup>lt;sup>70</sup> 1989. Oxford University Press, 3<sup>rd</sup> edition.

<sup>&</sup>lt;sup>71</sup> Ibid., 76. <sup>72</sup> Ibid., 77.

autonomy. Competence brings rewards of self-determination and potential detriments in terms of responsibility. Empowerment and support are essential to ensure that minors' decisions are truly competent rather than simply aligned with the views of others.

The extent to which autonomy interests are relevant to the minor's best interests and the priority they have over other interests depends in part on what we mean by autonomy. As Hope, Savulescu and Henrick<sup>73</sup> point out, in modern medicine freedom from unwanted interference – which amounts to respect for patient autonomy – is protected by the law relating to consent. However, the definition of autonomy is contested. The authors propose three aspects of autonomy, each of which admits of several distinctions:

*To be autonomous one must make evaluations.* The ideal of the autonomous person is the person who forms desires for how her life is to go (life plans) and can act on those desires.

*Evaluations should be rational*, in the sense that decisions should be informed with a proper understanding of the relevant facts and should be consistent with a person's life plans.

*Desires higher in the hierarchy should be respected.* A person may have a simultaneous conflict in desires. For example, he may desire alcohol and desire not to have alcohol as his life plan is to be free from addiction. The later desire is higher and should be respected to the exclusion of the former desire.<sup>74</sup>

Eekelaar argues that basic and developmental interests might justifiably be prioritised over autonomy interests.<sup>75</sup> Coggon differentiates between different types of autonomy interest. Current-desire autonomy might be sacrificed in order to protect best-desire autonomy (long term interests) and even ideal-desire autonomy (defined by objective standard of values). Eekelaar's model of dynamic self-determinism

<sup>&</sup>lt;sup>73</sup> 2007. *Medical Ethics and Law: The Core Curriculum*. Churchill Livingstone, 2<sup>nd</sup> edition.

<sup>&</sup>lt;sup>74</sup> Ibid, p 34.

<sup>&</sup>lt;sup>75</sup> J. Eekelaar. 1986. The Emergence of Children's Rights. *Oxford Journal of Legal Studies*. 6(2);161.

focuses on the minor's evolving capacity to make rational choices.<sup>76</sup> Archard and Skivenes demonstrate that a minor's view is a relevant factor when contemplating his best interests, even if it is not necessarily determinative.<sup>77</sup>

Problems in linking autonomy and competence are compounded by variation in the way in which different illnesses can impact on minors' competence. A 14 year old with a chronic condition may have greater maturity, insight and understanding of a proposed treatment than an 18 year old with a similar, but acute condition. Some conditions make it particularly difficult to assess competence. Patients with eating disorders, for example, may be ambivalent about or resistant to treatment.<sup>78</sup> Their competence might fluctuate and the illness itself might affect capacity.<sup>79</sup> To give another example, treating patients with Chronic Fatigue Syndrome / Myalgic Encephalomyelitis is particularly challenging due to an absence of evidence on the efficacy of different treatment regimes.<sup>80</sup>

In law, the relationship between autonomy and competence is complicated by virtue of different legal tests which give patients who refuse treatment varying levels of authority.<sup>81</sup> A minor might be overruled in his best interests; adults generally have the authority to refuse medical treatment which others consider to be in their best interests, provided they have the requisite mental capacity; mental health patients (under certain circumstances) may be subjected to treatment even if they have capacity. In addition, variations in the conception of childhood and adulthood affect a patient's ability to make treatment decisions. 16/17 year olds are defined in the Mental Health Act 2007 as 'young people' rather than 'children' or 'adults'. 16/17 year olds can consent to treatment under the Family Law Reform Act s. 8, but cannot necessarily withhold consent.<sup>82</sup> They are assumed to have capacity under the Mental

Capacity. Medical Practitioners, Adolescents and Informed Consent Project, Workshop 1.

<sup>&</sup>lt;sup>76</sup> J. Eekelaar. 1994. The Interests of the Child and the Child's Wishes: The Role of Dynamic Self-Determinism. *International Journal of Law and the Family*. 8; 42.

 <sup>&</sup>lt;sup>77</sup> 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.
<sup>78</sup> J. Tan. 2011. Anorexia Nervosa, Decision Making Styles and Coercion. Medical Practitioners,

<sup>&</sup>lt;sup>78</sup> J. Tan. 2011. Anorexia Nervosa, Decision Making Styles and Coercion. Medical Practitioners, Adolescents and Informed Consent Project, Workshop 1. <sup>70</sup>

<sup>&</sup>lt;sup>79</sup> A. Stewart. 2012. Approaches to Treatment Decision Making in Adolescent Mental Health. Medical Practitioners, Adolescents and Informed Consent Project, Workshop 3.

 <sup>&</sup>lt;sup>80</sup> V. Larcher. 2012. CFS/ME How [far] does the Law Accommodate the Bio-Psychosocial Approach to Management? Medical Practitioners, Adolescents and Informed Consent Project, Workshop 3.
<sup>81</sup> M. Paul. 2011. Young People in Different Health Contexts: Decision Making, Consent and

<sup>&</sup>lt;sup>82</sup> Re W (A Minor) (Medical Treatment: Court's Jurisdiction) [1993] Fam 64, [1993] 1 FLR 1.

Capacity Act 2005, but cannot make end of life treatment decisions like their 18 year old counterparts and the Deprivation of Liberty Safeguards will not apply until they are 18.<sup>83</sup>

These tests reflect uncertainty about abilities of children to understand and take responsibility for their decisions. Children are physiologically different to adults. They undergo cognitive and hormonal changes in adolescence which may affect their decision-making ability.<sup>84</sup> Furthermore, children may be more impulsive, more dependent on joint decision making, their views may be less stable. Yet adults potentially suffer from these characteristics too.

For doctors, the ability of minors to make or contribute to a treatment decision concerns not only *whether* minors can decide, but also *how* they will decide (eg how much input is needed to develop understanding), *who* they want involved in the decision making process) and *why* they make a particular decision (is a refusal based on deeply held views, whim, fear etc). In addition to assessing competence, doctors set the range of choices and advise on the different possibilities. The legal tests for competence / capacity belie a much more individualised process at the clinical level.

As we have seen, recognition of children's rights leads us to question the dissociation of competence and authority to refuse treatment.<sup>85</sup> It also had an effect on the consent process itself. Despite the continued relevance of Re R and Re W in law, the rights-based approach has started to filter down into clinical guidelines on child consent. Consent is no longer viewed as an event, but a process; there is a clearer duty incumbent on doctors to inform and involve children (even if they cannot consent) - their views and decisions command respect. There are practical as well as human rights benefits in this approach – treatment is far more likely to be effective

<sup>&</sup>lt;sup>83</sup> E. Cave. 2013. Competence and Authority: Adolescent Treatment Refusals for Physical and Mental Health Conditions. *Contemporary Social Science*, 8(2) forthcoming.

<sup>&</sup>lt;sup>84</sup> A. Stewart. 2012. Approaches to treatment decision making in adolescent mental health. Medical Practitioners, Adolescents and Informed Consent. Workshop 3.

<sup>&</sup>lt;sup>85</sup> E. Cave. 2013. Goodbye Gillick? Identifying and Resolving Problems with the Concept of Child Competence. *Legal Studies*, advance online publication.

if children understand it and agree to it.<sup>86</sup> That this approach is at odds with existing case law limits its effectiveness and creates incoherence and inconsistency.

<sup>&</sup>lt;sup>86</sup> P. Alderson. 2011. Young People, Consent and Rights. Medical Practitioners, Adolescents and Informed Consent, Workshop 1.

## 4. International comparisons

In light of human rights developments, the definition of *Gillick* competence and its subsequent interpretation in the 1990s 'refusals' cases raises the possibility of a legal challenge. The ambiguities pose a number of dilemmas for clinicians, minors and their families, which will be considered in more detail in the next section. In this section, comparisons with other countries will be considered. One of the project outputs was an international annotated bibliography<sup>87</sup> which considers the different positions and relevant sources of information on them. In the course of the project, we focused on three very different practical solutions to the dilemmas outlined in the previous sections of this report. Each was presented in workshops by experts in the field and their comparative merits debated. We discussed whether there were lessons which might be learned and applied in a test case (or alternative route to reform) in England and Wales.

Scotland probably (there has yet to be a test case) protects minors right to consent and refuse treatment from the age of 16; Ireland has proposed a Bill limiting children's rights to refuse life sustaining medical treatment; Ontario has enacted legislation assuming capacity for all; and the most recent Commonwealth court decision, in the Supreme Court of Canada, has upheld the court's jurisdiction to overrule a competent refusal of treatment.

#### 4.1 Scotland

In Scotland, the age of majority is 16, and the right to consent to or refuse treatment appears to apply from that age. Section 1 of the Age of Legal Capacity (Scotland) Act 1991 states:

a person of or over the age of 16 years shall have legal capacity to enter into any transaction.

<sup>&</sup>lt;sup>87</sup> E. Cave. 2013. Adolescent Consent to Medical Treatment. In H. Montgomery (Ed) *Oxford Bibliographies in Childhood Studies*. New York: Oxford University Press, forthcoming. In addition, see Irish Law Reform Commission LRC 103-2011 which lists a range of international approaches to adolescent consent.

This includes giving consent (s. 9). The Children (Scotland) Act 1995 sets out parental responsibilities and powers, but these refer to 'children', a term which incorporates those under the age of 16 (s. 2(7)).

For under 16 year olds, s. 2(4) of the Age of Legal Capacity (Scotland) Act 1991 states:

A person under the age of sixteen shall have legal capacity to consent on his own behalf to any surgical, medical or dental treatment where, *in the opinion of a qualified medical practitioner attending him, he is capable of understanding the nature and possible consequences of the procedure or treatment* [emphasis added].

This provision, on a straightforward reading, secures a minor's autonomy rights in cases of both consent to and refusal of treatment. Best interests, it seems, are irrelevant.<sup>88</sup>

In the case of *Houston<sup>89</sup>* Sherriff McGowan commented that:

... it seems to me illogical that, on the one hand, a person under the age of 16 should be granted the power to decide upon medical treatment for himself while, on the other hand, his parents have the right to override his decision. I am inclined to the view that the minor's decision is paramount and cannot be overridden. The 1991 Act itself does not provide any mechanism for resolving a dispute between a minor and guardian but it seems to me that logic demands that the minor's decision is paramount.<sup>90</sup>

However, a lot hangs on whether doctors attending a minor who is in danger of dying or suffering irreparable harm are willing to accept that he really does understand and appreciate that by refusing a timely low-risk operation – say, removal of the appendix – the inflammation can cause rapture of the appendix which in turn may cause death. By adopting high standards of competence and functional autonomy, doctors in Scotland (as indeed in England and Wales) can overrule a minor's wishes.

 <sup>&</sup>lt;sup>88</sup> Scottish Law Commission Report 110, para 3.77. S. Elliston. 2012. Choosing and Refusing: A Scottish perspective. Medical Practitioners, Adolescents and Informed Consent, Workshop 2.
<sup>89</sup> Houston (Applicant) 1996 SCLR 943.

<sup>&</sup>lt;sup>90</sup> Ibid., 945.

#### 4.2 Ireland

In the Irish Republic the Law Reform Commission has sought to combine measures to strengthen the definition of competence with a clearer articulation of the circumstances in which the best interests test is relevant. In 2011 the Commission presented its report entitled 'Children and the Law: Medical Treatment'<sup>91</sup> together with a draft Bill proposing stand alone legislation.<sup>92</sup> The Commission originally proposed that the Irish Republic should establish a three-tiered system which combined the criteria of age and capacity. The main idea was as follows:

Between 16 and 18: There is presumption of capacity and competence to give and refuse consent to treatment.

Between 14 and 16 years: there is no presumption of competence, but a functional approach is adopted to establish whether the child is possessed of the required competence to decide on his treatment. Competence is assessed by a medical practitioner on the basis of the child's understanding and appreciation of relevant information. Specifically, the practitioner must establish (a) whether the child has sufficient maturity to understand the information relevant to making the specific decision and to appreciate its potential consequences; (b) whether his or her views are stable and reflect his or her values and beliefs; (c) the nature, purpose and utility of the treatment; (d) the risks and benefits involved in the treatment; and (e) any other specific welfare, protection or public health considerations. In case a minor who is deemed competent refuses life-sustaining treatment, the High Court should have powers to authorize the intervention.

Between 12-14 years: Doctors are required to adopt a functional approach, but they must consult with the child's parents and take their views into account.

After consultation, the Commission's three-tiered approach gave way to a simplified test which differentiates between over 16s and those under that age. This new test is similar to the English *Gillick* decision, but it contains rather more detail. Reflecting

<sup>&</sup>lt;sup>91</sup> LRC 103-2011.

<sup>&</sup>lt;sup>92</sup> Draft Health (Children and Consent to Health Care Treatment) Bill 2011.

the necessary application of the test in both judicial and clinical settings, it links the test of maturity and understanding to the specific decision rather than treatment as such. The draft Bill makes provision for a Code of Practice to provide detailed context-specific support.<sup>93</sup> The level of detail provided in relation to the timing and definition of competence is worthy of note. This is intended to guide clinicians and create a unified approach to child consent in court and practice. Further, the Commission attempted to clarify when a competent decision is subject to veto on welfare grounds. Its recommendation was that 16 and 17 year olds were presumed competent to consent to and refuse treatment but that the High Court might veto the minor's competent decision to refuse life-sustaining treatment.<sup>94</sup> The advantage is that this would create situations where the courts' veto of competent decisions is clearly inappropriate. Not that this proposal eliminates all ambiguity, given that that the idea of life-sustaining treatment might be narrowly applied to cases where refusal will lead in a short space of time to death, or widely to an treatment designed to sustain life.<sup>95</sup>

Children under 16 can consent and refuse where they have the requisite capacity,<sup>96</sup> subject to 'welfare, protection and public health considerations ...'.<sup>97</sup> The overall effect would be a clearer test for competence. Grounded in statute, there would be enhanced delivery and enforceability. A single statute governing young people's health care has distinct advantages over the numerous disparate tests for competence.<sup>98</sup> It also has potential to clarify the roles and responsibilities of parents, minors and doctors.

#### 4.3 Canada

Canada's system of rules regulating the extent and limits of children's and adolescents' consent and refusal to treatment bears interesting comparisons with

<sup>&</sup>lt;sup>93</sup> Draft Health (Children and Consent to Health Care Treatment) Bill 2011, s. 12.

<sup>&</sup>lt;sup>94</sup> LRC 103-2011, para 4.07.

<sup>&</sup>lt;sup>95</sup> E. Cave. 2012. A Comparison of 3 Models on Capacity and Best Interests of 16/17 year olds: England & Wales, Scotland and Ireland (reform proposals). Medical Practitioners, Adolescent and Informed Consent Project. Workshop 3.

<sup>&</sup>lt;sup>96</sup> LRC 103-2011, para 4.09.

<sup>&</sup>lt;sup>97</sup> LRC 103-2011, para 4.10.

<sup>&</sup>lt;sup>98</sup> M. Donnelly. 2012. Delivering a Workable Framework for Adolescent Decision-Making: The Role of Legislation and Codes of Practice. Medical Practitioners, Adolescents and Informed Consent, Workshop 3.

corresponding legal provisions in England and Wales, Scotland and Ireland. This is to be expected, given that the foundations of Canada's system of law derive for the most part from the English common law tradition (the main exception being private law in Quebec which follows the French civil law tradition).

The decision in England and Wales to allow 16 and 17 year olds to consent to treatment in the same way as adults, and the subsequent case of *Gillick* allowing minors under 16 to consent where competent, led to proposals for similar reform in the Uniform Law Conference in 1975. A spate of legislation resulted. Many provinces followed the approach taken in England and Wales rather than the approach favoured in the USA, where greater variety resulted from states each developing rules in response to different illnesses or classes of child (eg emancipated minors).<sup>99</sup>

Ontario stands out for its libertarian approach to consent. The Health Care Consent Act 1996 states that any capable person of whatever age can make medical treatment decisions. If they lack capacity the court or a guardian can consent on their behalf but must comply with their wishes (where known). Guidance is provided by the College of Physicians and Surgeons of Ontario.<sup>100</sup> Unlike the Mental Capacity Act 2005, the test in Ontario is purely functional. This has the advantage of one standard for all, but the disadvantage that the test is easier to manipulate - which arguably leaves adults under-protected.

There is a considerable variety in the responses of the provinces and territories of Canada with respect to treatment refusals. In 2009 the Supreme Court of Canada put to the test the constitutionality of Manitoba's prioritisation of the minors' best interests over his autonomy rights. In *AC v Manitoba (Director of Child and Family Service)*<sup>101</sup> it was held that the court's veto of a competent treatment refusal to protect the best interests of a minor was constitutional. Justice Abella who delivered the main judgment took the view that:

<sup>&</sup>lt;sup>99</sup> See comparison of various measures in D.C. Day. 2007. The Capable Minor's Healthcare: Who Decides? *Canadian Bar Review.* 86(3), 379.

<sup>&</sup>lt;sup>100</sup> Consent to Medical Treatment 2001 (updated 2005). And see R. Geist, S. Opler. 2010. A Guide for Health Care Practitioners in the Assessment of Young People's Capacity to Consent to Treatment. *Clinical Pediatrics* 49(9); 834.

<sup>&</sup>lt;sup>101</sup> 2009 SCC 30.

There comes a time when it is in the child's best interests to exercise autonomy, whatever consequences the exercise of that autonomy might result in; her best interests are the exercise of autonomy. When the young person's best interests are interpreted in a way that sufficiently respects his or her capacity for mature, independent judgment in a particular medical decision-making context, the constitutionality of the legislation is preserved. Properly construed to take an adolescent's maturity into account, the statutory scheme strikes a constitutional balance between what the law has consistently seen as an individual's fundamental right to autonomous decision making in connection with his or her body, and the law's equally persistent attempts to protect vulnerable children from harm.

Thus, the test for best interests incorporates within it the autonomy rights and interests of the minor.

Giving the dissenting opinion, Justice Binnie said that:

Forced medical procedures must be one of the most egregious violations of a person's physical and psychological integrity. The state's interest in judicial control over the medical treatment of "immature" minors ceases to exist where a "mature" minor under 16 demonstrates the lack of need for any such overriding state control. In the present case, three psychiatrists and the judge at first instance accepted that C had capacity... Whether judges, doctors and hospital authorities agree or disagree with C's objection, the decision belongs to her, as the *[Canada's] Charter [of Fundamental Rights and Freedoms]* is not just about the freedom to make the wise and correct choice; it also gives her the individual autonomy and the religious freedom to refuse forced medical treatment, even where her life or death hangs in the balance, regardless of what the judge thinks is in her best interest.<sup>102</sup>

This decision represents a development in judicial thinking about adolescent patients' rights which may not leave unaffected courts in the UK and Ireland in the

<sup>&</sup>lt;sup>102</sup> 2009 SCC 30, at [87].

wake of the Human Rights Act 1998, and more especially Article 8.<sup>103</sup> By incorporating the idea of autonomy in the best interests test, the court is enabled to set the autonomy interests of adolescent patients side by side with their physical welfare interests.<sup>104</sup> On the other hand, arguably this does little more than swap medical paternalism for judicial paternalism.<sup>105</sup>

<sup>&</sup>lt;sup>103</sup> Article 8 of the Human Rights Act 1998 states: "(1) Everyone has the right for his private and family life, his home and his correspondence. (2) There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others."

 <sup>&</sup>lt;sup>104</sup> E. Cave. 2011. Maximisation of a Minors' Capacity. *Child and Family Law Quarterly*, 4;429.
<sup>105</sup> B. Lyons. 2012. Is it in the Child's Best Interests to be Incompetent?' Medical Practitioners, Adolescents and Informed Consent, Workshop 2.

### 5. Reform - Challenging current law

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

We have seen that the Department of Health<sup>106</sup> has called for doctors to seek court authorisation before relying on parental consent when a competent minor refuses treatment. Academics have subjected the 'refusals cases' to criticism on a number of grounds. And yet there has not been a test case.

The last court case was in 2003.<sup>107</sup> It is unlikely that children have stopped refusing treatment. Indeed there have been two media reports if cases where treatment refusals have been respected.<sup>108</sup>

- 1. In 2008 Hannah Jones initially withheld her consent to a heart transplant. Her parents supported her decision. In 2010 she consented to a heart transplant.
- In 2010 the media reported that Joshua McAuley, a Jehovah's Witness had died in hospital as a result of a road traffic accident, having refused to consent to a blood transfusion.

The fact that clinical decisions are generally made in a private forum 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.

There may be very valid practical reasons why it was not viable to pursue court authorisation of treatment in these cases.<sup>109</sup> That notwithstanding, the lack of court cases since 2003 is remarkable. During the course of the project we explored legal, ethical and practical reasons for the lack of court cases. In summary these include:

#### Procedural issues:

<sup>&</sup>lt;sup>106</sup> Department of Health. 2009. *Reference Guide to Consent for Examination or Treatment*, 2<sup>nd</sup> ed, Ch 3, para 15. <sup>107</sup> Po P (Modical Treatment: Part Interacts) [2002] EWHC 2227 (Eam.) See G. Douglas, [2004]

 <sup>&</sup>lt;sup>107</sup> Re P (Medical Treatment: Best Interests) [2003] EWHC 2327 (Fam.). See G. Douglas. [2004], Case Report – Medical Treatment Family Law 716.
<sup>108</sup> See, for example, E. Grice. 2008. Hannah Jones: "I Have Been in Hospital too Much". The

 <sup>&</sup>lt;sup>108</sup> 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.
<sup>109</sup> See commentary in E. Cave. 2011. Maximisation of a Minors' Capacity *Child and Family Law*

<sup>&</sup>lt;sup>109</sup> See commentary in E. Cave. 2011. Maximisation of a Minors' Capacity *Child and Family Law Quarterly*, 4;429 arguing that there were very practical reasons why Hannah Jones's refusal was respected.



#### Substantive issues:



#### 5.2 How might judges resolve the ambiguities?<sup>110</sup>

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.<sup>111</sup>

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.<sup>112</sup> It might go further still and decide that the court should no longer have the jurisdiction

<sup>&</sup>lt;sup>110</sup> This section is based on arguments put forward in E. Cave. 2013. Goodbye Gillick: Identifying and Resolving Problems with the Concept of Child Competence. *Legal Studies*, advance online publication.

publication. <sup>111</sup> A. McFarlane. 2011. Mental Capacity: One Standard for All Ages. *Family Law* 41; 479.

<sup>&</sup>lt;sup>112</sup> R. Taylor. 2007. Reversing the Retreat from Gillick? R (Axon) v Secretary of State for Health. *Child* and Family Law Quarterly. 19(1); 81.

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.<sup>113</sup>

A potential misconception that human rights developments require clinicians to accept competent refusals of treatment (compounded by the NHS Constitution's implication that only incompetent decisions can be vetoed), has two implications:

- On one hand it can lead to manipulation of the competence test so as to label a minor's decision incompetent in order that parents can provide the necessary consent for treatment considered by healthcare professionals to be in the minor's best interests.
- On the other hand, it might lead to decisions being respected which a court would overrule.

In either case there is potential to breach the human rights of the minor and potential for litigation.

Unfortunately, this misconception, combined with other factors which dissuade Trusts from involving the court (outlined above), make a test case in the near future unlikely. Yet, in the absence of legislative proposals, such as those in Ireland, a test case is the most likely source of legal clarification on a range of issues – from the relevance of competence when a minor refuses treatment, to the tests for competence and best interests – which medical practitioners, adolescents and their families require.

The DH 2009 guidance makes it unlikely that doctors will rely on parental consent to overrule a minor's *competent* decision. Instead, doctors might judge the minor's decision to be incompetent and rely on parental consent. Court authorisation is most likely in a case where parents support a minor's decision to refuse life sustaining treatment contrary to the advice of healthcare professionals, or where clinicians

<sup>&</sup>lt;sup>113</sup> As in the Canadian case of AC v Manitoba (Director of Child and Family Service) 2009 SCC 30.

judge the minor's refusal to be competent but parents disagree and want the court to authorise treatment.

If a case reached the courts it is unlikely that the court would abandon its inherent jurisdiction to overrule a competent decision in order to uphold the minor's autonomy rights. We have seen that a human rights analysis supports the retention of this jurisdiction to protect the best interests of minors. It is possible that greater recognition would be given to the competent minor's views by adopting the reasoning in AC v Manitoba (Director of Child and Family Service), where it was held that the competent view is one of a number of relevant factors when determining best interests.

Greater credence might be placed on the minor's competence by applying aspects of the Mental Capacity Act 2005 (MCA) to determine whether or not the minor has capacity to make a decision. The test would not be used in the same way as it is applied to adult, for this would mean assuming capacity and rebutting that assumption only where the patient is both functionally incompetent and also has an 'impairment of, or a disturbance in the functioning of, the mind or brain ... (section 2(1)). This would set the bar too low –most adolescents would be considered to have capacity if this test were applied.

Only part of the MCA test would apply to minors – namely the functional test set down in section 3 whereby the person is unable to decide 'on the basis that he cannot understand, retain, use or communicate his decision.' Chico and Hagger have argued that a failure to apply the MCA to minors was a 'missed opportunity'.<sup>114</sup> Sir Andrew McFarlane, suggests that the MCA scheme for evaluating capacity could be applied to 'otherwise Gillick competent [minors]... in place of the blunter instruments of 'age', 'intelligence' and 'understanding"<sup>115</sup>. This, he argues, would result in 'a move from paternalistic and protectionist approach to a rights based evaluation of each child as an individual against the context of the facts in a particular case'.<sup>116</sup> But this would not, as the title of his article suggests, constitute

<sup>&</sup>lt;sup>114</sup> V. Chico and L. Hagger. 2011. The Mental Capacity Act 2005 and Mature Minors: A Missed Opportunity? Journal of Social Welfare and Family Law 33(2);157.

A. McFarlane. [2011]. Mental Capacity: One Standard for All Ages' Fam Law 479, p 484-485. Lord Justice McFarlane is a Lord Justice of Appeal. <sup>116</sup> Ibid, p 484.

'one standard for all ages'. The fact that only one part of the two-part MCA test would apply would mean that the threshold for competence would be set very high. This is problematic because it either perpetuates the different thresholds for consent and refusal (which we have seen can be problematic) or raises the threshold for consent (which would mean that fewer minors would be considered Gillick competent to consent to treatment).<sup>117</sup>

A more radical alternative would be to apply the MCA to minors in its entirety. If a common law test, which enables the assumption of capacity to be rebutted, were developed alongside the statutory test (in the same way that a test has been developed for adults who have MCA capacity but lack functional capacity due to the undue influence of another<sup>118</sup>), there would truly be one standard for all. Minors' best interests would be protected through the rigorous test for capacity rather than application of the best interests test. A competent choice (to consent or refuse) would give the minor authority to make the choice.

 <sup>&</sup>lt;sup>117</sup> S. Gilmore and J. Herring. 2011. 'No' is the Hardest Word: Consent and Children's Autonomy. *Child and Family Law Quarterly* 23;3, p 12.
<sup>118</sup> DL v A Local Authority [2012] EWCA Civ 253.

### **Appendix: Project publications**

This final section outlines the project outputs:

Zenon Stavrinides, '<u>Adolescent Patients' Consent and Refusal to Medical Treatment: an Ethical</u> <u>Quandary in English Law</u>' (2013) Issue 8 *Humanicus* downloadable from http://www.humanicus.org/en-us/issues.html.

Emma Cave, '<u>Goodbye Gillick? Identifying and Resolving Problems with the Concept of Child</u> <u>Competence</u>' Legal Studies, advance online publication (2013). DOI: 10.1111/lest.12009

Emma Cave, <u>Adolescent Consent to Medical Treatment</u>. In Heather Montgomery (Ed), Oxford Bibliographies in Childhood Studies. (New York: Oxford University Press, 2013). Doi (forthcoming in 2013) 10.1093/OBO/9780199791231-0138

Emma Cave, '<u>Competence and Authority: Adolescent Treatment Refusals for Physical and</u> <u>Mental Health Conditions</u>' (2013) 8(2) Contemporary Social Science, forthcoming. doi:10.1080/21582041.2012.751502

Emma Cave, Julie Wallbank, <u>'Minors' Capacity to Refuse Treatment: A Reply to Gilmore and</u> <u>Herring'</u> (2012) 20(3) Medical Law Review, 423-449. doi: 10.1093/medlaw/fws003

Emma Cave, '<u>Maximisation of a Minors' Capacity'</u> (2011) 4 Child and Family Law Quarterly, 429-450.

Note: To access the 5 articles with 'DOI's', paste the DOI into the text box at <u>http://dx.doi.org/</u>. The browser will take you to a Web page (URL) associated with that DOI name.

#### Zenon Stavrinides, 'Adolescent Patients' Consent and Refusal to Medical Treatment: an Ethical Quandary in English Law' (2013) Issue 8 Humanicus, downloadable from http://www.humanicus.org/en-us/issues.html.

A moral and legal quandary appears to arise from the combination of two intuitively convincing ethical-legal principles for the medical treatment of minors, especially adolescent patients, which have a prominent place in the law of England Wales. First that the young patients' wishes and autonomous decisions should be respected and carried out, and second that their wishes should be overridden when they are deemed by a court of law to be harmful to their own best interests. This article argues that the two principles are not necessarily antagonistic when a young patient's wishes are based on his settled beliefs and an adequate maturity of understanding which form core elements of his personality and sense of self-worth. In extreme cases a minor may be in danger of death or serious harm if his refusal of clinically indicated treatment is finally accepted and carried out. In such

circumstances the imposition of a court-authorised intervention may be ethically justified. But the two principles operate in a precarious balance which varies with the circumstances of the case.

# Emma Cave, 'Goodbye Gillick? Identifying and Resolving Problems with the Concept of Child Competence' (2013) Legal Studies, advance online publication. DOI: 10.1111/lest.12009

The landmark decision of *Gillick v West Norfolk Area Health Authority* was a victory for advocates of adolescent autonomy. It established a test by which the court could measure children's competence with a view to them authorising medical treatment. However, application of the test by clinicians reveals a number of ambiguities which are compounded by subsequent interpretation of *Gillick* in the law courts. What must be understood by minors in order for them to be deemed competent? At what point in the consent process should competence be assessed? Does competence confer on minors the authority to refuse as well as to accept medical treatment? These are questions which vex clinicians, minors and their families. Growing numbers of commentators favour application of parts of the Mental Capacity Act 2005 to minors. In this article, the limitations of this approach are exposed and more radical reform is proposed.

#### 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

This definitive 6,500 word international bibliography was accepted for publication in July 2012.

#### Emma Cave, 'Competence and Authority: Adolescent Treatment Refusals for Physical and Mental Health Conditions' (2013) 8(2) Contemporary Social Science, forthcoming. doi:10.1080/21582041.2012.751502

This paper explores the relationship between competence and authority in relation to medical treatment refusals. Comparing provisions directed at adults and young people, she explores the options before the court if a test case is brought before the court to determine the extent of the minor's autonomy rights to be involved in or make medical treatment decisions at common law. At present, the common law rights of competent adults and minors stand in stark contrast. Adults can refuse life

saving treatment against the advice of doctors, but minors (even if they pass the legal test for competence) cannot do so if a parent or the court provides the necessary consent in the child's 'best interests'. Since the matter was last tested in court, children's rights - including their autonomy rights- have evolved. In light of this, if a minor can demonstrate his autonomy in relation to the decision should he, like a competent adult, be given the legal authority to decide? Cave asserts that academic arguments against the different levels of competence required to consent to and refuse medical treatment should be distinguished from arguments about the respective authority a decision to consent and refuse may carry. A close examination of the law relating to adults reveals that their decisional authority is context-specific. There are circumstances where adults too are powerless to refuse medical treatment, regardless of their competence. Statutes enacted post-Human Rights Act 1998 which apply to competent minors take a similar approach. Deference to children's autonomy rights does not necessarily require that their competent decisions are respected. In particular the paper considers Mental Health legislation, examining its aims and how they relate to the restrictions on competent adults and minors and the extent to which these provide examples which might be followed when the common law on adolescent treatment refusals is tested in court.

# 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

*Re R* and *Re W* allow a parent to consent to treatment a competent minor refuses, but the cases have not been tested post-Human Rights Act 1998. Gilmore and Herring offer a means by which they might be distinguished or sidelined. They interpret *Gillick* to say that in order to consent a minor need only have a full understanding of the particular treatment. They argue that the minors in *Re R* and *Re W* were refusing all treatment which requires a separate assessment of capacity – an assessment which was not made. We fear that this distinction would not be workable in clinical practice and argue that their interpretation of *Gillick* is flawed. From a clinician's point of view, competence cannot always be judged in relation to a specific treatment, but instead must relate to the decision. We show that a decision can incorporate more than one treatment, and more than one decision might be made about one treatment. A minor's understanding of a specific treatment is not

always sufficient to demonstrate competence to make a decision. The result is that whilst there might be situations when a parent and a minor both have the power to consent to a particular treatment, they will not share concurrent powers in relation to the same decision. Consequently a challenge to *Re R* and *Re W*, if forthcoming, would need to take a different form. We emphasise the necessity to minimise the dichotomy between legal consent and how consent works in medical practice.

## Emma Cave, 'Maximisation of a Minors' Capacity' (2011) 4 Child and Family Law Quarterly, 429-450.

Section 3(2) of the Mental Capacity Act 2005 requires doctors to take practical steps to help a person with impaired capacity to make a competent medical decision. This legal duty does not extend to minors under the age of 16. They must prove their competence where it is presumed in adults, and they can only make decisions in their best interests. Yet the General Medical Council's End of Life Treatment and Care guidance (2010) requires doctors to maximise a patient's capacity, and does not restrict its application to adults. This paper explores the implications of such a duty insofar as it applies to minors. If there is a duty to maximise a child's capacity to consent then the same duty applies when a child withholds consent. A child's competent decision to refuse treatment can be overruled in his best interests, but arguably the development of human rights increases the significance of capacity when determining best interests. If this is the limit of a competent child's right to give or refuse consent, then it is important to ensure that the child has an adequate opportunity to demonstrate his capacity. In this paper I argue that there is much to gain from maximising a child's capacity to consent, but there are also dangers that paternalism will creep in through the back door.