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Divergence in healthcare decision-making – seeking a consensus on the meaning and application of ‘best interests’

Introductory Section in support of the award of PhD by  
Publication

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## List of publications submitted for consideration

This application asks for the following publications to be taken into consideration:

- 2002 'Parental autonomy and immunisation: a true choice?' *Bulletin of Medical Ethics* 175: 13-18
- 2004 'How effective is the Human Rights Act 1998 in protecting genetic information?' in J. Tingle, C. Foster, K. Wheat (eds.) *Regulating healthcare quality: legal and professional issues*. Elsevier Health Sciences, London, 121-141
- 2004 (with A. Slowther, J. Goodall and T. Hope) 'Development of clinical ethics committees,' *BMJ* 328(7445): 950-952
- 2004 (with J. Kaye) 'Does the UK Biobank have a legal obligation to feedback individual findings to participants?' *Med Law Rev* 12(3): 239-267
- 2005 'End-of-life decisions' *New Law Journal* 155 (7174):666-667
- 2005 'Does the statutory regulation of advance decision-making provide adequate respect for patient autonomy?' *Liverpool Law Review* 26(2): 189-203
- 2006 (with G. Holt) 'The legal and ethical implications of therapeutic privilege - is it ever justified to withhold treatment information from a competent patient?' *Clin Ethics* 1: 146-151
- 2007 'The Mental Capacity Act 2005 and advance decisions,' *Clin Ethics* 2: 80-84
- 2007 (with J. Liddle) 'The Mental Capacity Act 2005: a new framework for healthcare decision making,' *J Med Ethics* 33:94-97
- 2008 (with L. d'Agincourt-Canning) 'Disclosure' in P. Singer, and A. Viens (eds.) *The Cambridge Textbook of Bioethics*, Cambridge University Press, Cambridge, 24 -30
- 2009 'Overriding competent medical treatment refusal by adolescents: when "no" means "no",' *Arch Dis Child* 94:487-491
- 2010 (with G. Stirrat, R. Gillon and K. Boyd) 'Medical ethics and law for doctors of tomorrow: the 1998 Consensus Statement updated,' *J Med Ethics* 36: 55-60
- 2010 'Online survey of the perceived need for ethics support in a large National Health Service Foundation Trust,' *Clin Ethics* 5:201-206

## INTRODUCTION

The concept of best interests lies at the core of my work. 'Best interests' underpins all healthcare decision-making whether orientated to treatment of an individual or which impact on a community. My publications explore the respect accorded to an individual's view of his own best interests in healthcare decision-making, both for contemporary and future decisions and how this may conflict with patient welfare, objectively perceived. They also consider the weight given to different perspectives of those involved in deciding what treatment option is 'best' for a patient lacking capacity and whose view predominates when there is conflict. I have also written on the tension between individual best interests and the wider interests of society. My publications have increasingly moved from describing the meaning and application of 'best interests', particularly with reference to the Mental Capacity Act 2005 (MCA), to focusing on how the legal provisions may be interpreted in practice - a translational approach. I have also explored the role of medical education in equipping doctors of tomorrow to make informed decisions about best interests and how clinical ethics committees may elucidate the meaning, and ensure the proper analysis, of best interests in a process for resolving conflicts in healthcare decision-making.

The importance of the assessment of best interests in healthcare decision-making cannot be overstated. Failure to acknowledge and give respect to the views of competent patients or the parents of young children may result in loss of trust in healthcare professionals and disengagement with services. Giving due regard to the values and wishes of adult patients who lack capacity is fundamental to protect and promote the interests of the most vulnerable members of society. However, the mere mantra of 'best interests' belies the complexity of the assessment and its application in practice. Clinicians, parents, family members and the patient himself may have differing interpretations of best interests. The weight given to these perspectives may depend not only on the level of evidence required to adduce these views but also on how far they move away from promoting the basic interests of the patient, such as dignity, freedom from pain and suffering, and life itself. My thinking on this topic has developed through my research and writing, particularly through the qualitative research I have undertaken, and I now come to the view that best interests imposes a normative standard which is interpreted through the subjective lens of the various stakeholders in the decision making process, as Atkins notes, "the problem of trying to capture something unique using tools proper to the general" (Atkins, 2000 p 73).

My approach to best interests in healthcare decision-making derives from a wide range of professional experience. After training as a solicitor I took an LLM in law and nearly 20 years ago

started teaching at Kingston University on a fractional appointment. I developed an interest in medical law and ethics, and following an MA in Medical Law and Ethics I taught this subject to final year law students at Kingston. Thus my initial emphasis was on the interpretation and development of best interests in case law and statute. My work with The Ethox Centre, University of Oxford focusing on clinical ethics support, enabled me to gain insight in to the role of clinical ethics committees as part of the *process* of decision-making and as a member of three clinical ethics committees I am able to observe the range of different clinical settings which give rise to challenging issues in best interests. More recently I have been involved with the Institute of Medical Ethics Education Project in developing the core medical undergraduate curriculum in medical ethics and law. If medical students are not confident about their knowledge of key medico-legal and ethical issues then as young doctors they will not feel able to challenge poor practice or promote better patient care “through using legal rules and an understanding of how law relates to and underpins good medical practice” (Preston - Shoot, 2011, p 6). I also teach medical law and ethics at the School of Medicine, King’s College London and this gives me first-hand experience of the way both medical students and clinicians approach the tension between respecting patient autonomy and the duty to ‘benefit’ the patient. Through my qualitative research focusing on practitioners’ interpretations of best interests my recent publications on adolescent decision-making (2009) and clinical ethics committees (2010) set the legal analysis in the context of the practice of medicine and methods of resolving divergence in decision- making.

In this Introductory Section I will demonstrate how my publications form a coherent body of knowledge through the exploration of the concept of best interests in different contexts of healthcare decision-making. I shall review my publications with reference to normative expectations and subjective accounts of best interests and the balance between the best interests of an individual and the wider interests of society.

## **Part 1 - The patient's assessment of his own best interests and the extent to which this is protected in law**

“Perhaps the most fundamental precept of common law is respect for the liberty of the individual. In a medical-legal context this means that a person's right to self-determination, to deal with his body as he sees fit, is protected by law” (Kennedy, 1991, p 320).

### **The provision of healthcare information to enable autonomous decision-making**

It is a well-established legal principle that competent, informed adult patients are considered to be arbiters of their own best interests in healthcare decision-making. The ethical principle of respect for autonomy is underpinned by law and professional guidance and is part of good professional practice. The concepts of ‘patient centred care’ and ‘shared decision-making’ resulting in increased patient involvement in treatment decisions have been associated with improved health outcomes (Say and Thompson, 2003). Information enables competent decision-making. As Kukla notes “patients cannot choose autonomously unless they are well informed, but they can exercise their autonomy *only* through the act of choosing once they are informed” (Kukla, 2007, p 27). The duty to inform and the correlative rights of patients to receive information are considered an important rebalance to the unequal power dynamic inherent in the clinician /patient relationship. Common law has evolved to establish the right of a patient to be given information of risks and alternatives of treatment options. The standard of disclosure appears to have shifted from the ‘reasonable doctor’ standard to a ‘prudent patient’ standard in recent years (*Pearce v United Bristol Healthcare NHS Trust*).<sup>1</sup> This prioritises patient autonomy and puts the focus on what information may be relevant for the patient to know in order to exercise a judgment about what treatment is best for him.

However, sharing information with the patient amounts to more than disclosure of facts. Professional judgment, patient welfare and the manner by which information is disclosed all have a bearing on the message given, or indeed withheld. A clinician may be concerned that disclosure of diagnosis, risks and alternative treatments may in fact be harmful to the patient and therefore would not be in his best interests. The concept of professional discretion to withhold information is explored by Whitney (2007) who considers that ‘silent decisions’ made by physicians who have decided not to impart information to their patients are “frequent, inevitable and entirely appropriate” and that doctors make such decisions “grounded in professional integrity”(Whitney, 2007 p 36). Professional discretion

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<sup>1</sup> [1999] E.C.C. 167, CA

thus relies on paternalistic and pragmatic concerns, but on further analysis, can this be warranted in the patient's best interests?

Therapeutic privilege permits the withholding of information by the clinician during the consent process on the grounds that disclosure of this information would lead to the harm or suffering of the patient. If a competent adult patient can make treatment decisions for rational or irrational reasons or for no reason at all (*Re T*)<sup>2</sup> is it possible to justify the withholding of information from a competent patient to avoid harm to him? In response to a challenge by a medical student, I and my co-author, Genevieve Holt, consider the doctrine of therapeutic privilege in our article, *The legal and ethical implications of therapeutic privilege - is it ever justified to withhold treatment information from a competent patient?* published in 2006. Our aim was to challenge the vague notion that "there may be wholly exceptional cases where objectively in the best interests of the patient the surgeon may be excused from giving a warning" (*Chester v Afshar*).<sup>3</sup> Although the doctrine of therapeutic privilege had been considered in the context of US and Australian jurisprudence any analysis of the legal and ethical bases for therapeutic privilege with reference to English case law and professional guidance had been indirect. Our contribution was to set the legal framework in the context of professional practice and we attempted to identify clinical situations when therapeutic privilege could be applied. It was instructive to co-author with a medical student who could inform the clinical and professional perspectives. I was responsible for the legal and ethical analysis (pp 146 – 149) and Genevieve reflected on the application of the doctrine in clinical practice (pp 149 – 150).

The *raison d'être* of information disclosure is to enable a person to make an informed competent healthcare decision which reflects his values. Therapeutic privilege reinforces the notion that 'doctor knows best' because disclosure of information is restricted at the discretion of the doctor. In our article we question whether, in deciding to withhold information, "a healthcare professional is either proficient or justified in making a value judgment about what is *best* for the *competent* patient" (p 46). However, we recognise that "to consider provision of information solely in terms of the rights of the patient (and therefore the correlative duty of the health care professional) discounts the 'ethical and social dimension of medical treatments' and may potentially harm the relationship" (p 149). In reality the discernment of what, when and how to disclose involves clinical and communication skills. O'Neill considers that "a theory of respect for patients must rely heavily and crucially on actual medical judgements to assess patient's current capacities to absorb and act on information

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<sup>2</sup> *Re T (Adult: Refusal of Treatment)* [1993] Fam. 95, 102 per Lord Donaldson M.R.

<sup>3</sup> [2005] 1 A.C. 134 para 16, per Lord Steyn

given in various ways” (O’ Neill, 1984 p 177). The ideal of collaborative autonomy which aims to achieve genuine engagement with the patient, to identify *what* information is important to *that* patient is difficult to achieve in time pressured practice where continuity of care is often an unrealistic ideal.

In their empirical study of health professionals’ perspectives on informed consent Heywood, Macaskill and Williams found that “there is a general reluctance to withhold information and the legal concept of a therapeutic privilege was largely unrecognised” (Heywood, Macaskill, Williams, 2010, p 159). The health professionals in this study may not identify with the concept of therapeutic privilege, rather they view withholding of information as “professional discretion in tailoring information to the needs of individual patients” (p 160). Professional discretion may equate with paternalism, as withholding of information may be a way of preserving the best interests of the patient in accordance with medical norms, to “promote health and to cure and prevent illness”(Kukla, 2007, p 32).

In our article we consider that where there is a *duty* to disclose information of risks inherent in a treatment, imposed by law and in accordance with professional guidance, the argument of professional discretion does not provide a sufficiently transparent limitation of patient autonomy. We conclude that “there are only a limited number of clinical situations where providing specific information to a patient under certain circumstances can arguably be expected to cause foreseeable and preventable serious harm to him or her” (p 150).

We presented a first draft of our paper at the Socio-Legal Studies Association Annual Conference in 2005. The article has been cited in the *Journal of Medicine and Philosophy* (2008), *Psychiatry* (2009) and the *Ghana Medical Journal* (2008) (see Appendix 3). No subsequent major publications have analysed the approach of English law to therapeutic privilege.

Following the publication of *Therapeutic Privilege* I was asked to co-author a book chapter on disclosure of information for *The Cambridge Textbook of Bioethics* with the renowned Canadian bioethicist Lori d’ Agincourt-Canning. I was responsible for the legal analysis (pp 24 - 26) while Lori contributed the material on ethics, policy and empirical studies (pp 24, 26 - 28). *The Cambridge Textbook of Bioethics* has an international and multidisciplinary audience and in our chapter *Disclosure* we consider not only the legal rights of patients to information about their healthcare but also the wider ethical and policy issues. Healthcare information is not value neutral and “the timing,



management and delivery of the information and the perceived attitudes of physicians” (p 27) are crucial to the process. We refer to empirical studies which show that patients’ meaningful involvement in decision-making enhances trust and respect. As we note in *Disclosure* (p 24),

“Physicians have a duty to inform patients about their illness and available treatment options and to help patients to decide which of the options is best for them based on the patient’s goal and values.”

In his seminal article on information disclosure Michael Jones states that “the law is not widely known and probably even less well understood by the medical profession” (Jones, 1999, p 106). In our short book chapter we aim to clarify the legal and ethical standards of disclosure with reference to case vignettes and we consider how disclosure should be approached in practice. Although much has been written on disclosure of information it is this cross disciplinary approach that makes the book “uniquely valuable” (JAMA. 2009; 301 (1):107).

*The Cambridge Textbook of Bioethics* was reviewed in the *Bulletin of the World Health Organization* as a “comprehensive and carefully designed textbook that will attract many users in the health professions. The chapters, written by a group of distinguished authors, are presented in a format that is well suited to interactive educational use” (*Bull World Health Organ.* (2008) 86 (8) p 655). Mark Siegler reviewing the book for the *Canadian Medical Association Journal* predicted *The Cambridge Textbook of Bioethics*’s longevity to be comparable with the Osler textbook of medicine (*CMAJ* (2009) 180(10) p 1041). It was highly commended in the British Medical Association Book Awards (2009).

### **Advance decision-making**

It is clear that for contemporaneous healthcare decisions doctors should give effect to a patient’s wish to refuse treatment “even though they do not consider it to be in his best interests to do so.”<sup>4</sup> Decisions taken in advance of loss of capacity which state the person’s healthcare preferences at a future time may be considered to enable the person’s narrative to continue after loss of capacity. But can an individual be the best judge of his future interests? Advance decision-making has been recognised at common law and in its Consultation Paper on Mentally Incapacitated Adults and Decision-Making, Medical Treatment and Research (No. 129) the Law Commission called for statutory regulation of advance decision-making. The Mental Capacity Act 2005 enables two formats

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<sup>4</sup> *Airedale N.H.S. Trust v Bland* [1993] A.C. 789, 864, per Lord Goff

for advance decision-making, 'advance decisions' and Lasting Powers of Attorney (LPA). Both of these documents have legal status but are, in the first instance, interpreted by healthcare professionals with care of the patient. I was interested to consider how the law may be interpreted in healthcare scenarios where a patient's refusal of treatment in an advance decision would put the patient's life at risk and where this would not accord with the patient's best interests as perceived by the treating clinician.

A series of articles *End of Life Decisions* (2005), *Does the statutory regulation of advance decision-making provide adequate respect for patient autonomy?* (2005) and *The Mental Capacity Act 2005 and advance decisions* (2007) are concerned with providing a critical appraisal of the statutory recognition of advance decisions. I explore in detail the two formats of advance decisions and Lasting Powers of Attorney and their respective advantages and disadvantages. Following publication of these articles I was invited to speak on advance decision-making at the 2<sup>nd</sup> Annual Conference, Institute of Medical Law, University of Birmingham in 2006 and the British Association for Emergency Medicine in 2007.

The article *End of Life Decisions*, aimed at a legal audience, was published within weeks of the MCA becoming law and was the first publication to consider the provisions of the MCA and advance decision-making. I explain the provisions of the MCA and question whether advance decisions are effective in articulating patient preferences for refusals of treatment where these diverge from a normative perception of the patient's best interests. I question whether doctors' attitudes to advance decision-making will alter as a result of the MCA. A survey of UK geriatricians' attitudes to advance decisions before implementation of the Act had demonstrated their difficulty in "reconciling the decision of the individual to forgo life sustaining interventions in certain circumstances within the health care team's remit and personal beliefs in preserving life" (Schiff, 2006, p 119). In my discussions with medical students I am struck by their concern that they may be failing in their duty to preserve life by respecting advance decisions.

As I note in the second article in the series, an advance decision may often lack the specificity required under the Act and this "highlights the gap between the legal requirements and medical reality" (p 200). I explore the legal framework in more detail and with reference to a case vignette, compare and contrast advance decisions, LPAs and how they may differ from best interests objectively considered. I conclude that although the legislation offers a chance to recognise the wishes of those who want to take some control over end of life decisions, the practicalities of

drafting advance decisions with sufficient specificity and the potential that LPAs may only be given effect where this accords with an objective view of best interests “may render advance refusals of life sustaining treatment ineffective in practice” (p 203). My views on the inherent fallibility of advance decisions seem to be validated by other authors in subsequent publications. Maclean, citing my article, considers that the MCA provisions only work when “healthcare professionals and/or the courts are comfortable with the patient’s decision” (Maclean, 2008, p 22), Sayers *et al* (2006, p 144) state that “both case law and the Mental Capacity Act 2005 can support a doctor’s paternalistic interpretation of an advance refusal” and Michalowski comments that “the new legislation as well as the common law apply a bias against the validity or applicability of an advance refusal of life-saving treatment” (Michalowski, 2005, p 960).

Having read my article in the *Liverpool Law Review*, the editorial committee of the new journal *Clinical Ethics* asked me to contribute an article for the edition of the journal focussing on the provisions of the Mental Capacity Act 2005. Therefore just after the MCA was implemented and with the benefit the recent publication of the finalised Code of Practice I developed my thinking in the article *The Mental Capacity Act 2005 and advance decisions*, aimed at a wider audience including healthcare professionals. I consider whether a Lasting Power of Attorney may give greater priority to a patient’s perspective of best interests than refusals of treatment expressed in an advance decision. Donees of LPAs must act in the patient’s best interests and they can bring to the discussion information of the patient’s values and preferences (Tonelli, 1997). I was particularly interested in the evidence that may be required of the donee of the LPA to substantiate his views and I draw upon studies of the accuracy of surrogate decision-making. Maclean considers that “if patients are unwilling to leave their fate in the hands of the medical profession, they would do better appointing a trusted proxy than relying on an advance directive” (Maclean 2008, p 22). I argue that because value judgments about quality of life and suffering, which are inherently part of a best interests’ evaluation, are difficult for a donee of an LPA to articulate with clear and convincing evidence, the views of the donee of the LPA are unlikely to be given effect where some medical benefit can be achieved through treatment.

Perhaps it could be concluded that although the state’s interest in protecting life may be displaced by contemporaneous self-determination, the need to protect incompetent adults is likely in practice to outweigh patient autonomy expressed in advance decisions. It seems counterintuitive that individuals should be able to bind themselves by a prior refusal of treatment to a course of action/treatment that may be of current clinical benefit (Dresser, 1994). However it is the notion of

'harm' that is at stake here because a patient may be harmed where there is a failure to recognise and give effect to his prior 'critical interests' (Dworkin, 1993) which he articulated in the advance decision/instructions to a donee of an LPA. In any event advance decision-making has not caught the popular imagination. A poll commissioned by the charity Compassion in Dying, reported in May 2011, has found that 60% of adults would want only comfort care at the end of life but only 3% had made their treatment wishes known in an advance decision.

There is more work to be done in this field and I intend to carry out qualitative research using clinical case vignettes to assess circumstances when healthcare professionals would respect advance decisions.

### **Resolving the tension between autonomy and beneficence in adolescent decision-making**

For adolescents with emerging autonomy others are also involved in the decision-making process - parents, healthcare professionals and ultimately the courts. They may be concerned whether the young person's decision is truly autonomous, and the extent to which best interests or respect for autonomy is the criterion for decision-making in rare but troubling situations of a refusal of medical treatment which would put him at risk of death or serious harm. Case law from the 1990's, including *Re R*<sup>5</sup>, *Re W*<sup>6</sup> and *Re E*,<sup>7</sup> which deliberated the ambit and authority of adolescent autonomy in treatment refusals, has been the subject of much academic debate (Bainham 1992, Eekelaar 1993, Brazier and Bridge 1996) despite the fact that such cases are relatively rare. Doctors and medical students I have spoken with are under the impression that if a young person refuses treatment "they can be treated anyway" although Nolan LJ in *Re W* made it clear that courts would not authorise "treatment of a distressing nature which offered only a small hope of preserving life" (p 94). The General Medical Council offers little clarification in its guidance *0 – 18 years: guidance for all doctors* reminding doctors that if young people refuse treatment, particularly treatment that could save their life or prevent serious deterioration in their health, this presents "a challenge that you need to consider carefully" (GMC, 2007, para 30). Even recently Gilmore and Herring have noted that there is "some uncertainty about the current position within the medical profession" (Gilmore, Herring, 2011, p 3).

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<sup>5</sup> *Re R (A Minor) (Wardship: Consent to Treatment)* [1992] Fam.11

<sup>6</sup> *Re W (A Minor) (Medical Treatment: Court's Jurisdiction)* [1993] Fam. 64

<sup>7</sup> *Re E (A Minor) (Wardship: Medical Treatment)* [1993] 1 FLR 386

To explore how these legal principles, much debated and argued over, would be considered in the cut and thrust of reality, I carried out qualitative research on the attitudes of those involved in differing professional capacities with adolescents. This work was funded by an award made under the HEFCE Promising Researcher Fellowship Scheme. It offers an original insight into the circumstances when professionals consider that the protection of current and future best interests of the young person outweighs respect for autonomy. I presented my initial framing of the legal and ethical issues at the Society for Legal Scholars conference in 2005. Following analysis and coding of the interview transcripts I presented an early draft of this paper at the International Congress on Law and Mental Health in 2007 and the findings of my qualitative study were published in *Archives of Disease in Childhood*, *Overriding competent medical treatment refusal by adolescents: when 'no' means 'no'* in 2009.

My study reveals that factors such as whether treatment is on-going or 'one off', the practicality of enforcing treatment and the young person's prior understanding/experience of illness were all relevant to study participants in concluding that 'no' means 'no'. While the article was still in draft form, the story of Hannah Jones became the subject of media furore. Hannah was a 13 year old girl whose refusal of a heart transplant was respected by the healthcare team, with whom she had a good relationship. A declaration from the court was never sought. I conclude in my article that "the recent respect given to the refusal by Hannah Jones of a heart transplant re-iterates the views of the participants in this study" (2009, p 491).

The factors that the participants in my study considered relevant to accord respect for adolescent decisions were also apparent in a US study of attitudes of paediatricians to refusals of medical treatment for minors. Talati *et al* found that paediatricians are "guided by a hierarchy of principles in deciding whether to respect a treatment refusal" (Talati, 2010). Prognosis and age are key factors. The paediatricians were less likely to respect a refusal from a younger minor and although "tolerance for refusals increases as prognosis becomes less favourable" they found that "even when prognosis is good, more paediatricians would respect a refusal when parent and minor both refuse than when either refuses alone" (Talati p 130). The editorial introducing this research questions whether it is "ethical to alter the degree of autonomy we afford adolescents based on how closely their choice reflects our own view of their best interests?" (Duncan, 2010, p 114).

One might postulate that adolescent autonomy is increasingly respected in light of the discourse of 'rights'. In my article I note that the Children and Family Court Advisory and Support Service

(CAFCASS) representative who was interviewed for the study did not remember a single such case after the passing of the Human Rights Act 1998, perhaps because “what a teenager or a young person may say is holding more weight than it used to.” Fortin considers however that “neither the medical profession nor the courts show great enthusiasm for adjusting their approach to children’s healthcare by reference to a framework of rights” (Fortin, 2009, p 368). Certainly clarification of the extent to which adolescent autonomy is respected in light of Articles 3, 5 and 8 of the European Convention on Human Rights (perhaps in conjunction with Article 14) in a test case would be welcome.

My article received two rapid responses following its online publication on 1<sup>st</sup> March 2009. A consultant paediatrician commented “Johnston makes an important point regarding the judging someone’s competence from the apparent wisdom of their decision” and a public health registrar wrote “thank you for highlighting this important topic that has wider implications than medicine alone.” My article was also cited in the publication of a debate of the Royal College of Paediatrics and Child Health. The RCPCH debate was held in April 2009 in the Ethics and Law session of their annual meeting. The motion proposed - “This House believes that we have gone too far in granting young people the responsibility for making decisions about their own healthcare” (Larcher *et al*, 2010, p 123) was overwhelmingly rejected. It seems then that the adolescent’s perception of his own best interests in healthcare is increasingly respected. In 2010 a newspaper ran a report of Joshua McAuley, a 15 year old Jehovah’s Witness whose refusal of blood products was supported by his parents and was respected by the treating doctors. In my study the adolescent psychiatrist identified the importance of input from the young person *and* the parents in assessing what treatment options were in the young person’s best interests. Support and on-going dialogue is crucial. Those at the cutting edge of these difficult decisions recognise that “the healthcare of a young person is not just one person’s business—it involves a collaboration of all parties involved and is not a purely autonomous decision taken by a young person” (Larcher, 2010 p 126).

## **Part 2 - The patient is unable to make a determinative assessment of his own best interests**

“But on other points he is simply at sea, and doesn’t know the least thing about them; he doesn’t know, and he doesn’t even suspect that he doesn’t know” (Dostoevsky, 1998, p 436).

### **The role of family and clinicians in determining the patient’s best interests**

If adult patients lack the capacity to make their own health care decisions then to what extent can their views impact on decisions taken on their behalf? Kuczewski (1999) considers that where an adult is unable to make healthcare decisions due to lack of capacity the patient’s story has a moral claim to be continued /finished in a way he would have wanted based on his own values. But what weight is given to these non-competent and marginally autonomous views? In *Re C Thorpe J.* noted that “the further capacity is reduced, the lighter autonomy weighs.”<sup>8</sup> The Mental Capacity Act 2005 sets out the best interests checklist, which requires the decision-maker (usually the consultant with care of the patient) to consider certain and possible gains/losses flowing from proposed treatment options. Not only are the medical outcomes to be considered but also wider welfare issues, including specifically the patient’s wishes and feelings and the beliefs and values that would be likely to influence his decision if he had capacity. These may be elucidated through discussion with relatives/carers and the decision-maker has a duty to take into account their views where it is practical and appropriate to do so. Within the hierarchy of factors included in the best interests’ appraisal it could be expected that clinical factors will predominate. Medical outcomes, although not always certain, may be seen as dependable and referable to evidenced outcomes. By comparison, family members may prove unreliable in their knowledge of the patient’s wishes, feelings and beliefs and may find them difficult to articulate with sufficient authority and to the necessary evidentiary standard.

The Law Commission’s proposals for reform of the law on incapacity and their focus on the best interests’ standard had caught my attention when I was studying for the MA in Medical Law and Ethics in the mid 1990’s and I continued my interest as the law developed, culminating in the MCA. I have been invited to speak on mental capacity at the Association of Anaesthetists conference (2004) and the Motor Neurone Disease conference with King’s College Hospital (2006). My presentation ‘Draft Mental Capacity Bill - prioritisation of views of best interests’ at the Socio-Legal

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<sup>8</sup> *Re C (Adult: Refusal of Treatment)* [1994] 1 WLR 290, 292

Studies Association conference (2004) was an early consideration of how legislation would evolve the meaning and application of the best interests test and these preliminary views were developed for a presentation at the international Law and Society Association Conference in the same year. More recently I have presented on best interests and the MCA at the Socio-Legal Studies Association conference (2011) with reference to interpretation of recent case law.

I drew upon my earlier work, which analysed the impact of the Mental Capacity Act and advance decision-making, for the article *Mental Capacity Act 2005: a new framework for healthcare decision making* (2007). My co-author Jane Liddle is a geriatrician and this article benefits from our different expertise and perspectives. I took the lead on this paper and was responsible for the interpretation of the statutory provisions (pp 94 – 96) and Jane focused on the new Court of Protection and the role of deputies (pp 96 – 97). Its publication in the leading bioethics journal *Journal of Medical Ethics* ensured that we reached a diverse audience. The article is cited in a range of practitioner journals including *Reviews in Clinical Gerontology* (2007), *Psychological Reports* (2008), *American Journal on Intellectual and Developmental Disabilities* (2009) and *Ethik in Der Medizin* (2009) (see Appendix 3).

The article reviews the statutory checklist for best interests and how it builds upon case law, and analyses the different perspectives of those who may input into the assessment. In the conclusion we acknowledge that “whether the provisions of the Act will alter current practice will depend to a large extent on the way they are interpreted by clinicians, and ultimately by the courts” (p 97).

The Court of Protection has jurisdiction to hear cases on all issues relating to adults who lack capacity to make any or all decisions. The number of welfare cases brought under the provisions of the MCA is “rising exponentially” (Pauffley, 2010, para 6). The Court operates in private, yet it is “essential that more judgments become available for information and critique” to enable expertise on the operation of the MCA to develop (Donnelly, 2011, p 305). Decisions of the Court of Protection which have been made public give some sense of how the wishes of the person lacking capacity are relevant in informing his best interests. In *Re S (Protected Person)*<sup>9</sup> Judge Marshall QC questioned “~~what~~, after all, is the point of taking great trouble to ascertain or deduce P's views, and to encourage P to be involved in the decision-making process, unless the objective is to try to achieve the outcome which P wants or prefers, even if he does not have the capacity to achieve it for himself?” (para 55).

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<sup>9</sup> [2010] 1WLR 1082



However in *DH NHS Foundation Trust v PS*<sup>10</sup>, a case concerning the treatment of an incompetent woman for cancer which would result in her sterilisation, the President indicated just how much weight is given to the clinical view of best interests. Wall P. stated he has “no difficulty in accepting” the evidence of the consultant psychiatrist; he “accepts the evidence” of the consultant gynaecologist and has “no hesitation” in accepting the evidence of both the consultant anaesthetist and the learning disability community sister. The President did not consider the views of the patient nor those of her family in the judgment and in the final paragraph noted that the procedure was in her ‘interests’ – rather than her *best* interests. As Herring had previously noted “rather than the judiciary too often relying on their own views, a more valid criticism is that there is too much weight attached to supposedly ‘expert’ objective evidence and not enough judicial assessment of it” (Herring, 2005, p 162). If the patient’s account of his values, wishes and feelings are marginalised, or at worse ignored, the focus of best interests shifts to the medical harms and benefits and renders respect for limited patient autonomy nugatory.

Although the MCA Code of Practice urges decision makers “not to take shortcuts in working out best interests” (para 5.13) and requires a proper and objective assessment to be carried out on every occasion, it is questionable whether there is both enough time and knowledge of the requirements of the MCA to make a thorough best interests’ assessment. There is evidence that NHS staff lack awareness about best interests’ decision-making under the MCA, in particular about the identity of the decision-maker. If doctors are not properly aware of their duties under the MCA then they will not be adept in performing best interests’ assessments in practice.

### **The role of medical education to enable adequate understanding of concept of best interests**

In 1981 Professor Ian Kennedy stated that “doctors are not uniquely competent to make ethical decisions. They receive no training to prepare them for such a role” (Kennedy, 1981 p 84). That may have been true then but in 1993 the General Medical Council (GMC) published *Tomorrow’s Doctors* which included a requirement that ethics and law be part of the core undergraduate medical curriculum. In 1998 the Consensus Statement produced by ethics and law leads in medical schools, put flesh to the dry bones of the GMC requirement by setting out core topics that should be included in the medical ethics and law curriculum, including informed consent and ‘new’ genetics. Ten years on it was felt necessary to update the Consensus Statement in light of the evolution in healthcare.

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<sup>10</sup> [2010] EWHC 1217 (Fam)

The Institute of Medical Ethics (IME) funded the original report on ethics in the medical curriculum (The Pond Report, 1987) and took on the task of reviewing and updating the Consensus Statement. In my role as project manager for the IME Education Project I was involved from the outset in the consultation process with all major stakeholders, including the GMC, the British Medical Association (BMA) and the Royal College of Physicians. The publication *Medical Ethics and Law for doctors of tomorrow: the 1998 Consensus Statement updated* (2010) co-authored with leaders in the field of medical ethics, was described by the editor of the *Journal of Medical Ethics* as “the most important paper in this month’s JME” (Holm, 2010, p 1). The new curriculum, expressed as learning outcomes, not only requires that students can demonstrate in practice “an understanding of the ethical challenges and legal requirements of determining and acting in the best interests of patients who lack capacity” (Stirrat, Johnston, Gillon and Boyd, 2010, p 58) but also “the ethical and legal aspects of the relationship between the interests of patients and their relatives/carers and, where relevant, how best to involve and respect the latter’s views.” (Stirrat, Johnston, Gillon and Boyd, 2010, p 57). The updated core content of learning for medical law and ethics has been endorsed by the GMC and BMA and is referred to in most papers published subsequently on medical law and ethics curricula including the *Journal of the New Zealand Medical Association* (2010) and *Annals Academy of Medicine Singapore* (2011) (see Appendix 3). I have presented on this topic at the Association for the Study of Medical Education conferences in 2009 and 2010.

Recently our article has been cited in a survey on law teaching in UK medical schools (Preston-Shoot, 2010) and an evaluation of student perceptions of their undergraduate medico-legal education (Preston-Shoot, 2011). In the latter article a study of two medical schools identified that even in their final year 73% of students reported little or no perceived knowledge of the core legal powers and duties relating to the MCA and the term ‘best interests’ was referred to by only 22% of them. Even so, a great majority of students recognised the importance of a sound understanding of law to demonstrate accountability and to protect vulnerable patients. The core content of learning is not prescriptive and the curricula of the 32 medical schools will vary greatly. Nevertheless our article states that “a foundation of medical ethics and law underscores and explores the key importance in good medical practice of benefitting the health of individuals and populations while minimising harm in ways that respect autonomy and are just” (p 57). Education of medical students and young doctors of the multi-faceted nature of best interests is crucially important - “if medical graduates do not know what they do not know and/or where to find it, they will be less able to advocate for and protect patients” (Preston-Shoot, 2011, p 6).

## **Due process in clinical decision-making – the role of Clinical Ethics Committees**

Medico-legal and ethical issues arising in clinical practice *are* difficult to resolve. The complexity and availability of medical interventions and the scope for disagreement between parents, family members, carers and clinicians about the meaning and application of best interests gives rise to increasing challenges to clinical decision-making. Resorting to legal intervention is costly, time consuming and potentially divisive. In recognising the potential for conflict between consultees in a best interests' assessment Dunn *et al* ask "in the context of everyday health and social care, what is to be done if there is disagreement between the decision-maker and those providing evidence?" (Dunn 2007, p 130). They note that there is very little practical advice in the MCA Code of Practice about the actual *process* of determining a patient's best interests. Over the past decade clinical ethics support, usually in the form of committees, has emerged as method of engaging discourse in healthcare decision-making which gives rise to ethical challenges. The UK Clinical Ethics Network (UKCEN) provides support for the growing number of clinical ethics committees (CECs) in the UK. I was project officer for UKCEN at The Ethox Centre, University of Oxford and have been invited to present at a number of seminars and conferences on the relationship between legal and ethical issues in clinical practice and the role of CECs. In May 2005 I was a member of the panel on the popular BBC Radio Four series 'Inside the Ethics Committee.'

I co-authored the article *Development of clinical ethics committees* (2004) with my colleagues at Oxford who are internationally renowned as leaders in the field of clinical ethics support – the "experts at Ethox" (McLean, 2008, p 104). This is a paradigm article written at the vanguard of clinical ethics support and is frequently cited in a wide variety of international publications (see Appendix 3).

We describe the nature of clinical ethics support and the function of CECs and we ask the question "does ethics support make a difference?" Outcomes may be very difficult to measure but we note that,

"although measuring specific outcomes of ethics support can be helpful, it ignores other dimensions of ethics support. An equally important aspect is the provision of an explicit and transparent process for engaging with the ethical dimension of clinical decision making. A model of ethics support that facilitates and informs a shared understanding of difficult ethical issues can support and reassure both clinicians and patients (p 951)."

Indeed in the US, Buchanan and Brock suggest 'institutional safeguards' including appeal to hospital CECs to prevent abuses regarding substituted judgement (Buchanan and Brock, 1989). It has been suggested that using a CEC as a neutral forum for clarification and discussion of the issues may avoid the need to resort to court (McLean, 2008). An audit of the nature of decisions discussed by CECs shows that dilemmas arising about best interests are the most frequent (DuVal, 2001). In my experience as a member of three CECs in different London healthcare trusts I am always impressed by the informed, reflective, multidisciplinary discussions teasing out 'best interests.' We have discussed cases as diverse as the appropriateness of resuscitating a baby born at 25 weeks gestation against the wishes of the parents; whether to offer pre-implantation genetic diagnosis for a couple to avoid the risk of genetic deafness; whether it is in a patient's best interests to perform a tracheostomy knowing that this will mean he will have to go to a full time nursing home when he had previously expressed a desire for independence. Feedback from clinicians who have referred cases for consideration are very positive, one stating "this is an issue which we have debated many times and have found no consensus so it was helpful to hear arguments from a different perspective."

Nevertheless clinical ethics support does not appear to have universal appeal. Currently about 85 NHS Trusts have a form of clinical ethics support. Research has been carried out to expound the *modus operandi* of existing CECs but there was a gap in how consultants perceive clinical ethics committees. I carried out original research on the perceived need for ethics support through an online survey of consultants in a NHS Trust *without* formal ethics support. The data produced was very illuminating because although a large majority of those responding to the survey thought that a form of ethics support in the Trust would be useful (p 204) nevertheless there is clearly some scepticism, and even perhaps antagonism to the concept (p 205). I presented my findings at the International Conference on Clinical Ethics Consultation in 2010. Shortly afterwards my article *Online survey of the perceived need for ethics support in a large National Health Service Foundation Trust* was published.

I describe the attitudes of consultants to ethics support including reasons for and barriers to using ethics support. Key reasons why consultants would use ethics support are to resolve uncertainty about the best way to proceed, to improve patient care, to avoid litigation, as a response to pressure from patient/family members and to enhance multidisciplinary discussion. At the heart of most clinical ethics dilemmas is the need to clarify the patient's best interests and to identify grounds for divergence of opinion. CECs can offer a transparent and informed process in difficult decision-making. The NHS Trust which was subject of the questionnaire survey has now set up a clinical

ethics advisory group and it will be useful to audit its work to consider whether it has achieved the aims of those who took part in the survey.

### **Part 3 – The extent to which societal interests may outweigh individual best interests**

"[T]he best interests standard has sometimes been interpreted as highly malleable, permitting values that are irrelevant to the patient's benefits or burdens and incorporating intangible factors of questionable value" (Beauchamp and Childress, 1994, p 180).

'Best interests' applies not only in the context of medical treatment for an individual but also at the interface between individual and public interests. A tension may thus arise between protecting personal health information from disclosure and circumstances when disclosure may be warranted in fulfilment of a public interest, for example to protect someone from a serious crime. Conversely what may be 'best' for an individual may be limited by relevant resources – time, money or manpower. Undue emphasis on the interests of the few may be at the expense of the majority or *vice versa*. Where the balance is set between best interests of an individual and the interests of society depends on the level of benefits and harms accruing.

Individual autonomy in healthcare treatment choices is respected where the person can make a competent decision based on adequate information. Competent adults are permitted to make choices to benefit others, for example by agreeing to donate organs to loved ones (and even altruistically to unknown recipients) provided that the risks come within appropriate boundaries and are understood. They can act for the collective benefit of society through consenting to take part in research, provided that their rights, safety, dignity and well-being are protected. However, an individual might expect that such altruism demands reciprocity - not only that personal information generated through research will be kept 'safe' but also if it has significance for future health and reproductive choices he will be informed.

#### **The role of the law in keeping 'safe'/ensuring appropriate disclosure of personal information generated through biobank research**

UK Biobank is a national study that will consider the contribution of gene and environment interaction in the development of disease. Researchers are focusing on development of common diseases such as cardiovascular disease, metabolic disorder and cancer. Individuals who fall within certain criteria are asked by their GPs to take part in the study which will require blood samples and completion of questionnaires over a period of about 10 years. UK Biobank raises significant issues around the safety of information collected and the extent to which the interests of those taking part

are safeguarded. As Laurie *et al* note, “human genetics and biobanks have taken some of the classic privacy concerns such as fear of misuse of personal information, stigmatisation of groups, and unjustified intrusion into private life, to new heights” (Laurie, 2010, p 315). They identify the core values at stake in respect of biobanks as privacy, public interest(s) and solidarity.

I presented a paper at the Medical Protection Society/Nottingham Law School, Health Law Conference in May 2002 and following that I was asked to contribute a chapter covering the same issues for the book *Regulating healthcare quality: legal and professional issues* published in 2004. My book chapter *How Effective is the Human Rights Act 1998 in Protecting Genetic Information?* appeared at the time when UK Biobank was in its infancy and the first pilot study had not yet commenced. In fact in his book *Genetic Privacy: a Challenge to Medico-Legal Norms* published in 2002 Laurie only briefly notes in respect of UK Biobank that “the study is currently on hold while wider issues are addressed, among which are questions of security of data and privacy protection” (p 297).

In the book chapter I consider the extent to which the law protects from unwanted disclosure genetic information generated through such research studies. The House of Lords Select Committee on Science and Technology recommended that the primary means of regulation should be the Data Protection Act 1998. However, I argue that the Act provides a rather blunt instrument for such finely drawn interests. I also consider in some detail the application and limits of the duty of confidentiality and the Human Rights Act 1998. Overall I conclude that “individuals taking part in the Biobank study cannot be assured that their genetic information will never be disclosed without their consent. Other interests, including the health interests of relatives may be of sufficient weight to override a participant’s right to privacy/confidentiality.” In 2010 Laurie *et al* go as far as to note that “access by police cannot be ruled out, indeed it should be positively contemplated and communicated to participants as a possible risk to their privacy if participating in a biobank project” (p 322).

In the chapter I also consider the obligations of UK Biobank to disclose research findings that are of relevance to the participants. Results from biobank research projects will include the intended general results of the study and potentially incidental findings that may be of relevance to the participant and his relatives. UK Biobank had not developed a policy for feedback of such results and, drawing on my previous work and ideas generated for my paper at the Law and Society Association Conference in 2003, I was prompted to write the article *Does the UK Biobank have a legal obligation to feedback individual findings to participants?* (2004) with my colleague at Ethox,

Dr Jane Kaye, then research fellow at the Oxford Genetics Knowledge Park. I focus on the legal analysis of the obligation to feedback individual findings and the moral obligation to do so and Jane draws on her extensive experience of governance of international biobanks to consider the policy issues. The moral justifications for feedback of individual results rely on arguments of respect for patient autonomy and reciprocity. We argue that “individuals who have agreed to participate in the UK Biobank for altruistic reasons, involving an active commitment for many years for the public good should not be denied information that may be life-saving” (p 244). We consider whether there might be a legal *duty* to provide individual feedback and indeed whether the European Convention on Human Rights gives rise to a *right* to such information.

Our article has been cited in a variety of publications internationally including *University of Cincinnati Law Review* (2006), *PLoS Biology* (2008), *Nature Reviews Genetics* (2008), *Journal of Epidemiology* (2008), *Medical Sociology* (2008) and *Philippine Law Journal* (2010) (see Appendix 3). The concepts we discuss have been adopted in articles on whole genome research and our article is cited as a key publication in the literature review for the Wellcome Trust (2009) on the “Ethical, Legal and Social Issues arising from the use of genome-wide association studies in Medical Research.” In 2007 Professor Brownsword cited our publication in his consideration of the prospects for a tort claim to be brought against UK Biobank (Brownsword, 2007).

Information disclosure is considered to promote autonomy by enhancing informed, rational choice and, therefore, despite the potential for increased anxiety and information overload, it is generally argued that the best interests of individual participants are promoted by disclosure of information to them. However the best interests of the participants to receive information must be balanced against the aims of the research project as a whole and the time and cost effectiveness to feedback individual findings. Elements to be considered in balancing disclosure and non-disclosure “can be identified as the nature and size of the health risk at stake, the validity of the research findings, and their clinical utility for the participant” (Bovenberg et al, 2009, p 239) and whether the obligation to disclose would impose a disproportionate burden upon biobanks. In our article we conclude that in the rare situation where incidental research findings reveal that a participant or his family is at risk of a serious *and* treatable genetic condition, UK Biobank has a moral and legal duty to feedback individual results to participants.

Recently, Bovenberg *et al* carried out a questionnaire study to assess the attitudes and information preferences of major stakeholders (participants/researchers) about how results derived from research



with large scale biobanks should be communicated to individual research participants. Interestingly a majority of participants and citizens (as potential research participants) were of the opinion that participants should be informed of gene mutations found through the study, even where health implications were unclear. In comparison 95% of the researchers did not agree with disclosure for uncertain health risks and a vast majority (74%) considered that participants should be informed only where there are consequences for prevention and treatment (p 232). Part of the consenting process to take part in such research studies should include information not only about risks and benefits of participation but also the relevance of findings for individuals and in what circumstances such information will be reported back to them. The conclusion of Bovenberg *et al* regarding individual feedback is in line with ours - "individual feedback should be given where the information relates to a serious health problem and where the possibility of an individual health benefit is realistic" (p 245). They consider that ethics committees have a role to play in reviewing the policy of a biobank regarding disclosure and also in resolving difficult individual cases. The UK Biobank Ethics and Governance Council has just recommended that UK Biobank "develops a framework of principles from which to decide whether or not feedback should be provided" (Annual Review 2010, p 9).

Considerable benefits will accrue to society over time through such research. Overemphasis on individual interests fails to acknowledge the importance of genetic solidarity and relational autonomy. An individualistic model of autonomy disregards "duties and obligations as well as relationships and the interests of the community" (Gauthier, 2002, p 275). In my book chapter *How Effective is the Human Rights Act 1998 in Protecting Genetic Information?* I note that "society is based on mutual cooperation and interdependence and....from a moral point of view at least, individual fulfilment should not be pursued at the expense of claims of others" (p 139).

### **Childhood immunisations – best interests of the child or society?**

The principle of fairness requires that "we are obliged to share the sacrifices that make possible social practices from which we benefit" (Shapsay and Pimple, 2007, p 414) and this principle can be applied to mass immunisation programmes for babies and children. As Biggs notes however, "considerations such as altruism and benefit to the wider community are valid and appropriate when adults or parents are making decisions *about themselves*, but the moral baseline is rather different when making proxy decisions for children" (Biggs, 2011, p 16). If a child is to *benefit* from herd immunity then to what extent should parents be at liberty to decline immunisation for their child because they do not consider immunisation to be in his/her best interests? In my first published

article, written at the height of the immunisation debate, *Parental autonomy and immunisation: a true choice?* (2002) I consider whether the parents' 'right' to make an autonomous decision about immunisation may be constrained in the interests of public health. I discuss the issue of payments to GPs to reach immunisation targets and I argue that this sets up a possibility of loss of trust between parents questioning immunisation for their child and the GP.

According to Mill, individuals should be free to pursue their aims as they see fit, although limits in the pursuit of autonomy (in this case parental autonomy exercised to benefit their child) are justified to protect others from 'harm',

“Whenever, in short, there is a definite damage, or a definite risk of damage, either to an individual or to the public, the case is taken out of the province of liberty, and placed in that of morality or law” (Mill, *On Liberty*, p 91).

In clear instances of harm state interference in parental decisions may be justified, but the utility that is gained from such interference should be balanced against the harms of coercion. There is a difference between parental refusal of *treatment* that is proposed to benefit *this child* and immunisation campaigns where although the individual child may benefit (but may suffer incidental harm) the principal aim is to benefit a population group. Dare considers that “immunisation is not a clear case under the harm principle” because the small numbers of parents refusing immunisation for their children is such that no real harm ensues from respecting their autonomy” (Dare, 1998, p 144).

Diekema argues that “parents may also use the best interest standard in refusing immunization on behalf of their children. While most mandatory vaccines are effective and safe, a small possibility of adverse reactions exists. For example, a parent might reasonably conclude that refusing the measles vaccine is in the best interests of a child living in a community with a high immunization rate” (Diekema, 2004 p 264). In the case of *Re C & F (Children)*<sup>11</sup> the mothers of girls aged 10 and 3 years old refused to have their daughters immunised, although the fathers wanted their daughters to receive all appropriate immunisations. Sumner J. considered that the children's best interests were served by receiving a programme of immunisations (and the mothers' appeals against this judgment were dismissed). In contrast, where there is no dispute between parents, their view that that immunisation is not in their child's best interests will not be challenged despite the risk to other children.

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<sup>11</sup> 2003 EWHC 1376 (Fam)

My article focuses on the Measles Mumps and Rubella immunisation programme for very young children and whether the best interests of individual children are congruent with the societal need for an immunisation programme leading to herd immunity. Should public health programmes focus on individual autonomy, requiring voluntary choice and altruism? O'Neill considers that public health policies may be undermined if their implementation depends on individual informed consent (O'Neill, 1984). Relational autonomy has appeal in public health programmes. The notion of individual contribution to public goods rests on the notion that "certain acknowledged goods would be threatened if individuals were allowed unfettered appeal to self-interest" (Dare, 1998, p 145). Thus, from a moral perspective, if not a legal one, the best interests of the individual may be swamped by an overwhelming benefit to society, although the boundaries of 'benefit' may be difficult to agree on.

## **CONCLUSION**

In this Introductory Section I have demonstrated that my publications submitted for consideration have all contributed to the on-going debate on best interests arising in various contexts in healthcare. My work has developed from interpretation and discussion of the legal framework to an understanding of the importance of the concept in the practice of medicine. Collaboration with colleagues has benefitted this translational approach.

My work has both led and responded to the increasing focus on respect for patient autonomy and the patient's perception of his own best interests in healthcare decision-making. My qualitative research on adolescent decision-making highlights the need for enabling dialogue and a genuine desire to hear the young person's views.

I have also anticipated how the law may respond to developments in clinical practice and research. My writing on advance decision-making and the best interests assessment under the MCA highlights the need to recognise the individual's values and preferences and the challenge this can present to clinical decision-making with competing conceptions of what may be 'best' for the patient. In my writing on biobank research I have considered how the law may respond to the need for an individual to know of research findings to promote his best interests and the implications for the viability of the research study overall.

I have come to realise that best interests is essentially a value based judgment and those involved in the process may have different perceptions of what is the best outcome. Therefore a shift from the decision itself to an appropriate process of decision-making may serve to give voice to the different narratives involved. As Atkins states “insisting that a decision be made from a fully objective perspective can only produce a decision that is further from the patient’s own point of view, not closer to it” (Atkins, p 78). Appreciation of the subjective character of experience enables a genuine respect for patient autonomy.

My contribution to the discourse on best interests’ decision-making in healthcare has been significant as evidenced by citation of my work by others. It remains contextualised and contemporary given my on-going involvement in the training of tomorrow’s doctors and my commitment to clinical ethics committees. There are further areas to be explored and developed in the consideration of how the framework of best interests serves law, medicine and society and the process by which consensus might be sought. I am well placed to continue in this endeavour.

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**APPENDIX 2 - Offprints of publications submitted for the award  
of Doctor of Philosophy by Publication**



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### **APPENDIX 3 - Citations of publications submitted for consideration for the award of PhD by Publication (using Google Scholar, June 2011)**

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