Transformative choice and decision-making capacity

Isra Black *
Lisa Forsberg
Anthony Skelton

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I. Introduction

Some jurisdictions index the exercise of certain legal capacities to mental or decision-making capacity—an individual’s legal right to take a decision depends, other things being equal, on their decision-making ability evaluated against a functional standard or "capacity test". In England and Wales, adults and minors must possess decision-making capacity in order to take legally valid decisions in respect of medical treatment.¹

A functional test of capacity includes cognitive criteria for assessing an individual’s ability to take a decision.² Evaluation of capacity against these cognitive criteria takes place in respect of a matter, for example, a decision about medical treatment on offer, at a given time.³ Importantly, the features of a matter germane to the assessment of capacity are not legally pre-specified. Rather, a judgement fixes "the information relevant to the decision", ⁴ or "what is involved" in the decision.⁵

This article is about what courts consider to count and what ought to count as capacity-relevant information for the purposes of refusal of life-prolonging medical treatment.⁶ We focus on whether this includes or ought to include the phenomenology of the options available to the agent—what the relevant states of affairs will feel like for them. For clarity, when we speak of the phenomenology of options, we have in mind a very familiar idea—what it is or feels like to have the experiences those options comprise or entail.⁷ For example, the phenomenology of eating good pistachio ice cream involves the felt experiential qualities of coolness, nuttiness, sweetness, pleasure etc.

Our discussion unfolds as follows. We briefly outline the law on adult and minor capacity in the context of medical decision-making. We then examine whether phenomenological information forms part of the informational basis of capacity tests in the law of England and Wales, and how this basis varies across adult and adolescent medical treatment cases. We identify an important doctrinal phenomenon. In the leading adolescent authorities, the courts appear to hold the first-personal phenomenology of the available options to count among the information that individuals seeking to refuse life-prolonging treatment must understand and appreciate in order to possess capacity, whereas adults in the leading cases on capacity to refuse medical treatment are not held to this (higher) standard.

We evaluate this differential treatment of adolescents and adults. We harness recent philosophical work on transformative choice—decisions involving options whose sensory character, and effect on our values and preferences, are grasped only through experience itself. We consider L.A. Paul’s argument that we require first-personal access to what a state of affairs feels like in order rationally to decide whether to accept or to avoid it.⁸ And its most prominent objection—that in situations of transformative choice, one may choose rationally in the absence of first-personal experience, provided one can estimate what a state of affairs will feel like using other sources (such as testimony). This literature establishes the importance of
phenomenological information to decision-making capacity, and a principled reason for both adolescent and adult capacity tests to hold such information relevant to the decision. However, we suggest that a legal policy justification—drawn from the value of individual decision-making authority—may support variance in the capacity-relevant information in the adolescent and adult functional tests, that is, exclusion of phenomenological information from the informational basis of the decision in the case of adults.

The significance of our contribution lies in its rigorous and contrastive doctrinal exposition of the informational bases of the adolescent and adult functional capacity tests in respect of refusal of (life-prolonging) medical treatment, in its philosophical and pragmatic interrogation of these bases, and in its conclusions regarding what capacity test(s) ought to include as information relevant to the decision in light of this analysis. *L.Q.R. 656*

A few clarifications are necessary before proceeding. The decisions on which we focus are refusals of life-prolonging treatment; we leave open whether our analysis generalises to other decisions for which capacity is required. We also leave aside discussion of other matters of relevance to adolescent capacity that have received extensive treatment elsewhere: claims to the effect that capacity depends on a choice’s degree of riskiness, *9* claims that there is an asymmetry in the capacity required to consent and to refuse respectively, *10* and mechanisms through which legally valid refusals of treatment might be denied legal effect, for example, in the case in which parents or courts possess the concurrent power to consent to treatment despite an adolescent possessing the capacity to refuse it. *11* And we defer analysis of the possibility that younger minors’ capacity is neither decision-nor time-specific; rather, it is global in a relevant sense. *12* Finally, we acknowledge that our analysis is grounded in such judicial dicta that exist following a comprehensive survey of reported judgments. Therefore, as Rosie Harding observes, "we cannot be clear as to the ways that the various submissions were framed". *13*

II. Medical Decisions and Decision-Making Capacity

In this section, we outline the law on minor and adult capacity in respect of medical decisions, ahead of engagement with the issue of whether the phenomenology of the available options is information relevant to the adolescent and adult capacity tests. *14*

1. Parental responsibility and children’s capacity regimes

i) Minors 15 years of age and younger

English law rebuttably presumes minors 15 years of age and younger to lack decision-making capacity. *15* Section 3(1) of the Children Act 1989 defines parental *L.Q.R. 657* responsibility as "all the rights, duties, powers, responsibilities and authority which by law the parent of the child has in relation to the child…". It follows that decisions in respect of the medical treatment of a minor aged 15 years or younger vest, by way of legal default, in the individual or individuals who exercise parental responsibility in the former’s regard. In the event of parental consent or refusal, treatment will, other things being equal, be lawful or unlawful to provide, respectively. *16*

Minors under 16 years of age may in principle acquire the legal power, other things being equal, to take their own medical decisions by rebutting the presumption of incapacity to give or to refuse consent to medical treatment through satisfaction of the conditions of the test laid down by Lord Scarman and Lord Fraser in *Gillick v West Norfolk and Wisbech AHA*, respectively:

"[A]s a matter of law the parental right to determine whether or not their minor child below the age of 16 will have medical treatment terminates if and when the child achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed…"

Provided the patient… is capable of understanding what is proposed, and of expressing his or her own wishes, I see no good reason for holding that he or she lacks the capacity to express them validly and effectively and to authorise the medical man to make the examination or give the treatment which he advises." *17*

ii) Minors 16 and 17 years of age

Section 8(1) of the Family Law Reform Act 1969 (FLRA 1969) provides that:
"The consent of a minor who has attained the age of sixteen years to any surgical, medical or dental treatment which, in the absence of consent, would constitute a trespass to his person, shall be as effective as it would be if he were of full age; and where a minor has by virtue of this section given an effective consent to any treatment it shall not be necessary to obtain any consent for it from his parent or guardian."

Minors aged 16 and 17 years of age, therefore, benefit from a presumption of legal capacity in respect of medical decisions, unless they lack mental capacity under the legal regime also applicable to adults, viz ss.1 – 3 of the Mental Capacity Act (MCA 2005). Under s.1(2) of the Act, capacity is rebuttably presumed. Section 2(1) of the MCA 2005 sets out the capacity test:

"a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.  "L.Q.R. 658  " 19

Section 3(1) of the Act sets out a functional test of capacity. It explains that "inability to make decisions" for the purposes of s.2(1) entails a person being unable:

"(a) to understand the information relevant to the decision, (b) to retain that information, (c) to use or weigh that information as part of the process of making the decision, or (d) to communicate his decision…".

These are individually necessary and jointly sufficient conditions. If any of the MCA 2005 s.3(1) abilities are found lacking in a person in respect of a particular decision at a particular time and the inability results from a mental impairment or disturbance, the presumption of capacity in s.1(2) of the Act is rebutted. 20

Section 3(4) of the Act provides a non-exhaustive specification of the information relevant to the decision for the purposes of s.3(1); it includes "information about the reasonably foreseeable consequences of—(a) deciding one way or another, or (b) failing to make the decision".

Section 8(3) of the FLRA 1969 provides that:

"Nothing in this section shall be construed as making ineffective any consent which would have been effective if this section had not been enacted."

On this basis, parental responsibility in respect of 16- and 17-year-olds subsists in the event that a 16- or 17-year-old minor lacks capacity—inter alios, parents may take a medical decision on the minor’s behalf. 21

2. Adult capacity

For adults, the outline legal position may now be simply stated. Individuals 18 years of age or older have legal capacity in respect of medical decisions, unless it is shown that—following the application of the s.2(1) and s.3(1) tests set against the information relevant to the decision—the presumption of mental capacity in s.1(2) of the MCA 2005 is rebutted.

III. Information Relevant to Mental Capacity and Phenomenology

In this section, we advance our central doctrinal claim:

In the case law on refusal of life prolonging medical treatment there is authority for the proposition that there exists a difference in the kind or scope of information held relevant to the decision for the purposes of determining adolescent and adult decision-making capacity, respectively.

In a series of cases, the courts require minors not only to demonstrate an understanding and appreciation of the states of affairs that may plausibly obtain as a result of their treatment decision, but seem in addition to require access to the first-personal phenomenology of those outcomes—what the experience of the relevant options will be or feel like for the adolescent from their own point of view. This contrasts with the position for adults, of whom the courts require understanding  *L.Q.R. 659  and appreciation of a narrower range of relevant information, exclusive of the phenomenology of the relevant options.
1. Adolescents to whom Gillick applies

Re E (A Minor) (Wardship: Medical Treatment), Re S (A Minor) (Consent to Medical Treatment) and Re L (Medical Treatment: Gillick Competence) each concerned Jehovah’s Witnesses under the age of 16 years who sought to refuse lifesaving blood transfusions. In each case, the court held the adolescent to lack capacity to refuse life-prolonging treatment. The courts motivate these decisions by requiring an adolescent, inter alia, to demonstrate that they understand and appreciate the following categories of information relevant to the decision for the purposes of the capacity test:

- the states of affairs that may plausibly obtain as a result of their choice (C); and
- the phenomenology of C or what C will feel like.

S includes C and all outcomes consequent on C, including those outcomes that follow C antecedent to what might be described as its final outcome. For example, and for our purposes, if C equals refusal of life-prolonging treatment, S is the process of dying and death, and F is the phenomenology of S. While we assume that no phenomenological properties attach to death (qua nonexistence), it is plausible that dying has a phenomenology.

In Re E, Ward J. was impressed by E’s "obvious intelligence [and] calm discussion of the implications [of his decision]", which included the "assertion even that he would refuse well knowing that he may die as a result". This seems to demonstrate that E understands and appreciates some relevant category S information—that S includes death. However, Ward J. held E not to possess decision-making capacity, because he lacked "full understanding of the whole implication of what the refusal of that treatment involves", viz:

"the pain he has yet to suffer, of the fear that he will be undergoing, of the distress not only occasioned by that fear but also—and importantly—the distress he will inevitably suffer as he, a loving son, helplessly watches his parents’ and his family’s distress… He may have some concept of the fact that he will die, but [not] as to the manner of his death and to the extent of his… suffering".

On one reading, E fails to grasp the consequences of his decision relevant to category S, viz, the process of dying. However, it is plausibly part of the ratio of Ward J.’s decision that E lacks capacity on category F—he fails to understand and appreciate the first-personal phenomenology of the manner of death—insofar as the emphasis is on the feelings consequent on refusing treatment and dying: pain, suffering, fear, distress and helplessness. *L.Q.R. 660

Re S admits of similar analysis. Johnson J. found S to lack capacity "commensurate with the gravity of the decision". While it seems clear that S understood and appreciated the ultimate consequence of refusal, she failed either to grasp the process of dying—the process aspects of category S—or the phenomenology of dying—category F, or she failed to grasp both. Like Ward J. in Re E, Johnson J. in Re S emphasises the importance of the first-personal experiential aspects of refusal. Again, it seems that they constitute the legal basis for the finding of incapacity:

"[S] does not understand the full implications of what will happen… an understanding that she will die is not enough. For the decision to carry weight she should have a greater understanding of the manner of the death and pain and the distress.'

In Re L, Sir Stephen Brown P. found L "certainly not ‘Gillick competent’ in the context of all the necessary details which it would be appropriate for her to be able to form a view about". From the evidence before the court, it may be that L understood and appreciated that death would in all likelihood follow refusal, her surgeon having explained that a "blood transfusion would be essential in order to save her life", to which she expressed a "clearly spoken… true wish" to refuse treatment. However, and although its presence was less explicit than in Re E and Re L, it appears that either a grasp of the process element of category S or category F are necessary to capacity. Sir Stephen Brown P. observed that:

"the girl herself has not been told or made aware [either by her surgeon or her father] of all the grave consequences, that is to say, the manner of the death [a ‘horrible death’ involving ‘very distressing’ gangrene], that would occur.”

The President subsequently converts this factual matter into a shortcoming that justifies the finding of incapacity: "[L] has not been able to be given all the details which it would be right and appropriate to have in mind when making such a decision".

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Importantly for our purposes, this move may imply that were L’s capacity tested under conditions of full disclosure, it would have been necessary, consistent with *Re E* and *Re S*, that she understood and appreciated what dying would *feel* like for her.

2. Adults to whom the MCA 2005 applies

We saw above that s.3(4) of the MCA 2005 non-exhaustively specifies the information relevant to the evaluation of an individual’s decision-making ability—*L.Q.R. 661* for the purposes of s.3(1) of the Act; it includes "information about the reasonably foreseeable consequences of—(a) deciding one way or another, or (b) failing to make the decision". Therefore, some conception of category *S* above—the states of affairs that result from the choice made—clearly is relevant information that an individual must understand and appreciate in order, other things being equal, to have decision-making capacity under the MCA 2005. The text of the statute leaves open, however, whether category *F*—the phenomenal properties of *S*—is information relevant to the decision, either in itself or as part of the reasonably foreseeable consequences of an individual’s choice. It is necessary to look to case law.

The MCA 2005 cases concerning medical treatment suggest that category *F* is not information relevant to the decision for the purposes of assessing capacity. *Re A (Capacity: Refusal of Contraception)* contains the most detailed discussion of what counts as capacity-relevant information for a medical decision—on the facts, contraception. 34 Here, the Local Authority argued that "reasonably foreseeable consequences" under s.3(4) of the MCA 2005 are:

"very wide words, clearly wide enough to import a requirement that the woman concerned is able to understand and envisage… what would actually be involved in caring for and committing to a child." 35

We interpret the Local Authority’s argument as including the requirement for understanding and appreciation of category *F* information—the individual must grasp what it will feel like to parent a child. 36 Bodey J. rejects this "social consequences" test, endorsing instead a capacity test for which the relevant information is confined to the "proximate medical issues" for reasons of public policy and practicality, respectively: 37 the "real risk of blurring the line between capacity and best interests"; 38 and the fact that the majority of decisions in respect of contraception occur during brief health care encounters. 39 The judge held that:

"[I]t is unrealistic to require consideration of a woman’s ability to foresee the realities of parenthood, or to expect her to be able to envisage the fact-specific demands of caring for a particular child not yet conceived (let alone born)…." 40

In respect of the "proximate medical issues", admittedly there is room to require understanding and appreciation of category *F* information as a condition of ability to take the decision. On this view, Bodey J. in *Re A* made two moves: first, the judge narrowed the category *S* information, excluding the "social" states of affairs—*L.Q.R. 662* that might plausibly obtain as a result of the choice; secondly, necessarily, the judge excluded the category *F* information attaching to this wider set of "social" outcomes. This would leave the category *F* information attaching to the proximate medical issues as information relevant to the decision. We do not, however, think this the best interpretation. If the public policy and practicality reasons speak against holding category *F* information relevant in respect of the realities of parenthood, they seem prima facie to speak against holding *F* relevant in respect of the proximate medical issues. Indeed, in the list of "immediate medical issues" that Bodey J. enumerates as relevant to the determination of capacity, there is no mention of the phenomenology of the matters relevant to contraception. 41

Our conclusion that category *F* is not capacity-relevant information for the purposes of s.3(1) of the MCA 2005 in medical treatment cases is better than the alternative for two further reasons. First, our interpretation of what the "proximate medical issues" entail is consistent with the dicta of Peter Jackson J. in *Heart of England NHS Foundation Trust v JB*—a refusal of life-prolonging treatment case—in which discussion of category *F* information is absent:

"[T]he question is whether JB can understand, retain and use and weigh the relevant information in coming to a decision… what is in my view required is that she should understand the nature, purpose and effects of the proposed treatment, the last of these entailing an understanding of the benefits and risks of deciding to have or not to have one or other of the various kinds of amputation, or of not making a decision at all.

What is required here is a broad, general understanding of the kind that is expected from the population at large. JB is not required to understand every last piece of information about her situation and her options." 42
We would highlight that calibration of relevant information to "a broad general understanding of the kind that is expected from the population at large" would seem to rule out inclusion of the phenomenology of the states of affairs that may plausibly obtain from an individual’s choice. For, in the case of many medical treatment decisions, we would not expect individuals to grasp the phenomenology attaching to the options—in JB’s case, amputation or leaving a potentially gangrenous limb untreated—since such facts are not readily accessible and thus not apt for inclusion in the notion of broad, general understanding.

Secondly, in *Re A* and *Heart of England NHS Foundation Trust v JB*, respectively, Bodey J. and Peter Jackson J. each draw on a (different) leading refusal of life-prolonging medical treatment case pre-dating the passage and entry into force of the MCA 2005. Of particular interest for our purposes is Bodey J.’s endorsement of Dame Elizabeth Butler-Sloss P.’s dictum in *Ms B v An NHS Hospital Trust* on the danger that more demanding tests for capacity—in A’s case, a broad, "social" and phenomenological conception of relevant information—blur the line between capacity and best interests such that an individual will possess capacity only if they make the decision others regard as "best" for them. In *Ms B*, this concern to distinguish capacity and best interests animates the President’s explicit rejection of the contention that the information relevant to the decision for the purposes of determining capacity includes category F.

Ms B sought to refuse mechanical ventilation. Her clinicians opposed this decision and maintained treatment for a significant period of time. In proceedings against the Hospital Trust for battery, Mr G, one of Ms B’s treating spinal consultants, argued that:

"patients needed to experience [the full range of environmental control systems for spinal cord injury] in order to know what life would be like … [Ms B] was unable to give informed consent, not because of a lack of capacity in general but her specific lack of knowledge and experience of exposure to a spinal rehabilitation unit and thereafter to readjustment to life in the community."

According to Mr G, in order to have capacity to refuse medical treatment, it is necessary for an individual to understand and appreciate what treatment feels like first-hand. An individual in Ms B’s position needs to undergo treatment, in order to gain epistemic access to its first-personal phenomenal properties, before we can determine that she understands and appreciates the information relevant to the decision. This approach would make a grasp of category F information a requirement for the possession of capacity.

Dame Elizabeth Butler-Sloss P. categorically rejected Mr G’s evidence and the proposition that category F is information relevant to the decision for the purposes of the test of capacity:

"I have the gravest doubts as to its legal validity and indeed its practicality. Even in issues of the utmost significance and gravity people, including patients, have to make decisions without experience of the consequences and his requirement is unrealistic.

[Mr G’s] view that not to have experienced rehabilitation means that the patient lacks informed consent cannot be the basis for the legal concept of mental capacity. If Mr G were correct, the absence of experience in the spinal rehabilitation clinic would deny Ms B or any other similar patient the right to choose whether or not to go to one. It is not possible to experience before choosing in many medical situations. That is not the state of the law nor, I assume, would the medical profession accept it for many fundamental and practical reasons."

Importantly for our purposes, Mr G’s argument is substantively similar to that advanced by the courts in the adolescent cases of *Re E*, *Re S*, and possibly *Re L*. In both *Ms B* and these adolescent refusal cases, the argument is that one must grasp the first-personal phenomenology of the available options in order to have capacity to choose one of them. Reading *Ms B*, *Re A*, and *Heart of England NHS Foundation Trust v JB*, together, since a grasp of category F information is not required for the possession of capacity, we may draw the following conclusion:

According to the leading cases, adults subject to the MCA 2005 need understand and appreciate only category S information to have capacity, whereas adolescents to whom *Gillick* applies are required to understand and appreciate category S and category F information in order to have decision-making capacity.

This conclusion leaves individuals aged 16 and 17 years to whom the MCA 2005 applies in an uncertain position. In principle, either the adult conception of information relevant to the decision, or the adolescent conception of capacity-relevant information
may apply. Regardless, we have shown that there exists a difference in the information judged relevant to the decision as between the adolescent and adult functional tests of capacity, which entails a difference in the extent of understanding and appreciation required of decision-makers. These differences require investigation, to which we shall shortly turn.

But first it is necessary to respond to an objection to our reading of the doctrine: that we misinterpret the case law in one of two ways. Either Re E, Re S and Re L do not disclose an approach that assesses adolescent capacity against a broader informational basis compared to adults, or the adult MCA 2005 case law requires individuals subject to the Act to understand and appreciate category F information such that adult capacity is evaluated on the same informational basis as adolescents. If this objection holds, adults and adolescents would be subject to the same standard of functional capacity. *L.Q.R. 665

3. A misreading of the doctrine?
One might object that we are making too much of Re E, Re S and Re L: they are merely three first instance decisions from the 1990s, each concerning Jehovah’s Witnesses. Re E, Re S and Re L do not, then, evince an approach that evaluates adolescent capacity to refuse life-prolonging treatment against a broader informational basis than is the case for adults. We have replies.

First, on examination of the reported minor capacity and medical treatment cases—most of which do not concern Jehovah’s Witnesses or refusal of life-prolonging treatment—none are inconsistent with Re E, Re S and Re L. 52 Indeed, the dicta leave plenty of room for category F to form part of the capacity-relevant information. In Re R (A Minor) (Wardship: Consent to Treatment), Lord Donaldson M.R. held, obiter, that Gillick "competence" involves:

"not merely an ability to understand the nature of the proposed treatment… but a full understanding and appreciation of the consequences… of the treatment in terms of intended and possible side effects and, equally important, the anticipated consequences of a failure to treat." 53

In Re X (A Child) (Capacity to Consent to Termination), expert evidence from an adolescent psychiatrist (accepted by Sir James Munby P.) took the view that:

"although X would understand termination and its effect—the death of her baby—she did not have a full understanding of what the pregnancy would involve—the later stages and the birth—and only a very limited understanding of what having a child means, the responsibilities it entails and the impositions it would place upon her." 54

True, none of the cases subsequent to Re E, Re S and Re L explicitly insist on understanding or appreciation of phenomenological information. However, none engage with their substance, let alone contain a statement to the effect that they are wrongly decided. This is likely for two reasons that are compatible with our interpretation of the law.

For one, there is often sufficient doubt whether the minor understands and appreciates the category S information—the states of affairs that may plausibly obtain as a result of their choice—to obviate forensic consideration of their grasp of category F. In Re C (A Minor) (Medical Treatment: Court’s Jurisdiction), Dr D2’s expert evidence (which Wall J. accepted) alluded to C’s inability to make a "realistic assessment of the short and long-term consequences of refusal" and observed that C’s "apparent consent is given only to the basics of treatment rather *L.Q.R. 666 than the whole substance". 55 In Re JA (A Minor) (Medical Treatment: Child Diagnosed with HIV), which concerned capacity in respect of antiretroviral therapy, Baker J. held that since JA:

"does not accept the diagnosis [of HIV seropositivity], it must follow, in my judgment, that he does not fully understand the implication of not receiving the treatment. He therefore lacks the understanding necessary to weigh up the information and arrive at a decision." 56

Because JA did not accept the basic fact of his diagnosis, 57 there was no need to proceed to a full analysis of whether he understood the implications of his choice. Similar analysis holds for Re X (A Child) (Capacity to Consent to Termination). 58

For another, the "concurrent consents" doctrine—according to which adolescents with capacity have the power to consent to medical treatment, but not to refuse it determinatively 59 —offers judges a more straightforward way to set aside minors’ medical decisions than approaches involving a capacity determination. Recourse to the doctrine explains why the court often fails adequately to address capacity prior to determining best interests in cases involving adolescents. 60
recent cases—why the court may accept minor capacity without detailed scrutiny: because it may override adolescent refusals regardless. However, the continued vitality of the concurrent consents doctrine, tells us little about the status of minor capacity doctrines or whether they require understanding and appreciation of phenomenological information. Such doctrines "lie in wait".

Secondly, we would deflect the concern that the reasoning in Re E, Re S and Re L is specific to the religion—or perhaps the Jehovah’s Witness faith, specifically—of the minors involved. The courts’ reasoning in Re E and Re S and possibly Re L in respect of the requirement to grasp the first-personal phenomenology of S is not unique to or inextricably bound up with the Jehovah’s Witness faith in particular, or refusals based on religious reasons in general. Even if an unwillingness to permit adolescents to martyr themselves motivates the *L.Q.R. 667 insistence on understanding and appreciation of category F information, the approach to adolescent capacity we articulate is applicable without recourse to facts relating to religious faith.

Thirdly, we are not alone in concluding that Re E, Re S and Re L disclose a different and more demanding functional test of capacity than that which applies to adults. Imogen Goold argues in respect of Re E and Re S that "children are required to understand more about their choices and their implications than competent adults". Emily Jackson observes that:

"in all [of Re E, Re S and Re L], the standard of competence demanded of children who wanted to refuse treatment was extremely high, and perhaps even unattainable." 65

Jackson further notes in respect of Re E, that:

"Of course, most adults do not fully understand what it is like to die, and it could therefore be argued that children like [E] are being held to an excessively demanding test for capacity." 66

This point is also made by Michael Freeman:

"Ward J.’s reasoning should be carefully studied. Were it applied to an adult, it is dubious whether refusal to be treated would ever be allowed." 67

David Archard and Marit Skivenes advance that "a child should not be judged against a standard of competence by which even most adults will fail", and proceed to explain how the English case law (inter alia, Re E and Re L) adopts a stringent account of capacity for adolescents that:

"would surely be beyond many adults who are nevertheless accorded the freedom to make their own decisions in situations similar to those faced by the young persons… [including] ‘full’ appreciation of the ‘whole’ implications, an understanding of all the relevant issues." 68

Our interpretation of Re E, Re S and Re L leads us to the same conclusion as these commentators. What our discussion adds is the isolation and scrutiny of a precise feature—phenomenological information—that establishes how the adolescent capacity test is different and in consequence more demanding than the adult functional test. *L.Q.R. 668

We turn now to the worry that we have misread the adult capacity doctrine. This requires only brief treatment. First, the exclusion of category F is consistent with a general concern among judges applying the MCA 2005 not to impose a standard of understanding and appreciation of relevant information that would "set the bar too high" for individuals whose capacity is challenged. For example, in L v J, Macur J. held that:

"it is not always necessary for a person to comprehend all peripheral details… the person under review must comprehend and weigh the salient details relevant to the decision to be made." 69

To clarify, our interpretation of the judicial approach is as follows:

Irrespective of whether the phenomenology of S might count among the salient details for the purposes of medical treatment decisions, since the phenomenology of S is often epistemically inaccessible, it cannot have salience relative to the decision to be made; for it to have salience would demand too much of adult individuals whose capacity is in question.
The dicta of Jackson L.J. in *RB v Brighton and Hove City Council*—endorsing Bodey J.’s "pragmatic" approach to the interpretation of s.3 of the MCA 2005 in *Re A*—illustrate the point well:

"In re A exposes the uncertain penumbra which surrounds MCA section 3. The information relevant to any big decision, such as whether to have a baby, is almost limitless… All long term decisions are made on the basis of peering into an unknown future. Any court applying the test set out in section 3 is imposing an impossible burden if it requires the person to understand and weigh up all information relevant to such decision." 70

Secondly, while it is true that some MCA 2005 case law concerning decisions not involving medical treatment seems to include category F as information relevant to the decision, 71 this fact does not take us very far in respect of whether the phenomenology of S is capacity-relevant for medical treatment decisions. It is axiomatic that the information relevant to the decision for the purposes of s.3 of the MCA 2005 will vary according to the kind of decision to be made. 72

Thirdly, we are mindful of the "inquisitorial" nature of proceedings in the Court of Protection. As Jackson L.J. notes in *RB v Brighton and Hove City Council*, "[t]he task of the court is to apply the statutory provisions, paying close heed to the language of the statute". 73 As such, first-instance MCA 2005 decisions are not straightforwardly precedent-setting. 74 However, insofar as the provisions of the *L.Q.R. 669* Act have an "uncertain penumbra", 75 judicial decisions undertaking clarificatory labour go beyond mere application of statute to factual context; they necessarily involve the formulation of legal standards for kinds of matter, which may be applied, distinguished or rejected by other first instance judges, 76 and subject to appellate consideration. 77 Therefore, we submit that our interpretation of the MCA 2005 case law and judicial decisions pre-dating the Act has authoritative, even if not binding, value within an “inquisitorial” system. The cases on which we base our claim that category F is not capacity-relevant information in adult medical treatment cases engage in detailed consideration of the information relevant to the decision in this context and are consistent with the general approach of the courts to the MCA 2005 functional test.

IV. Evaluating the Relevance of Phenomenology to Decision-Making Capacity

In this section, we critically scrutinise the relevance of phenomenological information to the adolescent and adult tests of capacity in light of the philosophical literature on transformative choice.

We argue above that the test for capacity contained in *Re E, Re S* and possibly *Re L* requires that an adolescent understand and appreciate the following categories of information relevant to the decision in life-prolonging medical treatment cases:

- S, the states of affairs that may plausibly obtain as a result of their choice (C); and F, the phenomenology of S or what S will feel like;

whereas in the adult case law considered, only category S is capacity-relevant information for the purposes of the test for inability to take a (medical) decision contained in s.3(1) of the MCA 2005.

What might account for the different requirements of understanding and appreciation of category F information as between adolescents and adults? A rational reconstruction reveals that the courts in the adolescent and adult cases employ different explanatory strategies, respectively.

In *Re E, Re S* and *Re L*, the courts seem to appeal to differences between adolescents and adults in terms of general experience and ability. First, the insistence on understanding and appreciation of category F information may appeal to an apparent lack of life experience on the part of adolescents as a class. On this view, the pool of experience from which adolescents draw is often too small and too shallow to furnish the requisite phenomenological information characterising the treatment options. Secondly, it may be that many adolescents lack, not insufficient breadth and depth of experience, but rather the ability to draw fitting phenomenological inferences applicable to their situation. The factors to which these explanations appeal prima facie supply a presumption against the ability to understand and appreciate category F information—the phenomenology of S—hence the need explicitly to demonstrate these abilities during the evaluation of adolescent capacity. *L.Q.R. 670*

In *Re S* and *Re L*, Johnson J. and Sir Stephen Brown P. comment on the lack of life experience possessed by the adolescents, respectively:
"Of necessity she has had a sheltered upbringing"; 78

“She has led what has been expressed to have been a sheltered life, not an unrealistically sheltered life, but nevertheless a sheltered life… It is, therefore, a limited experience of life which she has.” 79

In Re E, E’s youthful enthusiasm for his convictions may have blunted his ability adequately to assess what the states of affairs that might plausibly obtain as a result of his decision would be or feel like from his own point of view. Ward J. observes that:

“[T]eens express views with vehemence and conviction—all the vehemence and conviction of youth! Those of us who have passed beyond callow youth can all remember the convictions we have loudly proclaimed which now we find somewhat embarrassing.” 80

Conversely, our analysis of the adult cases above shows that the courts seem to exclude the capacity-relevance of phenomenological information on policy and practicality grounds. In particular, the desire not to "set the bar [of capacity] too high" seems of primary concern. 81

In what follows, we explain how the literature on transformative choice illuminates whether either of these strategies serves to justify differences in the relevance of phenomenological information to adolescent and adult capacity, respectively. But first we shall need briefly to discuss the relation between instrumental rationality and decision-making capacity.

1. Rationality and decision-making capacity

In order to evaluate the merits of the inclusion or exclusion of category F in the information relevant to decisions in respect of life-prolonging medical treatment, we must first provide an account of the normative standard that grounds—in part, in the case of the MCA 2005—the determination of whether an individual has capacity in English law.

In Re X (A Child) (No.2), Munby J. argues that capacity under the MCA 2005 and Gillick competence are "historically and conceptually quite distinct", insofar as capacity under the Act is a matter of "psychiatry", whereas Gillick competence is a matter of "child and adolescent psychology". 82 It is true that the MCA 2005 and Gillick competence fulfil different purposes. The former establishes whether an individual fails to meet the standard of decision-making presumed in adults, whereas the latter tests for an adolescent’s acquisition of the decision-making capacities commensurate with (respect for) agency. What Munby J.’s argument neglects, however, is that the same operative standard answers these questions of deviation or acquisition, respectively. 83

Both the MCA 2005 functional test and Gillick competence are concerned with an individual’s actual or functional decision-making ability. 84 We argue that this ability is evaluated by reference to a standard of instrumental rationality, that is, whether an individual behaves in accordance with what they value most, in light of what they believe. For a set of options, it is instrumentally rational to choose suitable means to the outcome expected to be best, where best is determined by an individual’s subjective valuations at a time and weighted for their beliefs about the probability of the outcomes consequent on the options obtaining. 85

The instrumental standard of rationality provides a very good explanation of the s.3(1) MCA 2005 functional test. The understanding criterion in s.3(1)(a) of the Act corresponds to grasping descriptively what the set of options entail. The using or weighing criterion in s.3(1)(c) of the Act requires an individual to appreciate the outcomes given what they currently most value, to assign probabilities, and to select the best option. The MCA 2005 s.3(1)(b) retaining criterion is essential to understanding, using or weighing.

There is ample case law on adult capacity that exemplifies a judicial commitment in principle to functional ability understood as instrumental rationality, that is, to evaluation of capacity on the basis of an individual’s own values, as opposed to what is "objectively" rational. For example, in King’s College NHS Foundation Trust v C, MacDonald J. held that:

"[An individual] is entitled to make her own decision [whether to accept treatment] based on the things that are important to her, in keeping with her own personality and system of values and without conforming to society’s expectation of what constitutes the ‘normal’ decision in this situation (if such a thing exists)..." 86
And in Heart of England NHS Foundation Trust v JB, Peter Jackson J. held:

"[T]he decision about whether to accept or reject medical advice involves weighing up the risks and benefits according to the patient’s own system of values against a background where diagnosis and prognosis are rarely certain, even for the doctors. Such decisions are intensely personal… There are no [objectively] right or wrong answers. *L.Q.R. 672

The temptation to base a judgement of a person’s capacity upon whether they seem to have made a good or bad decision, and in particular upon whether they have accepted or rejected medical advice, is absolutely to be avoided." 86

We contend that Gillick competence ought also to be understood as evaluating the instrumental rationality of a minor’s decision. First, while both Lord Scarman and Lord Fraser in Gillick hold that minor competence requires a sufficient degree of understanding "what is proposed", 87 an understanding-only conception of capacity qua intellectual comprehension engages in limited scrutiny of an individual’s mental processes—it neglects how relevant information is used to make a decision. 88 As Benjamin Freedman observes, "tests that focus upon understanding eliminate the notion of competence in favor of the notion of information". 89

Secondly, it is not obvious that Lord Scarman adopts an understanding-only conception of minor competence, since the judgment of Addy J. in Johnston v Wellesley Hospital is cited with approval: 90

"[T]he law on this point is well expressed in the volume on Medical Negligence (1957), by Lord Nathan, p. 176: ‘… an infant who is capable of appreciating fully the nature and consequences of a particular operation or of particular treatment can give an effective consent thereto…’. " 91

Appreciation is conceptually distinct from understanding insofar as it entails "the ability to apply information, including consequences of the decision, to oneself". 92 Moreover, Lord Scarman holds that "a doctor will have to satisfy himself that [the minor] is able to appraise" the additional "moral and family" questions relevant to the decision. 93 Appraisal requires the exercise of judgement, and therefore is conceptually distinct and more demanding than mere understanding; it approximates to the requirement to use or weigh the capacity relevant information.

Thirdly, in principle, Gillick competence requires evaluation of a minor’s capacity from the standpoint of their own values. 94 It is implicit in Gillick itself that a minor with capacity may consent to contraceptive treatment, but they are not required so to do: they will not lack capacity merely because they consent to or refuse treatment.

For all these reasons, we hold that the normative standard of instrumental rationality underpins both minor and adult capacity law in England and Wales. The significance of this underlying framework in respect of category F information is laid bare in situations of transformative choice, to which we now turn. *L.Q.R. 673

2. Decision-making capacity and transformative choice

The philosophical literature on transformative choice, decisions or experiences provides insight into the relevance of phenomenological information to instrumentally rational decision-making—and our ability to access such information and thereby make rational decisions. Engagement with this literature is therefore fruitful for the purposes of our discussion of the relevance of category F information to functional capacity under s.3(1) of the MCA 2005 and Gillick competence, respectively.

L.A. Paul identifies a category of "transformative choice" involving epistemically and personally transformative experience. Epistemically transformative experience involves an agent experiencing a radically new phenomenon from which:

"she gains new abilities to cognitively entertain certain contents, she learns to understand things in a new way, and she may even gain new information." 95

Personally transformative experience:
"can change your point of view, and by extension, your personal preferences, and perhaps even change the kind of person that you are or at least take yourself to be."  

Experiences that are epistemically transformative in nature are cognitively cut off or closed to us. In order to assign a subjective value to such experiences, according to Paul, we require first-personal access to their phenomenology or what it feels like to have them. This is because the subjective value of an experience is a function of what it feels like for the agent. Experiences that are personally transformative in nature are liable to change our point of view and therefore our preferences. This makes it hard to know the values—one’s current or one’s future—on which one should act.

"A radically new experience can fundamentally change your own point of view so much and so deeply that, before you’ve had that experience, you can’t know what it is going to be like to be you after the experience. It changes your subjective value for what it is like to be you, and changes your core preferences about what matters.

Paul argues that transformative experiences:

"constitute a class of experiences that raise a special problem for decision-making, at least, for decision-making made from the subjective perspective of the individual."

When we lack access to the relevant phenomenological and subjective information entailed in transformative choice, we are unable to assign it a subjective value and without its subjective value we cannot rationally choose from the options available on an instrumental standard.

We argue above that s.3(1) of the MCA 2005 and Gillick competence evaluate an individual’s functional decision-making ability against a normative standard of instrumental rationality. Therefore, we may apply Paul’s theory to the issue of decision-making capacity in situations of transformative choice. In such situations, an individual must understand and appreciate the following categories of information for the purposes of functional capacity:

- the states of affairs that may plausibly obtain as a result of their choice (C); and
- the first-personal phenomenology of S, or what S feels like from their own point of view.

Strikingly, F₁ reflects the conception of phenomenological information that the courts hold relevant to Gillick competence in Re E, Re S and possibly Re L. That is, these cases insist on understanding and appreciation of the first-personal phenomenology of S. Prima facie, therefore, there is strong reason to hold category F₁ to be information relevant to a decision in respect of life-prolonging treatment for the purposes of evaluating adolescent capacity. We test for understanding and appreciation of F₁ because it is essential to rational choice.

We are now able to appraise the first strategy the courts employ to explain variance between the adolescent and adult capacity tests in respect of the capacity-relevance of category F information—appeal to differences between adolescents and adults in terms of general experience and ability.

The difficulty for this strategy is that courts would be wrong to view the unestablished ability to grasp the first-personal phenomenology of S in situations of transformative choice as an issue unique to adolescents. For on Paul’s argument, one’s past and present experience cannot provide a sufficient basis from which to infer what it will feel like to refuse life-prolonging treatment, save in exceptional cases. The fact that adults may have more life experience or more robust reasoning skills does nothing to address the challenge Paul’s account of transformative choice poses for rational decision-making.

So prima facie, we have strong reasons for holding category F₁ to be information relevant to the decision to refuse life-prolonging treatment for both adults and adolescents. Whether such information is relevant all things considered depends on the satisfaction of two further conditions: first, whether a decision in respect of life-prolonging treatment involves transformative choice; secondly, whether F₁ is the conception of capacity-relevant information we ought to accept.

Decisions in respect of life-prolonging treatment may involve transformative choice, since one of the states of affairs that plausibly obtains as a result of refusing treatment is death. Evan Thompson argues that death—understood
as "the whole process of dying"—involves transformative experience, albeit of a particularly difficult kind given "[death’s] inevitability and finality, and the dissolution it entails". Thompson observes that the epistemically and personally transformative dimensions of death are "well documented by those who care for the dying and listen to what they have to say".

"Death is epistemically transformative because it teaches you things you cannot learn until you undergo it, and it is personally transformative because it deeply changes how you experience your self." As one illustration, Thompson refers to philosopher Ken Chung’s reflections on dying from pancreatic cancer and transformative experience. Chung writes:

"[T]here is something to knowing that you have a disease that’s going to kill you soon… I think it does transform you… If you are young, you still want to do things that can shape the rest of your life. If you are older or if you are sick like me, you might not care so much to shape the rest of your life as much as to live it and appreciate what you can. These differences between us are unavoidable and understandable. But it means that no matter how much some of you are there for me, I still feel alone. You do not know what it’s like to be dying, and you probably can’t know, until it happens to you."

There may be a further dimension of transformative experience in play in some life-prolonging treatment decisions. For some individuals, undergoing life-prolonging treatment may be epistemically and personally transformative. A Jehovah’s Witness who receives a blood transfusion may gain access to a new kind of understanding that in turn changes their perspective on their self and the world around them. Or an individual who has experienced chronic ill health may gain experience of the hitherto foreign concept of (improved) wellness and new insight into their values and preferences.

We add the following caveat: for some individuals with previous experience of serious illness or severe trauma, the choice to consent to or to refuse life-prolonging treatment may not be transformative in the way described. Perhaps this is the case for individuals who experience cycles of advanced cancer and remission, or those who have had "near-death" experiences due to accidents or inflicted suffering. But in most instances, for most individuals, a decision in respect of life-prolonging treatment will involve transformative choice. And this would be the case across adults and adolescents.

Is the most plausible conception of capacity-relevant phenomenological information? A common objection advanced by Paul’s critics is that it is unnecessary for an agent to know precisely what the outcomes of the available options feel like from their own perspective in order for their decision to count as rational on an instrumental standard. Rather, it is argued that one can garner relevant information from a variety of sources, including observation, partial analogues, testimony, and statistics. With this information in hand, an agent may act rationally in the cases envisaged by Paul, despite lacking first-personal phenomenological information about the outcomes of their options. It is helpful to set out in some detail Richard Pettigrew’s reasoning:

"[F]aced with uncertainty about the utilities I assign to possible outcomes of available acts, I simply fine-grain the possible states of the world to include the various possible utility hypotheses about which I am uncertain… [For an epistemically transformative experience, my credences about the utility hypotheses] must be based… on statistical evidence that summarises what other people report about their utility functions… We are accustomed to using statistical evidence based on facts about other people in order to make decisions about ourselves… Why is it different when the statistical evidence bears on the hypotheses about my own utility function?"

*Mutatis mutandis*, Pettigrew’s argument can support the following representative conclusions.

"[T]he only admissible evidence [on Paul’s view], is complete knowledge of the phenomenal character of the experience… this restricted view is false. We can use testimony, behavioral observation and inference from similar experiences to rationally estimate the value of new experiences."

"[O]ne can receive testimonial evidence about the value of certain experiences, and make a rational decision on that basis, even if one doesn’t know anything specific about what the experiences would be like."
If one is persuaded by these arguments against Paul, the requirement of understanding and appreciation of category $F_1$ information in the tests for capacity will lack warrant. Paul’s critics do not deny that phenomenological information is important to rational choice, however. Their objection to Paul does not imply *L.Q.R. 677* that, among categories $F$ and $S$, only category $S$ is capacity-relevant information. Rather, their arguments support the inclusion of a different version of $F$, according to which an individual must understand and appreciate, for the purposes of functional capacity:

$S$, the states of affairs that may plausibly obtain as a result of their choice ($C$); and $F_2$, the expected phenomenology for them of $S$, given the relevant evidence from observation, partial analogues, testimony, statistics and so on.

$F_2$ is weaker than $F_1$ because an individual need not possess the first-personal experiential information required by Paul in order to make a rational decision and, to wit, to have functional capacity. On $F_2$, for example, it would be sufficient for a Jehovah’s Witness offered a lifesaving blood transfusion, other things being equal, to understand and appreciate information relevant to the respective expected subjective experience of refusing, dying, and entering the Kingdom of Heaven, and consenting, living, and violating the fundamental tenets of one’s religion — or experiencing forced treatment that potentially involves the same. And the first-hand experience of spinal rehabilitation would not be necessary for Ms B in order rationally to refuse it. However, it would be important for these individuals to understand information provided by their clinicians about what they should expect to feel were they to undergo or to refuse treatment, and to appreciate that information by assigning appropriate subjective valuations in its light.

For these examples, the evidence required to support a rational decision may not be readily available to individuals at large, whether adolescents or adults. Generally, while we would not rule out that some adults have familiarity with the kinds of evidence required by $F_2$, we might question whether understanding and appreciation of such evidence represents the life experience of adults as a class. As such, $F_2$ does not provide more support than $F_1$ for the courts’ first explanatory strategy above—the appeal to differences in life experience or the ability to draw appropriate phenomenological inferences between adolescents and adults in order to justify inclusion of category $F$ information in the *Gillick* competence test, but exclusion of such information from the MCA 2005 functional test.

Whether we side with Paul or her opponents on the nature of the phenomenological information required for rational choice, and therefore whether we include $F_1$ or $F_2$ in the functional capacity test, what matters is that, either way, the s.3(1) MCA 2005 test and the *Gillick* competence test should include a requirement for understanding and appreciation of a category of information beyond $S$, in the neighbourhood of $F$. That is, unless the second explanatory strategy the courts employ—appeal to policy and practical reasons—justifies evaluating adolescents’ grasp of category $F$ information, but not adults’.

3. Setting the bar too high?

We argue above that the courts appeal to policy and practical reasons—particularly a concern not to set the bar of capacity too high—to exclude understanding and appreciation of category $F$ information from the adult functional capacity test. We *L.Q.R. 678* conclude this article by considering whether the worry of the bar’s position justifies different treatment of adult and adolescent capacity with regard to the grasp of phenomenological information, notwithstanding the principled reasons for its evaluation in respect of both groups. We have two points in this regard.

First, it is a mistake to think that adoption of $F_1$ as information relevant to decisions in respect of life-prolonging medical treatment for the purposes of the MCA 2005 functional test would raise the bar of capacity for most adults. We should not neglect that the MCA 2005 test for capacity contains a causal, "diagnostic" requirement. Under s.2(1) of the Act, inability to take a decision on the s.3(1) functional criteria must result from "an impairment of, or disturbance in the functioning of, the mind or brain". Since, on Paul’s view, the problem of transformative choice is general—affecting all agents not acquainted with the first-personal phenomenology of the outcomes of their options—for most individuals an inability to take this kind of decision will not be attributable to a mental impairment or disturbance. Therefore, while inclusion of $F_1$ as capacity-relevant information for adults would raise the bar of functional capacity for the purposes of s.3(1) of the MCA 2005, it would not set the bar of capacity higher all things considered, since the functional element would not interact with the diagnostic element in the way causally required for incapacity by s.2(1) of the Act.

Secondly, there is force in the argument that adopting $F_2$ as capacity-relevant information for life-prolonging medical treatment decisions for the purposes of s.3(1) of the MCA 2005 would raise the bar of capacity. For $F_2$ adds to the information an
individual must understand and appreciate in order to have capacity vis-à-vis the relevant decision. And insofar as $F_2$ involves phenomenological predictions based on information that is not (necessarily) first-personal in nature, it is compatible with the causation requirement of s.2(1) of the MCA 2005. That is, a mental impairment or disturbance may cause decision-making inability if it interferes with an individual’s functional processes such that they cannot understand relevant information, for example, testimony, about what their options entail in terms of expected phenomenology, or they cannot use such information to determine the value of their options based on what they expect them to feel like from their own perspective.

Would raising the bar in this way be justified? On the one hand, adoption of $F_2$ would make the MCA 2005 functional test sensitive to phenomenological information, which the literature shows is essential to rational decision-making in the case of transformative choice. Thus we might argue that inclusion of $F_2$ in the capacity-relevant information for adult decisions in respect of life-prolonging treatment would bring the functional test more in line with the standard of instrumental rationality, thereby justifying any associated increase in burdensomeness. Adoption of $F_2$ for purposes of the MCA 2005 would have the *L.Q.R. 679* added benefit of aligning the adult and adolescent standards of capacity-relevant information somewhat in life-prolonging treatment cases, assuming $F_1$ were maintained for adolescents subject to *Gillick*.

On the other hand, we ought carefully to consider the demandingness of the MCA 2005 functional test for capacity relative to other life decisions of a similar nature or structure. Individuals whose capacity is unchallenged are free to make transformative choices—for example, whether to have children—notwithstanding doubts about the rationality of their decision-making. 122

The institutional costs of interference—for example, those associated with information provision and evaluation of its grasp—may be a factor relevant to this latter stance. Matters of practicality apart, there is perhaps a more fundamental reason in play. The inclusion of $F_2$ in the capacity-relevant information might plausibly be said to threaten the value instantiated by individuals possessing the authority to make their own transformative choices, including life-prolonging treatment decisions. The argument—of which the courts seem mindful—therefore, is that we owe deference to individual decision-making authority and thus should be reluctant to intrude in important life decisions. 123 As such, individuals who come into contact with the social institutions tasked with application of the MCA 2005 ought not to be required to understand and appreciate a wider set of relevant information than individuals who make similar decisions in other domains of life. The dictum of Hedley J. in *A NHS Trust v P* is apposite:

"Most importantly, the Act provides: ‘A person is not to be treated as unable to make a decision merely because he makes an unwise decision’… The intention of the Act is not to dress [a putatively] incapacitous person in forensic cotton wool but to allow them as far as possible to make the same mistakes that all other human beings are at liberty to make and not infrequently do." 124

The value in deferring to individual decision-making authority may provide support for dispensing of understanding and appreciation of category $F$ information for life-prolonging medical treatment decisions for adults subject to the s.3(1) MCA 2005 functional test. If we owe adolescent decision-making authority less deference, all things considered, we might justifiably vary the respective standards of capacity-relevant information for adults and adolescents—to ask more of adolescents. This seems plausible. We may value decision-making authority to a lesser degree relative to other goods in the case of adolescents compared to adults. 125 And as a matter of parity of treatment between medical decisions and other life choices, we seem to ask as much of adolescents vis-à-vis medical decisions as we do other domains. 126 If we owe adolescent decision-making authority less deference, *L.Q.R. 680* positioning the bar of capacity so as to require adolescents to understand and appreciate the phenomenology of the options available to them is less worrisome than it is in the case of adults. *Re E, Re S* and *Re L* may defensibly and without inconsistency reflect the standard of capacity-relevant information for adolescents’ decisions in respect of life-prolonging treatment.

Isra Black

Associate Professor, Faculty of Laws, UCL

Lisa Forsberg

Research Fellow, Oxford Uehiro Centre for Practical Ethics, Faculty of Philosophy and Fulford Junior Research Fellow, Somerville College, University of Oxford
Anthony Skelton

Associate Professor, Department of Philosophy, University of Western Ontario

Footnotes

1 Some terminological clarifications. We employ decision-making capacity and capacity interchangeably. By minor we mean an individual 17 years of age or younger; by adolescent we mean an older minor. In keeping with the Children Act 1989, by "parent" we mean the—natural or legal—person or persons who exercise parental responsibility.


3 MCA 2005 s.2(1).

4 MCA 2005 ss.3(1)(a) and 3(4) (emphasis added).


6 The issue of information relevant to the decision for the purposes of capacity under the MCA 2005 is eliciting greater attention and importance. See e.g., A Local Authority v JB [2021] UKSC 52; [2022] A.C. 1322 (capacity to engage in sexual relations); Re A (Capacity: Social Media and Internet Use: Best Interests) [2019] EWCOP 2; [2019] Fam. 586; Re B (Capacity: Social Media: Care and Contact) [2019] EWCOP 3; [2019] C.O.P.L.R. 163 (capacity to use social media for communication).

7 For a detailed discussion of phenomenology in our sense, see Thomas Nagel, "What Is It Like to Be a Bat?" (1974) 83 Ph.R. 435. Phenomenology as we mean it is more basic than the related, yet distinct, notion of "phenomenological awareness" that Camillia Kong employs in Mental Capacity in Relationship: Decision-Making, Dialogue, and Autonomy (Cambridge: Cambridge University Press, 2017); phenomenological awareness is the virtue of being attuned to other individuals’ potentially divergent sense experiences.


11 Re R (A Minor) (Wardship: Consent to Treatment) [1992] Fam. 11; Re W (A Minor) (Medical Treatment: Court’s Jurisdiction) [1993] Fam. 64; Family Law Reform Act 1969 s.8; Re X (A Child) (No.2) [2021] EWHC 65 (Fam); [2021] 4 W.L.R. 11; cf. AB v CD [2021] EWHC 741 (Fam); [2021] Med. L.R. 365; see Anthony Skelton, Lisa Forsberg and Isra Black, "Overriding Adolescent Refusals of Treatment" (2021) 20 J. Ethics Social Phil. 221.

12 Re R (A Minor) (Wardship: Consent to Treatment) [1992] Fam. 11 at 26 (Lord Donaldson M.R.): "[w]hat is really being looked at is an assessment of mental and emotional age… ‘Gillick competence’ is a developmental concept and will not be lost or acquired on a day to day or week to week basis"; cf. Re JA (A Minor) (Medical Treatment: Child Diagnosed with HIV) [2014] EWHC 1135 (Fam); [2015] 2 F.L.R. 1030 at [69]; Re S (Child as Parent: Adoption: Consent) [2017] EWHC 2729 (Fam); [2019] Fam. 177 at [17].

Capacity alone is not determinative of the legal validity of an individual’s decision to consent to or to refuse medical treatment. In common with adults, minors must demonstrate that their decision is adequately informed: *Chatterton v Gerson [1981] Q.B. 432; [1981] 1 All E.R. 257*; and voluntary *Re T (Adult: Refusal of Treatment) [1993] Fam. 95; [1992] 4 All E.R. 649*. We assume these conditions are met in what follows.


*MCA 2005 s.2(5); see Re X (A Child) (No.2) [2021] 4 W.L.R. 11* at [57].

We assume these conditions are met in what follows.

*King’s College Hospital NHS Foundation Trust v C [2015] EWCOP 80; [2016] C.O.P.L.R. 50* at [32].


We use *F* to refer to phenomenology because *P* is common usage for person in mental capacity law. *F* also has mnemonic quality in respect of both phenomenology and feels like.


*Re E (A Minor) [1993] 1 F.L.R. 386 at 391.*

*Re S (A Minor) (Consent to Medical Treatment) [1994] 2 F.L.R. 1065 at 1076.*


*Re L (Medical Treatment: Gillick Competence) [1998] 2 F.L.R. 810 at 813.*


*Re L [1998] 2 F.L.R. 810 at 813; see Andrew Grubb, "Refusal of Treatment (Child): Competence—Re L (Medical Treatment: Gillick Competency)" (1999) 7 Med. Law Rev. 58. Note also in that at least some of the F-relevant information, in relation to dyspnoea, was deliberately withheld in Re E (A Minor) (Wardship: Medical Treatment) [1993] 1 F.L.R. 386 at 391 (Ward J.): "I am told by Dr T that soon [E] will be fighting for breath and that the struggle for breath is likely to be frightening. I did not judge it right to probe with him whether or not he knew how frightening it would be. Dr T did not consider it necessary to spell it out for him, and I did not feel it was appropriate for me to do so".*

*Re A (Capacity: Refusal of Contraception) [2010] EWHC 1549 (Fam); [2011] Fam. 61.*

*Re A [2011] Fam. 61 at [56] (Bodey J.).* The submissions of the Official Solicitor lend credence to our interpretation. "The Official Solicitor submits that this approach is 'fundamentally flawed'… It would, it is said, ‘set the bar too high’. It would catch and deny capacity to large numbers of women, including many would-be first-time mothers, who would presently be regarded as clearly having capacity regarding contraception": *Re A [2011] Fam. 61* at [57] (Bodey J.). That first-time parents would be caught out in particular by the Local Authority’s requirement seems grounded in the idea that one cannot know what it is like to have a child until one becomes a parent. Indeed, the choice to become a parent is the standard example used in the philosophical literature on transformative choice: L.A. Paul, "What You Can’t Expect When You’re Expecting" (2015) 92 Res Phil. 149.

*Re A [2011] Fam. 61 at [60]–[64].

*Re A [2011] Fam. 61 at [61].

*Re A [2011] Fam. 61 at [60].

*Re A [2011] Fam. 61 at [63].

Bodey J. held these to be "(i) the reason for contraception and what it does (which includes the likelihood of pregnancy if it is not in use during sexual intercourse); (ii) the types available and how each is used; (iii) the advantages and disadvantages of each type; (iv) the possible side-effects of each and how they can be dealt with; (v) how easily each type can be changed; and (vi) the generally accepted effectiveness of each": *Re A (Capacity: Refusal of Contraception) [2011] Fam. 61* at [64].

It is immaterial that Ms B [2002] 2 All E.R. 449 concerned the putative requirement to grasp the phenomenology of treatment, while Re E (A Minor) (Wardship: Medical Treatment) [1993] 1 F.L.R. 386; Re S (A Minor) (Consent to Medical Treatment) [1994] 2 F.L.R. 1065 and Re L (Medical Treatment: Gillick Competence) [1998] 2 F.L.R. 810 concerned whether adolescents are required to grasp the phenomenology of treatment refusal —the substance of the information to be grasped is the same across the options available to the agents, respectively.

It is important that those considering the issue should not confuse the question of mental capacity with the nature of the decision made by the patient, however grave the consequences. The view of the patient may reflect a difference in values rather than an absence of competence and the assessment of capacity should be approached with this firmly in mind. The doctors must not allow their emotional reaction to or strong disagreement with the decision of the patient to cloud their judgment…".

We are grateful to an anonymous reviewer for pressing us to clarify this argument.

We are grateful to an anonymous reviewer for pressing us to clarify this argument.
55. Re C (A Minor) (Medical Treatment: Court's Jurisdiction) [1997] 2 F.L.R. 180 at 195. Interestingly, the other expert—Dr W—expressed uncertainty "as to what is meant by ‘treatment information’": Re C [1997] 2 F.L.R. 180 at 196.

56. Re JA (A Minor) (Medical Treatment: Child Diagnosed with HIV) [2015] 2 F.L.R. 1030 at [74].

57. Re JA [2015] 2 F.L.R. 1030 at [76].


59. Re R (A Minor) (Wardship: Consent to Treatment) [1992] Fam. 11; Re W (A Minor) (Medical Treatment: Court's Jurisdiction) [1993] Fam. 64; Family Law Reform Act 1969 s.8; Re X (A Child) (No.2) [2021] EWHC 65 (Fam); [2021] 4 W.L.R. 11; cf. AB v CD [2021] EWHC 741 (Fam); [2021] Med. L.R. 365; see Anthony Skelton, Lisa Forsberg and Isra Black, "Overriding Adolescent Refusals of Treatment" (2021) 20 J. Ethics Social Phil. 221.

60. In Re W (A Minor) (Medical Treatment: Court's Jurisdiction) [1993] Fam. 64, W was found competent at first instance. While Lord Donaldson M.R. cast no doubt on that finding in the Court of Appeal, the issue was not ventilated. In Re M (Medical Treatment: Consent) [1999] 2 F.L.R. 1097 at 1100; (2000) 52 B.M.L.R. 124 at 128, the Official Solicitor appears to argue that M lacks capacity, then elides into best interests language. The latter provides the rationale for Johnson J.'s decision to override M's refusal of treatment. In Re P (Medical Treatment: Best Interests) [2003] EWHC 2327 (Fam); [2004] 2 F.L.R. 1117, Johnson J. omits to discuss P's capacity prior to overriding the latter's refusal. In F v F (MMR Vaccine) [2013] EWHC 2683 (Fam); [2014] 1 F.L.R. 1328, the capacity of two children aged 15 and 11 is not discussed by Theis J.

61. See Re E (Children: Blood Transfusion) [2021] EWCA Civ 1888; [2020] Fam. 130; A Teaching Hospitals NHS Trust v DY (A Child) [2021] EWHC 1037 (Fam); (2021) 180 B.M.L.R. 169; Re X (A Child) (Medical Treatment) [2020] EWHC 3003 (Fam); [2021] 2 F.L.R. 88; Re X (A Child) (No.2) [2021] 4 W.L.R. 11; NHS Trust v CX (Medical Consent: Capacity to Consent to Treatment) [2019] EWHC 3033 (Fam); (2020) 174 B.M.L.R. 119.


63. See e.g., Re E (A Minor) (Wardship: Medical Treatment) [1993] 1 F.L.R. 386 at 394 per Ward J.: "My jurisdiction is a protective one. It may be, as… Justice Holmes, held in… Prince v Massachusetts (1944) 321 US Reports 158, that: 'Parents may be free to become martyrs themselves, but it does not follow that they are free in identical circumstances to make martyrs of their children before they have reached the age of full and legal discretion when they can make choices for themselves.' There is compelling and overwhelming force in the submission of the Official Solicitor that this court, exercising its prerogative of protection, should be very slow to allow an infant to martyr himself.".


72. See A Local Authority v JB [2022] A.C. 1322 at [69]–[70].
We take this conception of instrumental rationality to be a normative standard for decision-making applicable to real-world conditions: Paul, Transformative Experience (2014), at pp.19–24. See also Paul Weirich, Realistic Decision Theory: Rules for Nonideal Agents in Nonideal Circumstances (Oxford: Oxford University Press, 2004). We understand the subjective values relevant to instrumental rationality to be capacious: they may extend to matters concerning others for their own sake (e.g. a loved one’s well-being) and other things capable of being valued (e.g. the environment). See e.g., Amartya Sen, The Idea of Justice (Cambridge, Massachusetts: Belknap Press, 2009), at p.182.

King’s College NHS Foundation Trust v C [2016] C.O.P.L.R. 50 at [97]. See also Airedale NHS Trust v Bland [1993] A.C. 789 at 866 (Lord Goff): “if an adult patient of sound mind refuses, however unreasonably, to consent to treatment or care by which his life would or might be prolonged, the doctors responsible for his care must give effect to his wishes, even though they do not consider it to be in his best interests to do so”. For a survey of similar dicta in the pre-MCA 2005 case law, see Ms B v An NHS Hospital Trust [2002] 2 All E.R. 449 at [14]–[27]. While detailed discussion is beyond the scope of discussion in this article, we note that none of the capacity rationales identified in Kane and others’ content analysis of MCA 2005 case law is inconsistent with our argument that instrumental rationality is the normative standard that governs ability to take decisions for the purposes of s.3(1) of the Act: N. Kane et al, "Applying decision-making capacity criteria in practice: A content analysis of court judgments" (2021) 16 PLoS ONE e0246521.


Gillick v West Norfolk and Wisbech AHA [1986] A.C. 112 at 188–189 and 169, respectively.

In A Local Authority v JB [2022] A.C. 1322 at [61], Lord Stephens equates functional capacity with mere understanding and suggests that the MCA 2005 requires more than this approach by evaluating an individual’s ability to use or weigh. Respectfully, this seems a mistake.


That is not to say that the practice of the courts reflects comfort with this principle: see fnn.10 and 11; Goold, "Children and Consent to Medical Treatment", https://s3-eu-west-1.amazonaws.com/content.gresham.ac.uk/data/binary/3648/2021-10-25-1300_GOOLD-T.pdf. See also fnn.9 and 10 for academic discussion of risk-relative capacity and asymmetry of capacity to consent and to refuse, respectively.

Paul, Transformative Experience (2014), at p.11.

Paul, Transformative Experience (2014), at p.16.

Paul, Transformative Experience (2014), at pp.8–11. Paul discusses Frank Jackson’s thought experiment involving Mary who knows all physical facts obtainable about colours, yet gains new knowledge about the world the first time she sees colour: "Epiphenomenal Qualia" (1982) 32 Phil. Q. 127 at 130.

To elaborate on the concept of subjective values, Paul writes that, "I take such values to extend past the merely qualitative, and to capture the rich, complex nature of lived experiences resulting from our sensory as well as our nonsensory cognitive phenomenology… A subjective value need not be determined solely by the experience’s cognitive phenomenological character. But even in that case, the subjective value is discovered or made cognitively accessible by the discovery of the phenomenological character": Transformative Experience (2014), at p.12.

For other lines of criticism, see Elizabeth Barnes, "What You Can Expect When You Don’t Want to be Expecting" 91(3) Phil. Phenomenol. Res. 775; John Campbell, "L.A. Paul’s Transformative Experience" 91(3) Phil. Phenomenol. Res. 793.

The difficulty in this case may be access to sufficient, e.g. testimonial, evidence of the relevant kind.
A NHS Trust v P [2013] EWHC 50 (COP); [2013] C.O.P.L.R. 405 at [10]; see also Local Authority X v MM [2009] 1 F.L.R. 443 at [58] per Munby J.: "[T]he court must adopt a pragmatic, common sense and robust approach to the identification, evaluation and management of perceived risk… just as wise parents resist the temptation to keep their children metaphorically wrapped up in cotton wool, so too we must avoid the temptation always to put the physical health and safety of the elderly and the vulnerable before everything else”.

See Skelton, Forsberg and Black, "Overriding Adolescent Refusals of Treatment" (2021) 20 J. Ethics Social Phil. 221.