Patient Rights to Participate in Treatment Decisions: Choice, Consultation and Knowledge

Emma Cave
Nina Reinach*

Durham Law School, University of Durham, UK

Abstract

Article 8 of the European Convention on Human Rights supports the right to participate in decisions that affect our lives. Article 8 was a relevant factor in the Supreme Court decision of Montgomery v Lanarkshire Health Board [2015] which makes significant advances in patient-centred care. Focusing on adult patients with capacity, this article considers Article 8’s influence across three routes to participatory protection: the right to choose, the duty to consult, and the right to know. We set out current limitations of the right to choose and consider the potential for Article 8 to influence the extension of a wider duty to consult and right to know. We find that there are impediments to legal development. Patient status leads to the elevation of aspects of participation that do not always comply with patient needs and expectations. We consider a reimagining of our expectations of patient rights to better acknowledge the relevance of partnership between patients and professional experts and to extend information provision beyond informed consent.

1. Introduction

An important human rights principle is the right of citizens to participate in decisions that affect their lives. This is given legal affect by virtue of the common law which is influenced by Article 8 of the European Convention on Human Rights (‘ECHR’). In the context of patient rights to participate in decisions about them, Article 8 was a relevant factor in Montgomery v Lanarkshire Health Board (Montgomery).1 There, the Supreme Court recognised the doctrine of informed consent and applied a new patient-centred test to determine breach of the duty of care incumbent on healthcare professionals (HCPs) to disclose information to patients. In this article we point to different formulations of patient participatory rights supported in domestic common law and consider their limitations. While Article 8 is considered one of the more dynamic rights relevant to health care law, we argue that its effect on the right...
to choose, the duty to consult and the right to know is limited. We have two connected explanatory aims: to point out the limitations of participatory rights in order to provide balance to the autonomy-focussed reception of Montgomery and to explore the concept of ‘patient’ in the development and limitation of patient participatory rights. We propose a reimagining of expectations of patient participatory rights to acknowledge and accommodate the necessary partnership between patients and HCPs in patient-centred care and to move beyond the limited focus on treatment choice.

Article 8 protects private and family life. It is a qualified right and exceptions apply, including necessary and proportionate actions ‘for the protection of health or morals, or for the protection of the rights and freedoms of others’. Section 6 of the Human Rights Act 1998 (‘HRA’) makes it unlawful for a public authority to act in a way that is incompatible with a person’s rights under the ECHR. As a result, the courts develop the common law with ECHR compatibility in mind and public authorities, such as NHS Trusts, can have their decisions overturned if they are not compatible with the ECHR. Article 8 is relevant to reproductive rights, mental illness, end of life care, gender identity and a huge range of other issues in healthcare law.2 Our concern is with one aspect of its influence: patient participatory rights, which we argue take three principal legal forms: the right to choose, the duty to consult and the right to know.

The scope of ‘private life’ is broad and the European Court of Human Rights (ECtHR) has said that it cannot be exhaustively defined.3 The influence of Article 8 on domestic developments in patient participation flows from recognition by the ECtHR that protection of ‘private life’ extends beyond freedom from interference,4 and incorporates a positive obligation on states to respect a person’s physical and psychological integrity.5 The sphere of private life includes the right to self-determination, or autonomy.6 More specifically, the ECtHR has supported informed consent through recognition of a right not to be subject to compulsory medical treatment, though there are instances where treatment without consent is considered a proportionate interference with Article 8.7 It

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3 Paradiso and Campanelli v Italy [GC], no 25358/12, para 159.
5 X and Y v The Netherlands [1985] ECHR 4, para 22.
has also recognised an Article 8 right to compensation for negligently caused damage.\footnote{Vasileva v Bulgaria [2016] ECHR 273, para 63; Eryigit v Turkey [2018] ECHR 318, para 49.}

There is wide disagreement about the role of human rights in domestic health care law. Kennedy and Grubb described medical law as a ‘sub-set of human rights law’,\footnote{I. Kennedy & A. Grubb, Medical Law, 3rd edn. (London: Butterworths, 2000), 3.} whilst Mason and McCall Smith saw it as ‘tinkering round the edges’.\footnote{J.K. Mason & A. McCall Smith, Law and Medical Ethics, 6th edn. (London: Butterworths 2002), 31.} In the context of health decisions, we expose some of the limitations of remedies designed to interpret and uphold the right to self-determination. We start by exploring the right to choose. The boundaries of this right are restrictive: through the law of negligence, the \textit{Montgomery} decision protects a right to choose between or decline medical treatment options that HCPs are willing to support. Article 8 has also given rise to a duty to consult that has the potential to enhance participatory rights, but this mechanism too has so far proved limited. A right to know underlies the \textit{Montgomery} judgment and has potential application beyond the choice amongst treatment options and to counter some of the consumeristic tendencies of the right to choose by acknowledging the role of professional expertise.

\section{The Right to Choose}

Article 8 upholds rights to autonomy, dignity and integrity. Not all patients are able to make decisions for themselves, in which case they retain an interest in participation. The Mental Capacity Act 2005 requires support to help patients make a capacitous decision,\footnote{Mental Capacity Act 2005, s 1(3).} and the involvement of patients who lack capacity to the extent of their capabilities.\footnote{Mental Capacity Act 2005, s 4(4).} The Mental Health Act 1983 incorporates participatory safeguards, such as the right to an advocate\footnote{Mental Health Act 1983, s 130A.} and the Children Act 1989 requires consideration of the ‘wishes and feelings of the child concerned’.\footnote{Children Act 1989, s 1(3)(a).} Article 8 imposes on states procedural requirements to ensure those lacking capacity can participate in the process and that their individual needs are met.\footnote{Shtukaturov v Russia App. No. 44009/05, ECtHR (2008), [65]; Herczegfalvy v Austria (1993) 15 EHRR 437, [91].}
The focus of this article is on adults with capacity, for whom the right to choose has gained support within and outside the context of healthcare. Lord Hobhouse in Commissioner of the Police of the Metropolis v Reeves laid out the general principle:

Where a natural person is not under any disability, that person has a right to choose his own fate. He is constrained in so far as his choice may affect others, society of the body politic. But, so far as he himself alone is concerned, he is entitled to choose.\(^\text{16}\)

For adult patients with capacity, consent is a primary method of protecting patient rights to participate in decisions made about them. At common law, consent provides a defence to what would otherwise be a battery and potentially a criminal assault. To be valid, consent must be voluntary, capacitous and broadly informed. Though ethical and legal adherence to the requirement for consent has historical foundations, it is rarely utilised as a form of redress in cases of inadequate patient participation. The law of battery requires only that the patient is informed ‘in broad terms’,\(^\text{17}\) cases are few\(^\text{18}\) and the courts have proved reluctant to develop it further.\(^\text{19}\)

The law of negligence is more promising. It requires reasonable care to avoid causing injury or loss to another person. The Bolam standard asserts that an HCP is not liable in negligence: ‘If he has acted in accordance with a practice accepted as proper by a responsible body of medical men skilled in that particular art’.\(^\text{20}\) Where once the Bolam test governed all professional negligence, the Supreme Court in Montgomery disapplied the Bolam test in informed consent cases, which are not considered to be a matter of medical expertise.\(^\text{21}\) The Bolam test remains relevant to treatment and diagnosis, subject to a ‘gloss’ applied in Bolitho:\(^\text{22}\) Where HCPs provide evidence that they would have adopted the course of action taken by the defendant, it must be shown that the course of action was based on logic and was defensible.

Jonathan Montgomery has argued that the concept of the ‘patient’ is diminishing in light of Article 8’s ascending relevance.\(^\text{23}\) But we will argue that,

\(^{16}\) Commissioner of the Police of the Metropolis v Reeves [2000] 1 AC 360, [394].
\(^{17}\) Chatterton v Gerson [1981] QB 432, per Bristow J, 443.
\(^{18}\) For example, Appleton v Garrett (1995) 34 BMLR 23 (QBD) (fraudulent dental treatment).
\(^{20}\) Bolam v Friern Hospital Management Committee [1957] 1 WLR 583, 587 per J. McNair.
\(^{21}\) [2015] UKSC 11, [85].
\(^{22}\) Bolitho v City Hackney HA [1998] AC 232.
within the law of negligence, Article 8’s relevance is muted by a dominant notion of patient vulnerability and reliance on professional expertise.

2.1. Information disclosure

The most significant advancement of the right to choose in the law of negligence is the disapplication of the *Bolam* test in cases involving a failure to warn patients of the risks and alternatives inherent in medical treatment. Thus, the legal development of a doctrine of informed consent provides redress in certain cases of inadequate patient participation.

Informed consent protects choice within the context of medical treatment decisions. It requires a higher level of information disclosure than the law of battery. Eminent scholars have set out the legal development in detail which we present only in summary. In 1985, the House of Lords in *Sidaway* set out the standard of disclosure. The judgments pulled in different directions. Only Lord Diplock fully endorsed the application of *Bolam* to cases of risk disclosure. Subsequent cases, however, initially left HCPs to determine what risks should be disclosed to patients prior to treatment. The resulting deference to HCPs was not limited to negligence and pervaded other aspects of healthcare law. A backlash ensued and change came about in an evolutionary fashion. The paternalistic ethos was gradually challenged in the lower courts.


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24 See, for example, A. MacLean, ‘The Doctrine of Informed Consent: Does it Exist and Has it Crossed the Atlantic?’, *Legal Studies* 24 (2004), 386.
25 *Sidaway v Board of Governors of the Bethlem Royal Hospital and the Maudsley Hospital* [1985] AC, 871.
26 See analysis of Lords Kerr & Reed in *Montgomery* [2015] UKSC 11, [57].
29 Such as *Pearce v United Bristol Healthcare NHS Trust* [1998] EWCA Civ 865; Lord Woolf’s obiter statement in *Bolitho v City Hackney HA* [1998] AC 232 that ‘if there is a significant risk which would affect the judgement of a reasonable patient, then in the normal course it is the responsibility of a doctor to inform the patient of that significant risk’; *Wyatt v Curtis* [2003] EWCA Civ 1779.
In 2015, the Supreme Court in *Montgomery* reshaped the law, signalling a break with the paternalistic era that followed *Sidaway*. Lords Kerr and Reed (giving the leading judgment) recognised that self-determination ‘underlies the right to respect for private life protected by Article 8 of the ECHR’. The facts, very briefly, are these: Nadine Montgomery sought damages for the injuries sustained by her son during childbirth. Despite her short stature and diabetes, she was not advised of certain increased risks associated with vaginal delivery. The birth was complicated by shoulder dystocia and her son suffered hypoxia resulting in cerebral palsy. Had she known the risks, Nadine Montgomery argued she would have asked for a caesarean section delivery. The Court found that the majority judgment in *Sidaway* was the wrong approach and preferred instead Lord Scarman’s minority view which has been adopted and developed in Australia. In *Montgomery*, it was decided that patients should be told what a reasonable patient would want to know, and what the particular patient wants to know, if the doctor should reasonably be aware of it.

In the next sub-section, we briefly highlight the nature and limitations of the protection of the right to choose in *Montgomery* and a selection of subsequent cases in order to outline some of the ways in which the HCP-patient relationship defines the scope of patient participatory rights and the correlative duties of HCPs.

2.2. Patient autonomy and partnership

*Montgomery* has been celebrated by commentators as a landmark judgment, though others have commented that the decision merely affirmed that which had already developed and evolved in practice, forming a ‘belated obituary’ of medical paternalism.

In the spirit of Article 8, Lady Hale in *Montgomery* stated:

*It is now well recognised that the interest which the law of negligence protects is a person’s interest in their own physical and psychiatric integrity, an important feature*
of which is their autonomy, their freedom to decide what shall and shall not be done with their body.38

Lords Kerr and Reed opined that ‘optimisation of the patient’s health’ is no longer ‘an overriding objective’, because ‘patients are now widely regarded as persons holding rights, rather than as the passive recipients of the care of the medical profession’.39 This reiterates Lord Scarman’s sentiment in Sidaway (cited in Montgomery), that ‘the patient’s right to make his own decision, (...) may be seen as a basic human right protected by the common law’.40 Adequate information about the risks inherent in proposed treatment options needed to be provided by HCPs, to enable patients to reach their decision in a balanced manner. Developing this view, the court in Montgomery demonstrates a shift in the understanding of patient autonomy protection as going beyond the disclosure of risks, to require comprehensive information enabling patients to choose what ‘shall and shall not be done with their body’.41

The protection of patient autonomy, however, is subject to practical barriers and legal exceptions. Recognition of the importance of patient autonomy in Montgomery and other cases such as Chester v Afshar and Rees v Darlington Memorial Hospital NHS Trust might have resulted in a new cause of action within the law of negligence to extend access to justice when patient autonomy is curbed. Purshouse has argued that this would problematically distort the coherence of tort law; a view that has found favour in recent judicial decisions. In Shaw v Kovac the Court of Appeal held that a failure to obtain consent does not give rise to a separate head of damages.46 The daughter of a patient who had died following trans-aortic valve implantation argued he would not have

38 [2015] UKSC 11, [108].
39 [2015] UKSC 11, [74]-[75].
43 [2005] i AC 134.
44 [2003] UKHL 52.
46 Shaw v Kovac and University Hospitals of Leicester NHS Trust [2017] EWCA Civ 1028.
had the treatment if properly informed. She was awarded damages to cover funeral expenses, plus pain, suffering and loss of amenity prior to death. She appealed on the basis that a failure to obtain informed consent should give rise to a conventional award of compensation. Her claim failed. It risked a proliferation of claims where a failure to disclose risk would not in fact have deterred or delayed treatment.

Furthermore, whilst Montgomery changes the law on breach of duty, the paternalistic Bolam test may still have relevance to clinical judgements about the relevance of alternative treatments and to the invocation of the therapeutic exception. Montgomery does not change the law of causation, which can act as a significant barrier to redress, particularly if multiple factors (including poor health) are attributable towards a condition. The 2005 House of Lords decision of Chester v Afshar (Lords Bingham and Hoffmann dissenting) modified the test for causation in a failure to warn case in order to uphold the autonomy and dignity rights of the patient. However, the case has since been ‘clarified’, to make clear that ‘but for’ causation must still be shown. In Khan the Court of Appeal was disinclined to establish liability by applying Chester, preferring instead to rely on Lord Hoffmann’s SAAMCO principle that limits the scope of the duty of care. Chester is gradually being confined to its facts.

Even in relation to breach, Dunn (et al.) point to a disconnect between a patient-centred approach, which is clearly articulated in Montgomery, and primacy of autonomy. The two-part materiality test requires disclosure of risk that a reasonable patient in the patient’s position would consider significant and, where the doctor should reasonably be aware, that the particular patient would consider significant. The second part protects autonomy, but only requires the


\[50\] [2005] 1 AC 134, [14], [18], [22].


\[52\] Khan v MNX [2018] EWCA 2609.

\[53\] South Australia Asset Management Corporation v York Montague Ltd [1996] UKHL 10, [19] per Lord Hoffmann. The valuer was not liable for the losses resulting from market fluctuations rather than the valuer’s negligence. The scope of duty is determined in line with the purpose of the rule imposing the duty.

HCP to go so far in ascertaining patient values. In some cases, this protection will be dependent on the patient volunteering information about their values.

Herring et al describe a shift in value to patient autonomy that is not absolute\textsuperscript{55} – rather, that Montgomery encompasses a model of consent based on autonomy through partnership and shared decision-making where the patient is an active partner. Courts post-Montgomery are not simply holding HCPs accountable for failing to enhance patient autonomy through participation. Rather, they are also holding patients accountable for their own decisions where their autonomy has been respected and where they have exercised their right to choose treatment. This accords with Montgomery, where the court advocated for patients ‘accepting responsibility for the taking of risks affecting their own lives, and living with the consequences of their choices’.\textsuperscript{56} Indeed, Montgomery is in accordance with general principle: in Reeves, cited above, Lord Hobhouse’s assertion of the right to choose was:

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subject to the important qualification (...) that a person may not complain of the consequences of his own choice. (...) [T]he person’s choice becomes, so far as he is concerned, the cause. The autonomy of the individual human confers the right and the responsibility.\textsuperscript{57}
\end{quote}

In Holdsworth,\textsuperscript{58} the court held the patient responsible for the decision to pursue a knee replacement. Although other options had been outlined, the patient was ‘unwilling to contemplate any other treatment’ other than knee replacement, and the ‘reality is that the claimant was determined to have surgery’.\textsuperscript{59} Even in Lunn,\textsuperscript{60} where the HCP failed to advise on any alternative courses of action, it was held that the HCP was not responsible for the patient’s belief that she had no option other than to proceed with the particular treatment.\textsuperscript{61} Simil-

\footnotesize{\textsuperscript{56} [2015] UKSC 11, [81]. And see [93] and [95].}
\footnotesize{\textsuperscript{57} [2000] 1 AC 360, 395. Note that on the facts, responsibility was apportioned equally. The plaintiff was administratrix of a person who had committed suicide in police custody. The police were aware of the suicide risk, which they were under a duty to prevent. Yet the victim voluntarily caused harm to himself. Both causes were contributory.}
\footnotesize{\textsuperscript{58} Holdsworth v Luton and Dunstable University Hospital NHS Foundation Trust [2016] EWHC 3347 (QB).}
\footnotesize{\textsuperscript{59} [2016] EWHC 3347, [47].}
\footnotesize{\textsuperscript{60} Lunn v Kanagaratnam [2016] EWHC 93 (QB).}
\footnotesize{\textsuperscript{61} [2016] EWHC 93, [22].}
early, in *Worrall*, the court held that the HCP was not to blame for the patient getting hold of ‘the wrong end of the stick’.

In these cases we see accountability balanced between HCPs and patients, and that both parties to the relationship retain a sphere of responsibility. *Montgomery* promotes and protects patient autonomy but does not end deference to HCPs. *Montgomery* does not provide citizens with an unfettered right to choose medical treatment: it gives patients a limited right to choose between or reject options set out or agreed by HCPs.

The significance of *Montgomery* lies neither in its sounding a ‘death knell of medical paternalism’, nor in its acclaiming unbridled influence of patient autonomy. We agree whole-heartedly with Brazier and Farrell that *Montgomery*, rather than heralding an era of ‘unfettered patient autonomy in which theirs is the right to demand medical treatment’, confines autonomy within the limitations and contextual matrix of the HCP-patient relationship.

### 3. The Duty to Consult

The right to choose is not the only mechanism by which the right of citizens to participate in healthcare decisions is protected. The duty to consult has developed under Article 8, as was acknowledged in *Montgomery*.

Jonathan Montgomery recommends that we move on from the limitations of negligence and that: ‘We should now be talking not about informed consent, but the “duty to consult”’. We consider there to be merit in his suggestion that entitlement to know what decisions are being made has importance beyond...
decisions to offer treatment.\textsuperscript{70} However, we draw attention to factors that are likely to limit the extension of the duty to consult.

In \textit{Tracey} a failure to consult a patient with capacity before imposing a do not attempt cardio pulmonary resuscitation (DNACPR) notice breached Article 8.\textsuperscript{71} Ryder LJ stated:

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The duty to consult is integral to the procedural obligation to ensure effective respect for the article 8 right, without which the safeguard may become illusory and the interest may not be reflected in the clinical judgment being exercised. That interest is the autonomy, integrity, dignity and quality of life of the patient. It is accordingly critical to good patient care.\textsuperscript{72}
\end{quote}

The requirement to consult is not limited to patients and it is not limited to the protection of autonomy. The ECtHR has found breaches of Article 8 in states that lack procedural safeguards to ensure the participation of patients who lack capacity in a range of decisions made about them.\textsuperscript{73} However, the right is contextual\textsuperscript{74} and as such is dependent upon the circumstances and the nature of the decision.\textsuperscript{75} The welfare of the patient is one such relevant consideration. In \textit{Tracey} it was made clear that there is a presumption in favour of patient participation: ‘There need to be convincing reasons not to involve the patient’.\textsuperscript{76} Evidence of reasonable belief that consultation would cause physical and psychological harm (as opposed to mere distress) would be enough to justify exclusion.\textsuperscript{77}

Sometimes the consultation of those other than the patient is required to ensure that the patient’s rights are upheld. The Mental Capacity Act 2005 requires consultation where practicable, so that where a person lacks capacity, their wishes, feelings, values and beliefs can be assessed in order to reach a determination of their best interests.\textsuperscript{78} Like \textit{Tracey}, \textit{Winspear}\textsuperscript{79} involved a lack of consultation about DNACPR. In this case, the patient was a 28-year-old man

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\textsuperscript{71} \textit{R (on the application of Tracey) v Cambridge University Hospitals NHS Foundation Trust} [2014] EWCA Civ 822.
\textsuperscript{72} [2014] EWCA Civ 822, [95].
\textsuperscript{73} See, for example, \textit{Zohentner v Austria} [2009] ECHR 1119, [65] (concerning sale of property).
\textsuperscript{74} [2014] EWCA Civ 822, [31], [34] and [52].
\textsuperscript{75} \textit{Tysiak v Poland} (2007) 45 EHRR 42, [115].
\textsuperscript{76} [2014] EWCA Civ 822, [53].
\textsuperscript{77} [2014] EWCA Civ 822, [54], [56], per Longmore MR; [96] per Ryder LJ.
\textsuperscript{78} Mental Capacity Act 2005, s 4(6)-(7).
\textsuperscript{79} \textit{Winspear v City Hospitals Sunderland NHS Foundation Trust} [2015] EWHC 3250 (QB).
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with cerebral palsy and related health conditions. He lacked capacity to make a decision. The hospital did not consult his mother, Ms Winspear, or other family members before making the DNACPR decision. The court held that this decision breached Mr Carl Winspear’s Article 8 right to dignity. Similarly, in ZH\textsuperscript{80} a failure to follow procedures to consult set out in Section 4 of the Mental Capacity Act 2005 breached Article 8 and in this case also constituted a battery.

The procedures upon which the duty to consult is founded are strongest where statute makes them a requirement. To date, remedies for failure to consult have focused on serious medical decisions at the end of life. A duty to consult does not entail a right to choose and it relies on existing procedures to clarify the extent of information that must be communicated. As with the right to choose, we argue that the duty to consult is shaped by the HCP/patient relationship. The duty is patient-focused: whilst it was Ms Winspear who should have been consulted, the court’s focus was on the effect this had on Mr Carl Winspear’s Article 8 rights. Her claim for damages failed: ‘Her legitimate interest was as Carl’s carer, it is his best interests and right to respect for private life that is under consideration.’\textsuperscript{81} Similarly, in Glass v United Kingdom\textsuperscript{82} where a mother established Article 8 violation with respect to a hospital decision regarding her son’s life-sustaining treatment made without her involvement, the European Court of Human Rights considered the case from the perspective of the patient.\textsuperscript{83}

The duty to consult has potential for extension and this might facilitate protection of those who lack a right to choose. It might, for example, be utilised to address limited access to justice in cases involving children where they or their proxy are inadequately informed.\textsuperscript{84} We would suggest that the concept of the patient and the HCP-patient relationship has been and will be central to its development. Escaping the confines of negligence does not render the concept of ‘patient’ irrelevant.

4. The Patient’s Right to Know

Lady Justice Arden (now Lady Arden), celebrates Montgomery for emphasising the patient’s right to know, claiming: ‘It represents a paradigm

\textsuperscript{80} ZH v Commissioner of Police for the Metropolis [2013] EWCA Civ 69.
\textsuperscript{81} [2015] EWHC 3250 (QB), [63] per Blake J.
\textsuperscript{82} [2004] 1 FLR 1019.
\textsuperscript{83} [2004] 1 FLR 1019, [72].
shift in the role of the doctor. (...) The doctor or clinician is no longer wholly in control of the treatment options. The patient herself must be fully involved in those choices.\(^\text{85}\) The first sub-section considers the content of the right to know and its potential for extension, and the next sub-section considers who has a right to know.

4.1. The right to know ... what?

*Montgomery* does not only protect choice. It also protects the right to information needed to make the choice. We begin this sub-section by articulating the nature of the right to know set out in *Montgomery* and subsequent cases, before turning to its potential application beyond treatment choice.

Emphasis on knowledge is potentially process-driven and grounded in a thin notion of autonomy.\(^\text{86}\) However, the Supreme Court in *Montgomery* considered the *manner* of information disclosure as well as the extent of its provision. *Montgomery* requires that HCPs provide information that is intelligible and accessible to the patient, thereby not ‘bombarding’ them with information\(^\text{87}\) and that information be tailored to the needs of the particular patient and thus that standardised consent forms and the provision of general information leaflets will not suffice.\(^\text{88}\) The case also encourages the participation of patients in the flow of information – recognising that patients often do their own research and rely on alternative sources of information to the HCP\(^\text{89}\) – and that patients are generally entitled to ongoing dialogue with the HCP.\(^\text{90}\) *Montgomery* moves away from HCPs merely disclosing risks and embraces information provision in a way that allows patients to become partners equipped to engage in the decision-making process.

Lords Kerr and Reed acknowledge that the needs of patients are variable and some will need more information than others. They recognise:

*I[t has become far easier, and far more common, for members of the public to obtain information about symptoms, investigations, treatment options, risks and side-

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\(^{87}\) [2015] UKSC 11, per Lords Reed and Kerr, [90].

\(^{88}\) [2015] UKSC 11, per Lords Reed and Kerr, [8].

\(^{89}\) [2015] UKSC 11, per Lords Reed and Kerr, [76].

\(^{90}\) [2015] UKSC 11, per Lords Reed and Kerr, [90].
effects via [the] media (...) It would therefore be a mistake to view patients as uninformed, incapable of understanding medical matters, or wholly dependent upon a flow of information from doctors.  

Jonathan Montgomery comments that the model outlined in Montgomery remains based on the assumption that professionals hold the knowledge and that patients know little or nothing. He points to a flawed asymmetry; that HCPs are tasked with and responsible for the transferral of information to the patient and hold all the power to control the flow of information. This suggests a paradox in the apparent contradiction of these assertions given their Lordship’s assumption that Nadine Montgomery was medically uninformed and dependent on them for information. However, it is our respectful submission that this is consistent with the court’s acceptance that information can come from multiple sources, and its requirement that HCPs check that patients are adequately informed before commencing treatment. Some patients will have the inclination, time and resources to research matters independently, whilst others will not. The decision enhances autonomy within the HCP-patient relationship.

The model of ‘patient’ endorsed in Montgomery is that of a citizen who must take responsibility for their informed decisions; who is potentially capable of accessing a broad range of information; who might want to involve others in the decision; who may or may not seek recommendations from the HCP. The HCP, meanwhile, is responsible for determining the range of options to put to the patient (including the potential option of no treatment) and ascertaining that the patient has the information needed to make a decision. Herring et al suggest that Montgomery enhances ‘autonomy-through-partnership’, by making dialogue integral to the decision-making process and putting the informed patient at the heart of the matter.

This is further demonstrated in cases subsequent to Montgomery. For example, in Middleton, Mrs M was diabetic and gave birth to a child with severe disabilities as a result of shoulder dystocia. It was argued that she was not in-

91 [2015] UKSC 11, [76].  
formed of the material risks associated with vaginal birth. The court considered Mrs M’s ‘careful and considered approach’\(^97\) and found that, had she been given the chance, ‘she would have gone away and researched matters’\(^98\) and ‘importantly, would have been fully aware of the relevance of fetal size and the reason for its relevance’.\(^99\) In Webster,\(^100\) a claim succeeded when a mother was not given sufficient information that delaying labour risked complications resulting in the child being born with disabilities. The court held that, had she been adequately informed, she would have sought an earlier delivery\(^101\) and that this conclusion was supported by the patient’s ‘willingness to take responsibility for her pregnancy’.\(^102\) These cases demonstrate the significant weight placed by courts on the need for patients to contribute to the flow of information between HCPs and patients. Where patients are denied the opportunity to influence this flow, HCPs can be held liable.

The cases of Tasmin\(^103\) and Barrett\(^104\) further demonstrate that patients must be given the opportunity to participate in the decision-making process, even if they choose to defer to the HCP. It was asserted in Montgomery, that: ‘A person can of course decide that she does not wish to be informed of risks of injury’,\(^105\) though it remains the case that the provision of some basic information is necessary for the patient’s consent to be considered valid. In Tasmin,\(^106\) the court found it unacceptable that the couple in question felt estranged from a decision-making process in which they had wanted to participate.\(^107\) These cases highlight the importance of collaboration and active partnership underlying the HCP-patient relationship. John Coggon warns of the folly of assuming a universal view of patients:\(^108\) patient autonomy and responsibilities differ according to the context. The rights of some patients are served by allowing them to elect others to decide on their behalf. It is not the aim of partnership between HCPs and patients to require the uniform provision of information,

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\(^97\) [2015] EWHC 775, [30].
\(^98\) [2015] EWHC 775, [30].
\(^99\) [2015] EWHC 775, [30].
\(^100\) Webster (a child and protected party, by his mother and Litigation Friend, Butler) v Burton Hospitals NHS Foundation Trust [2017] EWCA Civ 62, [41].
\(^101\) Webster (a child and protected party, by his mother and Litigation Friend, Butler) v Burton Hospitals NHS Foundation Trust [2017] EWCA Civ 62, [41].
\(^102\) Webster (a child and protected party, by his mother and Litigation Friend, Butler) v Burton Hospitals NHS Foundation Trust [2017] EWCA Civ 62, [41].
\(^103\) Tasmin v Barts Health Trust [2015] EWHC 3135 (QB).
\(^105\) [2015] UKSC 11, [85] per Lords Reed and Kerr.
\(^106\) [2015] EWHC 3135 (QB).
\(^107\) [2015] EWHC 3135 (QB), [60].
but rather to respond appropriately and within certain confines, to the needs, values and wishes of the patient.

Whilst a right to know underlies the *Montgomery* decision, reliance on negligence as a means of protecting that right has resulted in over-emphasis on one aspect of patient participation that may be at odds with patient needs. As we have articulated above, the distinction between selection of treatment and choice between treatment options flows from the perceived relevance of medical expertise: *Montgomery* established that judges do not need medical expert advice to determine whether disclosure of risk and benefits is sufficient. Aspects such as advice, information on prognosis and diagnosis, can, however, prove relevant to the patient’s ability to make informed choices. The role of HCPs in enhancing patient participation does not stop at treatment. Whilst it might seem logical from a legal perspective to dissect information disclosure cases from *Bolam*, a patient perspective might require reconsideration of *Bolam’s* application in other aspects of participation, including advice on prognosis and diagnosis.\(^{109}\) Treatment choice is not the only aspect of patient participation.

There are indications that the *Montgomery* judgment might lead to a more generally applicable patient legal right to know. First, it has been applied in relation to non-disclosure of post-operative risk: in *Spencer*, the court found that a patient was not given sufficient information on the likelihood of developing post-operative deep vein thrombosis to be able to recognise the signs and mitigate the risks. H.H.J. Collender QC said: ‘In the light of the *Montgomery* decision, (...) I should pay regard to what the ordinary sensible patient would expect to have been told’.\(^{110}\) Second, the same reasoning was applied in *C v County Durham & Darlington NHS FT*, when a patient was not informed in a timely manner of a diagnosis of Crohn’s Disease.\(^{111}\) Third, *Montgomery* was applied in *Gallardo*, which involved a failure to inform a patient of prognosis when a malignant tumour was discovered during abdominal surgery.\(^{112}\) Whilst these developments are tentative, they suggest a willingness to extend *Montgomery’s* remit beyond the traditional emphasis on disclosure of risk, to pre-treatment, post-operative and post-treatment scenarios.

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\(^{109}\) *Sidaway v Board of Governors of the Bethlem Royal Hospital and the Maudsley Hospital* [1985] AC, 893, Lord Diplock criticises approaches that seek to dissect the doctor’s duties into separate components.

\(^{110}\) See *Spencer v Hillingdon Hospital NHS Trust* [2015] EWHC 1058, [68].


\(^{112}\) *Gallardo v Imperial College Healthcare NHS Trust* [2017] EWHC 3147 (QB).
Looking beyond Montgomery, there are other indications that the judiciary is willing to extend the duty of care by analogy in order to protect patients’ right to know. Darnley\textsuperscript{113} concerned alleged negligence of non-clinically trained reception staff. Bolam was not relevant here and nor did the case concern a treatment choice. It is nonetheless highly pertinent to patient participation and choice and illustrative of a judicial conception of patient vulnerability. The Supreme Court held that the duty to take reasonable care not to cause physical injury to the patient\textsuperscript{114} incorporates the duty not to provide misleading advice – in this case, inaccurate information about waiting times in A&E that led the patient to leave before being assessed and suffer harm. In both Montgomery and Darnley the absence of (or mis-) information is perceived as a deficit in autonomy that restricts patient responsibility for the resulting decision. Purshouse argues that the focus on patient vulnerability and dependence is particularly marked in Darnley.\textsuperscript{115}

4.2. Who has a right to know?

The focus of the right to know in Montgomery is the patient. However, there is potential for the right to know to extend beyond the immediate HCP-patient relationship. A right to know has developed in the ethical literature in the context of genetic information. Because knowledge can have both benefits and costs to the patient – for example, knowledge of susceptibility to untreatable and unpreventable conditions may cause psychological harm – the debate extends to the right not to know. Both can be grounded in autonomy because, whilst a thin conception of autonomy links choice with knowledge and information, a thicker conception requires reflective endorsement of decision-making processes, including the choice not to know.\textsuperscript{116}

There is potential for the right to know genetic information to be given legal protection. In 2017, the Court of Appeal in ABC v St George’s Healthcare Trust\textsuperscript{117} overturned the High Court decision that the case was unarguable. The claimant is the daughter of a man with Huntington’s Disease: an autosomal dominant genetic condition where the child of an affected person has approximately a 50 per cent chance of inheritance. The claimant argues that the hospital who

\textsuperscript{113} [2018] UKSC 50.  
\textsuperscript{117} ABC v St George’s Healthcare NHS Trust and others [2017] EWCA Civ 336.
treated her father owed a duty of care to share his diagnosis with her, despite his lack of agreement. Pregnant at the time, she claimed that armed with the relevant knowledge, she would have sought genetic testing, discovered the sad news that she had inherited the condition, and sought a termination of the pregnancy. Denied that opportunity, she is claiming damages for the wrongful birth of the child. It is reported that the case will go to trial in 2019.\textsuperscript{118} The father was the primary patient. The case will determine whether the daughter might also be owed a duty of care; in general, a duty is not owed to non-patients due to lack of proximity and/or that it would not be fair, just and reasonable to impose a duty.\textsuperscript{119} Article 8 may be influential in this regard. However, whilst Lord Irwin did not preclude an argument based on Article 8 at trial, he said: ‘I am unconvinced that the Convention adds anything to the common law or can provide a basis for action if the common law does not do so.’\textsuperscript{120}

The claim is based on either there being a special relationship between the daughter and the defendant, or an assumption of responsibility, either of which would entail a duty of care to protect the daughter’s ‘welfare and psychological and/or physical well-being’.\textsuperscript{121} The ethical dilemma in genetic cases calls for balance between patient confidentiality and the interests of relatives. Professional guidance already acknowledges an ethical duty to others that may warrant breaching the duty of confidentiality to the primary patient in order to protect the public interest.\textsuperscript{122}

We have argued that the common law articulation of the right to choose medical treatment and the duty to consult draw on perceptions of what it is to be a patient. The ABC litigation, however, focuses on the duty owed beyond the immediate HCP-patient relationship. Previous cases have resisted such an extension of the duty of care. In \textit{Bot v Barnick}\textsuperscript{123} a claim for damages for losses that resulted from alleged negligent advice about a partner’s mental state was struck out on the basis that it did not involve negligent advice given to a patient. If a duty is found to exist following ABC, then it would seem to extend beyond

\textsuperscript{118} R. McKie, ‘Woman Who Inherited Fatal Illness to Sue Doctors in Ground Breaking Case’, \textit{The Observer} (25 November 2018).
\textsuperscript{120} [2017] EWHC 3132 (QB).
\textsuperscript{121} [2017] EWHC 3132, [19]-[20].
\textsuperscript{122} [2018] EWHC 3132 (QB).
the patient, to third parties. Lord Irwin acknowledged that there is limited
domestic precedent for such a development, but opined that the development of
the duty of care is a matter for the court. This might indicate judicial willing-
ness to break down the distinctions between citizens and patients: to reduce
reliance on the HCP/patient relationship as an ‘excuse’ for deference. We may
be on the threshold of a reorientation ‘abandoning the idea that it is concerned
principally with the position of people as “patients”, as suggested by Jonathan
Montgomery.

On the other hand, if an extended duty is recognised, it might simply em-
brace a more relational notion of autonomy and bring family members under
the definition of ‘patient’. The Latin ‘pator’ means ‘to suffer’, but the Cam-
bridge Dictionary sets out a considerably wider definition: ‘a person who is re-
ceiving medical care, or who is cared for by a particular doctor or dentist when
necessary’. It incorporates the GP’s registered but currently healthy patients,
the person who seeks medical advice but not treatment and the emergency pa-
tient the doctor elects to treat whilst on holiday. If the court in ABC finds for
the daughter, it might extend the definition of ‘patient’ to family members with
healthcare needs whom the HCP ought reasonably to have in contemplation.
If so, it could constitute a further example of the adaptation of the HCP-patient
relationship in order to balance and protect the autonomy, dignity and integrity
of patients.

5. Conclusion

The various participatory rights are not equally important and
UK law has elevated the right to choose amongst treatment options in the context
of informed consent as the most deserving of remedy in cases of breach. In
doing so, the courts have forged new protections of patient autonomy whilst
retaining scope for HCPs to protect and promote the interests of patients. Our
first aim was to articulate the limits of the right to choose, which we believe
serves as a useful balance to the celebration of autonomy rights that followed

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124 [2017] EWCA Civ 336, [62].
Montgomery. We argue that the acknowledgement of the narrow scope of negligence and the right to choose necessitates greater focus on the legal protection of other aspects of patient participatory rights. The choice of medical treatment is but one aspect of the patient’s journey through diagnosis, prognosis, treatment and care.

The duty to consult has potential in this regard, but cases have focused on serious decisions at the end of life. A right to know has greater potential. In Montgomery, Lords Kerr and Reed recount that the Hippocratic Corpus advised doctors to limit information so as to avoid doing harm. They point to several developments that lead away from this assumption today, including consumerism, availability of information and human rights. We have focused on the latter. A right to know underlies Montgomery and has potential for expansion beyond treatment choice, but the courts were clear in Shaw v Kovac that this will only go so far. This leads us to surmise that the power of article 8 lies less in its provision of access to justice in cases of inadequate information or advice and more in the principles it endorses that feed into practitioner guidance.

Our second aim was to explore the concept of ‘patient’ in the development and limitation of patient participatory rights and to propose a reimagining of expectations of patient participatory rights to acknowledge and accommodate the necessary partnership between patients and HCPs in patient-centred care. The right of citizens to participate in decisions that affect their lives is multifaceted, but in healthcare law it has developed within the context of the HCP patient relationship. In Montgomery, the Supreme Court was grappling not with enhancing patient autonomy absolutely, but rather, doing so within the scope of this relationship. We agree with Devaney and Holm that Montgomery does not signal the end of deference to HCPs. The partnership model endorsed in Montgomery concedes a wide sphere of control to HCPs over the options that are available to patients. It also sets out (subject to limitations) the HCP’s deference to patients insofar as their informed decisions command respect.

This is not to say that deference to HCPs will not be challenged and, should it be found unnecessary, revoked. As Lords Kerr and Reed made clear in Montgomery:

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130 [2015] UKSC 11, [74].

131 [2015] UKSC 11, [75]-[76].

It is (...) necessary to impose legal obligations, so that even those doctors who have less skill or inclination for communication, or who are more hurried, are obliged to pause and engage in the discussion which the law requires. This may not be welcomed by some healthcare providers; but the reasoning of the House of Lords in Donoghue v Stevenson [1932] AC 562 was no doubt received in a similar way by the manufacturers of bottled drinks.\textsuperscript{133}

The point was endorsed in ABC: judges are entitled to develop the common law.\textsuperscript{134} It is not adherence to paternalism that prevents development of participatory rights, but acknowledgement of the necessity and utility of partnership.

The GMC’s draft guidance on consent sets out principles that require supported decision-making in all cases, that emphasise listening as much as talking and demand that information provision is tailored to the patient’s individual needs.\textsuperscript{135} There is more to do and in time, guidelines may move away from the focus on consent to encompass the broader range of information provision in healthcare.

\textsuperscript{134} [2017] EWCA Civ 336, [61]-[63].