Choice and Health Care: Fact or Fallacy

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Abstract

The University of Manchester

Doctoral Programme in Bioethics and Medical Jurisprudence

Ingrid Ann Whiteman

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Choice and Health Care: Fact or Fallacy

This thesis sets out to examine the place of patient choice in English health care, primarily within the National Health Service and in relationship to English law with regard to (a) informed consents and information and risk disclosure, and (b) confidentiality and privacy in relation to the access to and management of patient information. The analysis is underpinned with a limited review of the associations between choice and respect for individual autonomy. Health policy rhetoric has been laden with references to pro-patient choice in recent years and yet this research re-affirms that in law (still) it is the negative patient choice that carries weight in matters of consent to treatment. There is (still) no place for real demand. Similarly, in individual medical information access and management there is no sanction for demand, even negative patient choice is bounded. In both aspects of health care the ‘choices’ are (rightly) limited and can hardly constitute choice as the consumer-patient might see it. What the three papers contribute is the recognition that restrictions in patient choice are necessary; to be supported and for some individuals should be even more fettered than that of the general public in the interest of that general public. The papers examine the language of choice and find it lacking in transparency, with the reality dissociated from patient engagement, information dissemination and shared decision making; so compromising trust. If the health care system is to genuinely respect the individual autonomy of the capable adult and not utilise choice language as covert method of policy implementation, the language of what is on offer and why, the reasons for information acquisition and use and why, needs to be part of the patient-practitioner discussion as well as clarified in policy.
Declaration

No portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.

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_________________________________________ Date

Ingrid Whiteman
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This work is dedicated to my Mum, Margaret, from whom I learned to question, argue, debate, agree and be thoroughly determined.
The Author

My background is in medicine; as a general medical practitioner, medical educator, and deanery fellow in practice development. I was given the opportunity during my career in general practice to pursue my interests by undertaking an MA in Health Care Ethics and Medical Law at the Centre for Social Ethics and Policy, Department of Law, University of Manchester, in 2002/03. My career in medicine was curtailed by the diagnosis and consequences of Multiple Sclerosis. The upside of this was that my experiences inspired me to apply for and enter the first cohort of the University of Manchester Ph.D. Programme in Bioethics and Medical Jurisprudence. It has proved to be an eventful, positive, thought provoking and major learning experience.

Presentations

European Society for Philosophy of Medicine and Health Care, 22nd European Conference
Tartu, Estonia: 21 August, 2008

Presentation Title: ‘Choice and Challenge in Health Care’

Institute of Science, Ethics and Innovation/Centre for Social Ethics and Policy
Manchester, United Kingdom, Christmas Seminar: December, 2010

Presentation Title: ‘Choice in the NHS – Benign Paternalism Meets Soft Coercion’

Poster Presentation

Royal College of General Practitioners, Annual Primary Care Conference, 2010
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Papers

1.
Title: The Fallacy of Choice in the Common Law and NHS Policy

_HCA_ DOI 10.1007/s10728-011-0198-4


2.
Title: The decline of medical confidentiality – medical information management: The illusion of patient choice

*Clinical Ethics* OnlineFirst 17 June 2015
doi:10.1177/1477750915591293

3.
Title: Medical Privacy: Health Professionals and Ministers

*Submission pending*
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B (Adult: Refusal of Medical Treatment) [2002] 2 All ER 449.


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Bolam v Friern Hospital Management Committee [1957] 2 All ER 118

Bolitho v City and Hackney HA [1997] 4 All ER 771.

Bolitho v City Hackney Health Authority [1998] AC 232.

C (Adult: Refusal of Medical Treatment), Re [1994] 1 WLR 290; [1994] 1 All ER 819.

Campbell v Mirror Group Newspapers Ltd [2004] UKHL 22.

Canterbury v Spence 464 F2d 772, 780 (1972)


Case C-368/98 Vanbraekek [2001] ECR I-5363;

Case C-157/99 Geraets-Smits and Peerbooms [2001] ECR I-5473; Müller-Fauré and van Riet


David Spencer v Hillingdon Hospital NHS Trust [2015] EWHC 1058 (QB).

Douglas v Hello! Ltd (No 3) [2006] QB 125.


Fairchild v Glenhaven Funeral Services Ltd., [2002] UKHL 22 at 60.

Gartside v Outram (1856) 26 LJ Ch 113

Gold v Haringey Health Authority [1987] 2 All ER 888, CA.
H (a healthcare worker) v Associated Newspapers Limited and N (a health authority) [2002] EWCA Civ 195, Lloyds Rep Med, 210 CA.


Hunter v Mann [1974] 1 QB at 772.


Ms B v An NHS Hospital Trust [2002] 2 All ER 449.

Montgomery (Appellant) v Lanarkshire Health Board (Respondent) (Scotland) [2013] CSIH 3;[2010] CSIH 104; [2015] UKSC 11 at 75


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R v Brown [1994] 1 AC 212, HL.


R (Ann Marie Rogers) v Swindon Primary Care Trust and the Secretary of State [2006] EWCA Civ 392.

R (Linda Gordon) v Bromley Primary Care Trust [2006] EWHC 2462 (Admin).


R (on the application of Oliver Leslie Burke) v The General Medical Council [2005] EWCA Civ 1003.

R (on the application of Burke) v General Medical Council [2004] EWHC 1879 (Admin).


R v Bedford PCT v the Secretary of State for Health ex parte Watts [2003] EWHC 2228.


Rees v Darlington Memorial Hospital NHS Trust [2003] UKHL 52, HL.

Regina v Salford Area Health Authority (respondent) ex parte Janaway [1988] 2WLR 442; HA [1988] 3 All ER 1079 249.

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W v Egdell [1990] 1 All ER 835.

Wilscher v Essex Area Health Authority [1988] 1 All ER 871, HL


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Access to Health Records Act 1990

Care Act 2014


Health Act, 2009

Health and Social Care Act, 2012

Mental Capacity Act 2005, s. 3(2).

Mental Health Act, 2007 c9

National Health Service Act 2006 s. 251-252

Police and Criminal Evidence Act 1984


Tribunals of Inquiry (Evidence) Act 1921 s1 (1)(b).

**Table of Statutory Instruments**

NHS (Venereal Diseases) Regulations 1974 (SI 1974 No 29)

Abortion Act and Abortion Regulations 1991 (SI 1991 No 499)

Health Service (Control of Patient Information) Regulations 2002 (SI 2010/659)


**Table of EU Directives**


Directive 95/46/EC (the Data Protection Directive)

**Other**

The Barcelona Declaration Policy Proposals to the European Commission November 1998, by Partners in the BIOMED-II Project, Basic Ethical principles in Bioethics and Biolaw; incorporating autonomy, dignity, integrity and vulnerability.


### List of Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>AIDS</td>
<td>Acquired Immunity Deficiency Syndrome</td>
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<tr>
<td>ANH</td>
<td>Artificial Nutrition and Hydration</td>
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<td>BMA</td>
<td>British Medical Association</td>
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<tr>
<td>BMJ</td>
<td>British Medical Journal</td>
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<tr>
<td>CCG</td>
<td>Clinical Commissioning Group</td>
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<tr>
<td>CQC</td>
<td>Care Quality Commission</td>
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<tr>
<td>CO</td>
<td>Conscientious Objection</td>
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<tr>
<td>CPD</td>
<td>Confidential Personal Data</td>
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<tr>
<td>CPRD</td>
<td>Clinical Patent Research Data Link</td>
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<tr>
<td>CS</td>
<td>Caesarean Section</td>
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<tr>
<td>CSU</td>
<td>Commissioning Support Unit</td>
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<tr>
<td>DoH</td>
<td>Department of Health</td>
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<tr>
<td>DPA</td>
<td>Data Protection Act</td>
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<tr>
<td>ECHR</td>
<td>European Convention on Human Rights</td>
</tr>
<tr>
<td>ECJ</td>
<td>European Court of Justice</td>
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<tr>
<td>ECtHR</td>
<td>European Court of Human Rights</td>
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<tr>
<td>ETP</td>
<td>Electronic Transmission of Prescriptions</td>
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<td>EU</td>
<td>European Union</td>
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<td>GMC</td>
<td>General Medical Council</td>
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<tr>
<td>GP</td>
<td>General Practitioner</td>
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<tr>
<td>GPES</td>
<td>General Practice Extraction System</td>
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<td>HCP</td>
<td>Health Care Practitioner</td>
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<td>HMO</td>
<td>Health Management Organisations</td>
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<td>HRA</td>
<td>Human Rights Act</td>
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<td>HSCA</td>
<td>Health and Social Care Act</td>
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<td>HSCIC</td>
<td>Health and Social Care Information Centre</td>
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<td>Abbreviation</td>
<td>Full Form</td>
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<tr>
<td>MCA</td>
<td>Mental Capacity Act</td>
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<td>MS</td>
<td>Multiple Sclerosis</td>
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<tr>
<td>NCCSDO</td>
<td>National Co-ordinating Centre for NHS Service Delivery and Organisation</td>
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<tr>
<td>NHS</td>
<td>National Health Service</td>
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<tr>
<td>NHS CRS</td>
<td>NHS Care Record Service</td>
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<tr>
<td>NICE</td>
<td>National Institute for Health and Care Excellence (formerly Clinical Excellence)</td>
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<tr>
<td>PCT</td>
<td>Primary Care Trust</td>
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<tr>
<td>PSA</td>
<td>Parliamentary Standards Authority</td>
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<tr>
<td>QMAS</td>
<td>Quality Management and Analysis System</td>
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<td>QOF</td>
<td>Quality and Outcomes Framework</td>
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<tr>
<td>RCGP</td>
<td>Royal College of General Practitioners</td>
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<td>SHA</td>
<td>Strategic Health Authority</td>
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<tr>
<td>SUS</td>
<td>Secondary Uses Service</td>
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<td>UKCAA</td>
<td>United Kingdom Civil Aviation Authority</td>
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Chapter 1 – Choice: The Problem

In the United Kingdom (UK) before the development of political initiatives utilising the language and rhetoric of patient choice, health care ethics and law would focus on the use and at times misuse of the terms autonomy, liberty and questions over rights to bodily integrity and privacy; rarely was there specific talk of patient ‘choice’. Choice featured in the literature as part of ethical debates endeavouring to clarify what respect for individual autonomy actually meant. The express reference to patient choice in health care is a much more recent phenomenon. Patient ‘choice’, per se, was a rarely used term in health care-legal matters even as far back as 2004, emerging with the case of Chester v Afshar\(^3\) in 2004. However with Montgomery v Lanarkshire Health Board in 2015, the courts may now appear to identify the patient as a consumer, ‘holding rights’:

…patients are now widely regarded as persons holding rights, rather than as passive recipients of the care of the medical profession. They are also widely treated as consumers exercising choices a viewpoint which has underpinned some of the developments in the provision of healthcare services.\(^4\)

This parallels and complements the language of the National Health Service (NHS) Constitution:

You have the right to make choices about the services commissioned by NHS bodies and to information to support these choices. The options available to you will develop over time and depend on your individual needs.\(^5\)

The language of ‘choice’ now permeates legal, ethical and policy debates. What choice means in health care and whether that choice in any sense equates to ‘consumer choice’ is less clear. In

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4 Montgomery (Appellant) v Lanarkshire Health Board (Respondent) (Scotland) [2013] CSIH 3; [2010] CSIH 104; [2015] UKSC 11 at 75.

this thesis I seek to indicate how in fact choice is restricted in matters of treatment availability, consents related to those treatments and the access and use of (my) medical data. Such restrictions on choice are not limited to NHS care given that actions within the private health care sector can have affects in the public sector. I also argue that restrictions on ‘choice’ are not necessarily to be deplored. What is of concern is that for many patients the rationale for the choices on offer or not on offer are opaque or unexplained which undermines the idea of putting the patient at the centre of their own management.

This thesis considers how patient choice ‘talk’ is really being utilised and interpreted by the English law as well as in health policy and practice. Inevitably this raises issues of patient consent and that includes not only consents relating to treatment but also the choices available to us over our medical information. Every step of the way common themes emerge. Transparency, information and shared decision making ought to have a core role in a functioning, resource limited publicly funded health care system; even if the latter actually requires a diminution in real individual choice. The question arises as to how genuine is this policy of individual patient choice; how realistic is this as a policy within a collectivist system like the NHS and what should patient choice mean in the face of such apparently confounding qualities and the complex interweaving of the policy, law and ethics?

As the largest provider of health care in the UK the focus of much of the thesis is on the NHS. However it is recognised that the private sector plays a significant role (sometimes within the NHS) and some patients do opt to seek treatment and care within that sector. The ‘choices’ may be different or the same but opting for private health care does not change the argument that the individual and their choices cannot be considered in isolation from the wider community, a point highlighted in Paper 3 in reflecting on the choice limitations for individuals who undertake responsible roles with societal implications.

1.1 The Origins of the Research

I undertook this thesis partly as a result of my own background and experience. At the time of undertaking this period of research I had taken early retirement from a portfolio career in the NHS that included general medical practice and postgraduate medical education and practice

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6 One example might be the exclusion clauses in insurance policies that rule out treatment for chronic diseases. This results in the burden of chronic (expensive) disease being managed by the NHS.
development. This early exit was as a result of a chronic neurological condition that warranted significant engagement with the NHS. At the same time as I was leaving practice, patient choice was becoming high profile in NHS dictats and health policy. The germline of this thesis came after numerous conversations with former colleagues still in medical practice. They appeared deeply unimpressed by the realities and practicalities of being expected to offer choice in many aspects of their patient’s NHS health care. In addition, along with the repeated and frequent changes in health policy there were fears of litigation.

Two areas were of particular concern. Practitioners were already engaging in complex and formulaic written consent to treatment process, with little time to discuss issues fully with the patient. The addition of having to apparently ‘offer choice’ was seen as adding to the complexity of the already unsatisfactory consent process and practitioners feared penalties for failing to offer or explain choices to the patient. The choice rhetoric also found a place in the context of patient information access and management. This was at the same time as practitioners were being expected and required to upload vast quantities of confidential patient data to distant data banks via electronic extraction systems. The risks of breaching confidentiality in order to function in practice were proving threatening and worrisome as practitioners were recognising that patient opt-out procedures were at best limited. The tension for practitioners was that as human beings they too would want an expectation of choice in their health care and data management and yet they recognised the need for a limit to free, unfettered choice, first so that the system can be managed correctly and in order to literally afford choice at some level.

1.2 The Scope of the Thesis

This thesis was thus initially designed to analyse and reflect on the aspects of patient choice in the NHS identified above. I argue that a lack of clarity in the use and hence meaning of choice in the NHS context results in a term that is flawed and sometimes fallacious. Such disparities in interpretation apply across the NHS spectrum from patients and practitioners, to providers (of care) and policy makers, and this incongruity is reflected by the English legal system and influenced via the European courts. In the event, as the thesis developed it became apparent that in relation to many matters of consent including control over our personal information and data, the talk has been more rhetoric than reality. What also emerged during the research period, and was addressed in
Paper 1, is that having a choice of provider and/or treatment whilst intrinsically valuable to the patient does not mean that they opt to exercise choice as presented.\(^7\) Limitations on choice ought to not necessarily be condemned given the requirements of a resource limited publicly funded NHS and the difficulties that too much choice can bring.\(^8\) It has been argued, for example, that too much choice can bring a diminution in autonomy rather than the expected increase in self-determination by overwhelming the patient,\(^9\) infantilising the patient\(^10\) and by making the patient ‘implicitly responsible’\(^11\) for their choices made even if the outcomes are poor ones. A more genuine place for those in the position of providing NHS interventions is a combination of transparency at all stages of the process and greater patient involvement in honest discussions about the nature and availability of the treatments available within the limits of NHS resourcing.\(^12\) In addition, shared decision making has been found to enhance in the patient an intrinsic and real sense of involvement in their own care with a recognition as to how and why the NHS operates as it does, with not all choices able to be met, despite the persistence of ‘choice’ talk. The same open conversations about the need for and use of the patient’s data would apply. These recommendations and findings have the essence of an argument put forward as far back as 1986, by Harvey Teff, in developing further the notion of a ‘therapeutic alliance:\(^13\)

…where the doctor and patient have an indisputably shared goal of restoring the patient to health…if the patient so desires, for their relationship to be a collaborative one, aimed at establishing a “therapeutic alliance.”

As the thesis evolved, partly as a result of my own background, the analysis of ‘choice’ in health care came to focus on matters of consent and medical information and its management. Further the research rekindled an interest in the limits of confidentiality and privacy. I began to consider whether for some people their information management ‘choices’ were and ought to be more

\(^9\) Ibid., p. 103-104.
restricted more than the already limited choices on offer to members of the general public via the NHS. These were people whose role and responsibility in society had the potential to create harms should the person’s health be significantly adversely affected.

But what does choice mean? In promising choice there is a need to be clear about interpreting a term like choice; about what is and what is not on offer. The dictionary definition of choice is as follows:

Choice:...‘the act or power of choosing…the preferable or best part.’"14

This thesis wants to go further and asks whether health care choice, that is, where an agent gets to choose the preferable or best part, is a ‘fact’ or actually a ‘fallacy, defined as follows:

| Fact:...a truth; truth; reality; or real state of things...15 | Fallacy:...an apparently genuine but really illogical argument; deception...16 |

This thesis indicates that there was and is a confusion and conflation when the term choice is used. Sometimes it is clearly a reference to the patient having the ability to make a choice and at other times it is about what choices were on offer. There is little about enabling patients to act on the choices available to them and less still on those that are unavailable. This has resulted in my proposal to reduce or abandon the term choice in favour of discussing and engaging with the patients and by using terms such as treatment options available and establishing patient preferences. Both concepts require additional time in their management in contrast to the process of just presenting the patient with a series of ‘choices’ from which to ‘choose’. Further, choice is not necessarily ‘consumer choice’ and does not always entail being able to have what you want. Intuitively the language of consumerism does not fit well with medicine and ‘my’ choices have to be balanced with ‘others’ needs particularly when the health care system is publicly funded.

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15 Ibid., p. 601.
16 Ibid., p. 605.
1.3 Brief Historical Context

It might be argued that not until the 20th century did the majority of people have any choice in relation to health care. It was the Liberal Government’s National Insurance Act in 1911 that resulted in free general practitioner (GP) care of working people earning under £160 per year. The resulting scheme was managed by ‘panels’ or independent insurance committees and GP’s opposition to the scheme was resolved by making the system capitation based, that is payments made per person on the GP’s list; a system of payment that remains today in spite of all the changes in policy and practice. If a person was not covered by the terms of the Act they either privately self-funded medical care, or in the absence of funds received nothing at all except perhaps acceptance in to a workhouse. As for the pre-NHS hospitals service as Ham points out, the so-called voluntary hospitals excluded the chronically sick and those with infectious disease, in favour of managing the acutely unwell. The former group had no option but to enter a workhouse. In 1929, after the Local Government Act, responsibility for infirmaries and workhouses became that of local authorities. After a complicated journey, and following on from the Beveridge Report, the National Service Act of 1946 was implemented in 1948. At inception, 90% of GPs were contracted to work for the NHS, despite vociferous opposition from the doctors previously. Within two months of the NHS becoming operational, 93% of the population had joined the scheme rising rapidly to 98%. Somewhat ironically those who had previously paid for health care, and what relative freedoms that provided, if they opted to enter the NHS they would have their ‘choices’ limited by the necessary constraints of the system.

In its early years the NHS might be seen as offering the choice to have funded care but little choice of what that care would be. Not until 1990 did the politicians laud choice in the NHS. However the literature shows that this concept of choice within the National Health Service was by no means new though rarely talked about or debated. Prior to 1990, in theory, patients did have a choice of both consultant and hospital when being referred by their General Practitioner (GP). Patients also

18 Ibid.
ought to have been able to choose their own GP, although in reality rather the reverse happened. Few patients appeared to realise the choices available to them and only the most vociferous exercised their choice. GPs were able to utilise local knowledge of hospitals and specialists to advise on those most suited to address a clinical need. In principle and in a paternalistic manner the GP, in effect, acted as a proxy for choice.

The political embrace of patient choice is more fully outlined in Chapter 2 and only briefly introduced here. 1990/91 saw the Conservative Government start a trend towards emphasising patient choice; the Patient’s Charter was notable at the time for its ‘rights talk’ although the Charter itself has disappeared into obscurity. The contracting process of fund-holding enabled some GPs to negotiate alternative care providers for their patients aiming to reduce waiting times for their patients and thus, to an extent, there were some choices available, albeit limited, as dictated by contract, and not open to those patients registered with non-fund-holding practitioners. The holy grail of choice really came after so called New Labour swept in to Government in 1997. By 2000, a choice agenda for health, (housing and education) was much vaunted via the Department of Health (DoH) as the way forward, apparently endeavouring to put the patient first in many facets of NHS provision. By 2010 and after some eight years planning it was the Conservative-Liberal Democrat Government of the day that introduced a policy that claimed to be patient choice focused; finally and controversially enacted as the Health and Social Care Act 2012, which came into force in 2013. This is applicable in England and it should be noted that the devolved nations of Scotland and Wales and Northern Ireland have not adopted a patient choice agenda in their provision of health care. With the HSCA 2012 again the talk was of putting the patient at the centre of the decision making both about their care and consent to treatment and in the access to and use of their information; ‘no decision about me without me’ has proved not to be the case and, more controversially perhaps, nor should it be in all situations.

26 DoH, Liberating the NHS No decision about me, without me Government Response to the Consultation Liberating the NHS: No decision about me, without me (London: NHS Commissioning Policy & Sponsorship, 2012) Gateway Reference 18444 1-6.
1.4 Patients, Practitioners and ‘Pundits’

Aside from the politicians there are a number of key participants involved in the practical application of the health care patient choice agenda. The patient ought to be paramount given this ‘no decision about me without me’ philosophy and might be expected to relish the opportunity of choice in their health care. It could be expected, as noted above, that the practitioner would be more hesitant. Patient related literature regarding the NHS choice agenda has been rather limited despite the rhetoric promising huge positive changes for the patient. What there has been appears largely anecdotal, individual and case related and, interestingly, often written when the patient also happened to be a health care practitioner. Patient support group literatures have tended to reiterate policy rather than undertake any reflective analyses. Insightful the reports were but they did not carry substantive evidence. Mold undertook an overview of patient representative groups, the nature and remit of which have undergone frequent and rapid changes in structure. As he identifies, the state has taken on the role more and more by constructing ‘quasi-statutory’ bodies that ‘displaced’ the ‘advocacy’ of the patient-as-a-consumer. Inevitably therefore, I would suggest, independent patient representation on the choice agenda and matters arising became less probable.

In 2010 Coulter reinforced previous findings that what patients valued most was the offer of choice; this was of intrinsic value to the patient. Patients wanted more involvement in treatment decisions and whilst they also valued the opportunity to see an alternative care provider, the majority opted not to choose and remained within their locality, at the local hospital for example. A limited review of patient and consumer representative groups was indicative of a degree of caution, if not some suspicion, when it reviewed choice policy. Note this comment from the Democratic Health Network:

27 Ibid.
30 Willis, J., ‘Thank you, no’, British Journal of General Practice, (August 2006), 640. ‘...we have opted out of the common health record...very few people realise that they have the choice.’
32 Ibid., 518
33 Coulter, A., n.7 above.
Why are we talking about extending choice when we know that any real choices going will be exercised by those who need least support? …because those who make policy…only think in terms of markets and consumers where choice is a sacred word.

This echoes commentary from Brazier and Glover:

Measures…are designed to ease the burdens on the NHS and increase patient choice. They could be seen as mirroring the consumer-oriented services…will shopping for medicine offer a recreation for the ‘worried well’ and fail to meet the needs of the sick.  

In 2012 the health ‘think-tank’, The King’s Fund, performed a comprehensive analysis that clearly showed if patients’ preferences are given greater attention, there is a reduction in the probability of misdiagnosis. A more fully informed patient is better able to indicate their preference for the most personally suited treatment choice, (even if from a very limited range), reducing the likelihood of adverse outcomes:

…by providing patients with more and better information about options, outcomes and evidence…trying to eliminate preference misdiagnoses, so that patients receive the care they need (and no less), and the care they want (and no more).

Initially there had been few independent analyses of choice policies in the NHS and what there were seem to have concentrated on the views of providers rather than users. In one report GPs (utilising ‘Choose & Book’ systems) are labelled ‘enthusiasts, sceptics or paternalists’, although there is no clarity as to how this categorisation was made, by what criteria, and upon whose definitions. The General Medical Council (GMC) and other health care regulatory and professional organisations appear to have avoided engaging in the choice agenda directly. What is noteworthy is that in the GMC document Good Medical Practice, the word choice is not used at all – (patient)

37 Ibid., pp. 1-2.
preference is, once: ‘Work in partnership with patients. Listen to and respond to, their concerns and preferences.’

1.5 Summary

Part 1 of this thesis is primarily a background and introduction to many of the elements, questions and conclusions developed in the papers that follow. Following this introductory chapter, Chapter 2 Choice: Politics, Legal and Ethical Backgrounds sets out to review the origins and underlying principles of the patient choice agenda from political, legal and ethical perspectives. It starts to consider whether the language of choice is no more than rhetoric and begins to consider a change in that language. In addition, from the legal perspective, matters relating to medical information management, the use of patient data, confidentiality and privacy are reviewed prior to more detailed consideration in Papers 2 and 3. Chapter 3 Legal Approaches: Choice, Information Disclosure and Treatment Demand relates to my first published paper and gives consideration to how choice language and its interpretation has developed in law with regard to consent to treatment, treatment refusal and pertinent treatment demand. That paper was published in 2011 and Chapter 3 also addresses the 2015 decision of the Supreme Court in Montgomery v Lanarkshire Health Board. The question has arisen as to whether Montgomery has endorsed in law an era of consumer choice and demand in health care. I argue not. In Chapter 4, Choice: Political and Philosophical Approaches, I identify the political and philosophical background that underpins and leads to a patient choice agenda as well as considering and exploring respect for an individual’s autonomy, or self-determination, its importance and relationship to choice. This chapter reflects on the complexities inherent in using a term like ‘patient choice’ which, at first approach, would appear relatively simple and feels so pro-patient positive. Chapter 5 Research Questions and An Introduction to the Papers introduces my three papers and indicates the nature of my research. The research was desk based and involved critical doctrinal analysis of law and ethics as well as a review of the established and evolving research literature on patient choice in law, ethics, policy and practice, and of the reality or otherwise of individual patient health care choice.

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40 Ibid., Under the introductory checklist entitled: Duties of a doctor registered with the General Medical Council. No page number.
Chapter 2 – Choice: Policy, Legal and Ethical Backgrounds

Choice matters because it is at the heart of the Government’s public service reform agenda to empower patients, reduce inequalities in access to healthcare and improve health outcomes for patients.¹

2.1 Introduction

The aim of this chapter is to provide an overview of the political, legal and ethical debates that generated the work in this thesis and the papers that follow. I start with politics because patient choice in publicly funded health care is a political issue. In this chapter I argue that for all the talk of patient engagement in decision making no political party would pursue a patient choice agenda unless it had political benefits; choice becomes a tool of utility, out of necessity maybe but not simply because any Government has developed an enhanced respect for the individual. Policy therefore is imperative and this chapter provides a brief overview of how choice, or choice language, became central to all political parties’ agendas on health care. I do not attempt a political analysis nor do I track the development of the political agendas in full, I simply explain how choice language made its entrance to policy debates. To some extent I consider these debates from my own perspective – as a medical practitioner and as a patient. In addition to the politics and subsequent policies running the patient choice agenda, there are the legal and ethical components to engaging patients in that health care choice agenda and individual patient choice in particular. Note this from Lord Kerr, in the Supreme Court:

…patients are now widely regarded as persons holding rights, rather than passive recipients of the care of the medical profession. They are also widely treated as consumers exercising choices….²

As a result, the superficially simplistic idea of now offering the patient choice when previously there was little or none is anything but simple, now the patient is to be considered having an active contribution and role in choices and outcomes. Following an analysis of policy I address a number of legal themes involving choice, consent and confidentiality and ethical themes centred on choice

² Montgomery v Lanarkshire Health Board [2015] UKSC 11, at 75.
and respect for individual autonomy. All these aspects will go on to be developed further in later chapters and the papers that follow.

2.2 Policy Themes

When I first embarked on this thesis and analysis of patient choice, there were three main political parties active in England (Conservative, Labour and Liberal Democrat), and all three had something to say on the topic. The rhetoric was powerful, although those at the frontline of medical practice were often less than impressed.

The Conservatives had, first under Margaret Thatcher and then John Major, sought to introduce market forces into the previously centrally administered and apparently crumbling system. Choice was seen as integral to this marketisation. Talbot-Smith and Pollock conducted a particularly cogent analysis of (NHS) ‘funding and resources’ of the time.

The Labour Government that had been elected in 1997 made full use of the idea of choice within the NHS. The concept became something of a flagship mantra for the party:

Giving patients more choice about how, when and where they receive treatment is one cornerstone....Another is giving the public a bigger hand in shaping local health care systems.

As for the Liberal Democrats one of their pre-2010 general election health consultation papers read as follows:

A key part of the Liberal Democrat philosophy is a belief in personal autonomy….we believe policies to strengthen choice should concentrate on giving people greater influence over how services are developed...

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5 Liberal Democrat Federal Policy Consultation Paper No. 86, Policy Projects Team, Liberal Democrats, 4 Cowley Street, London, SW1P 3NB. pp. 5-22. [ARCHIVED].
And note:

The Labour Government has promoted patient choice as a key driver….It is doubtful whether this notion of choice alone truly responds to what patients want from the NHS…

Pollock reviewed the increasing role of the private sector. Conservative Policy documents of the time, though short on detail, indicated an expansion of policies more usually associated with the Labour party, to include co-payments initiatives for those who can ‘choose’ [my quotes], or would rather self-finance enhanced care packages. It has been the Conservative Party (in coalition with the Liberal Democrats) who undertook the most radical re-organisation of the NHS since its inception. The 2010 White Paper Equity and Excellence: Liberating the NHS and associated documents, proposed the current comprehensive changes to health strategy in England enacted via the Health and Social Care Act, (HSCA) 2012. April 2013 saw the HSCA 2012 actioned with the largest shake-up in National Health Service (NHS) policy and practice since the service was established in 1948. It was a re-modelling programme that has not been without controversy although many of the arguments have been focused on competition and market forces. The complex issues associated with the stated early reform priority of putting the patient at the centre of their own health care did not result in much comment.

What is the outcome of the cumulative political emphasis on ‘choice’? Patient choice became enshrined in primary legislation (Health Act, 2009) that formed the cornerstone of the NHS Constitution, also first launched in 2009, although subtly yet significantly amended in March 2013. In addition, shared decision making between patient and practitioner has been a central tenet of health service policy in England for some years, ‘no decision about me without me’. Shared decision making is not the same as choice. Has the emphasis on choice language diluted and

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6 Ibid.
9 Pollock, A.M., n. 7 above, pp. 261-263.
12 Health Act, 2009, c. 21, part 1, Ch 1.
diverted from the key issue; that of engaging the patient at the centre of their own treatment programme in a transparent manner?

Clinicians, with General Practitioners (GPs) taking the lead, were now responsible for the majority of health care commissioning decisions in the English sector of the NHS. Strategic Health Authorities (SHAs) were merged then disbanded and Primary Care Trusts (PCTs) abolished in favour of NHS England and locality oriented Clinical Commissioning Groups (CCGs) and now there is the advent of a programme of devolved CCG/Local Authority consortia that combine health and social care.¹⁵ Financial savings of 20 billion pounds had been demanded by 2015. The rhetoric remained patient focused¹⁶ and as such the patient could look forward to being integrally involved in decisions about their own treatment,¹⁷ with correspondingly high expectations on what health care is available and accessible. In order to fiscally 'afford' the choices inherent to the reforms might well have, and still need to, result in a reduction in service availability and accessibility, decisions that are made by clinical commissioners. Yet when the clinical commissioner is also the GP he/she must remain the patients' advocate and adviser; often a first point of contact when engaging NHS services.

From a political perspective it would seem all the key players of the time emphasised that choice in the NHS was 'good', although treatment availability and accessibility did not form part of the rhetoric. If treatment is not available, or available but not accessible, then choice as a term must be redundant. A tension appears to have emerged in the patient-practitioner relationship. The choices on offer may actually be limited or become limited while still the concept is promoted, and decisions made in a less than transparent manner despite the rhetoric of choice and engagement of the patient in their own health care management. Policy and practice failed also to acknowledge the fact that too much choice can be so overwhelming and problematic that people are unable to choose.¹⁶ ¹⁹ Choice policy raised questions as to how so many people would each get their preferred choice in health care and could the system legitimately function if everyone got their ‘choice’? One (prime) example of ‘choice change’ that remains active is “Choose and Book”, a

¹⁶ DoH, n. 1, above, p. 1 and p. 16 para., 2.18.
policy that was originally developed in 2004.\(^{20}\) In this referral system the patients are assisted in choosing between four and six providers for the service that they and their GP have agreed is needed. At first glance this seems a positive and improved service for the patient. The ‘devil may have been in the detail’ however, as the decision as to whom, what or where is on that pick list of providers was pre-set thus:

Patients will be able to choose a provider for their elective care from within a range of services commissioned by their PCT…[now CCG’s – my addition] it may not be possible to offer the full range of […] choices….choice of hospital may not be appropriate for all services…The choice options will be based on locally commissioned service.\(^{21}\)

It is noted that some of these providers were and still are in the private or managed sector,\(^{22}\) some proving successful and some not.\(^{23}\) Is this enhanced choice, different choice or little if any choice at all? And as GPs remain financially incentivised not to refer where possible, what might this do for patient choice?\(^{24}\)

The past fifteen years have seen the language of health policy increasingly appear to endorse patient choice. Only now in 2015 has the rhetoric, if not the practice, been in retreat. The law has almost been ‘playing catch-up’ alongside policy, only to find it catching up with a policy that is becoming defunct.

2.3 Legal Themes

In Paper 1 (2011) I developed a number of arguments to suggest that while choice language has begun to influence English case law, choice was not central to the law relating to consent to treatment and what was meant by choice was far from clear. In 2015 the decision in the Supreme


\(^{21}\) Ibid., ‘Choose & Book’, pp.5-6.


Court in Montgomery v Lanarkshire Health Board might appear to suggest that fifteen years after choice entered the political agenda, the law belatedly caught up with policy. I shall deal with ‘informed consent’ and the impact of Montgomery in the next chapter in which I also address treatment demand, contending that the law has not and does not sanction unfettered patient-as-consumer choice. In this section I offer a brief introduction to some of the other basic legal issues relating to choice and health care. I will address the law in England (and Wales), taking into account, where needed, European Human Rights law and European Union law. I limit my full analysis to the competent adult patient and do not deal with minors. Mental capacity is noted only in the context where it may be argued that the threshold for capacity may be used to undermine what the Court sees as an unwise choice. In this chapter I also introduce questions of choice with regard to patient confidentiality, data access and management more fully dealt with in Papers 2 and 3.

Law, as much as health policy, seems to undergo an evolutionary process, sometimes in fits and starts, rather than develop via smooth incremental steps. Both this thesis and the first published article were conceived and constructed long before the Supreme Court decision that might yet prove to be a ‘game changer’ in the world of health care choice and consents. In Chapter 3, I will (inter alia) look at consent as the ability to make a choice, express one’s preferences and protect one’s bodily integrity in whatever form the individual opts for, be that agreeing to treatment, declining treatment and importantly having the necessary time and information to consider the options.

2.3.1 Choice – Consents and Capacity Matters

Choice as rhetoric and as a concept has found its place in the language of English judges in matters connected with consent, confidentiality and capacity. The complex nature of choice was recognised by Lord Hope in Chester v Afshar in 2004:

For some [patients] the choice may be easy - simply agree or to decline the operation. But for many the choice will be a difficult one, requiring time to think, to take advice and weigh up the alternatives.

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25 Montgomery, n. 2 above.
26 Ibid.
In other words choice is not about the patient being able to ‘choose whatever he wants’, this is not necessarily an integral part of the consent process.

Skegg\textsuperscript{28} as far back as 1999, in a critical analysis of English law and its emphasis on so called informed consent, rather than information disclosure about [treatment] alternatives stated:

> It is the overwhelmingly great emphasis on consent (even ‘informed’ consent), rather than on choice. Consent does, of course, involve choice. However the choice is usually a matter of whether or not to consent to a particular proposal. The role of consent is often seen to be that of protecting a practitioner from a risk of legal proceedings: information is disclosed to ensure that consent is ‘legally effective’.\textsuperscript{29}

Newdick talks of ‘the Evolution of the Law of Informed Consent’.\textsuperscript{30} Evolutionary the law may be, seen in the sense that legal decisions are made, time moves on, change and amendments occur, but not, ‘…a cumulative change…gradually working out.’\textsuperscript{31} It seems more that the law has evolved in fits and starts along the way rather than as a smooth and structured process.

One form of choice seems clear and undisputed. The adult patient with mental capacity has an unfettered choice to agree to or refuse treatment proposed by his/her doctor. Capacity is the key question as for people for whom capacity is limited or lacking, permanently or transiently the right to choose is displaced and the provisions of the Mental Capacity Act 2005,\textsuperscript{32} and subsequent developments via the Mental Health Act 2007,\textsuperscript{33} come in to play allowing others to choose for the patient. In early cases where judges address and endorse choice what seems noteworthy is that the choice rhetoric first appears in cases concerned as much with an individual’s capacity as with their consent.

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\textsuperscript{29} Ibid., 149.
\textsuperscript{33} Mental Health Act, 2007 c 9.
In *Re T*[^34] (1993), from Lord Donaldson:

> An adult patient … has an absolute right to choose whether to consent to medical treatment, to refuse it or to choose one rather than another of the treatments being offered.

And:

> … the patient’s right of choice exists whether the reasons for making that choice are rational, irrational, unknown or even non-existent.

At first glance therefore the patient’s choice became paramount. The decision in *Re T* went against the patient’s wishes however, as her decision was considered to be defective, given the conditions of the case. Donaldson L. J.’s comments could be interpreted as a misuse of the concept of choice and capacity, little more than rhetoric therefore? Further, and pertinent perhaps in the light of the recent decision in *Montgomery*, is that the hospital hampered T’s decision-making with a lack of information about the possibility of T’s death without blood transfusion or being advised that any blood substitute products were of little use in the case of severe haemorrhage. Somewhat perversely, and in the same year as *Re T*, Lord Donaldson, in *Re W*[^35] made the analogy that a patient’s consent was a ‘legal flak-jacket’, a way of protecting the practitioner from the patient. This resonates with Skegg’s comments noted above. In other words choice having been offered, though not necessarily as part of an engaged discussion, during the consent process, might serve in favour of protecting the doctor rather than the patient. As for Lord Donaldson’s language of the patient’s rights and choice in *Re T* (above) this thesis does not argue for absolute *unlimited* choice.

[^34]: *T (Adult: Refusal of Medical Treatment), Re* [1993] Fam 95; [1992] 3 WLR 782; [1992] 4 All ER 649, CA. A young woman (20y) was 34 weeks pregnant and was injured in road traffic accident. Caesarean Section (CS) was required. Despite not being a Jehovah’s Witness (JW) after T’s mother visited, subsequently T declined blood transfusion; she signed a form to that effect and that also released the hospital of any liability. Haemorrhage ensued post CS and the hospital stated that it could not lawfully administer blood to T. The Court of Appeal granted a court order sought by T’s father and boyfriend authorising a blood transfusion that saved T’s life.

[^35]: See *Re W (A Minor) Medical Treatment: Court’s Jurisdiction* [1993] Fam 64 CA where Donaldson, LJ likened consent to a ‘flak jacket’ for doctors. W was a 16 year old female with anorexia who failed in an attempt to have her refusal to treatment managed as if she had been of adult status.
Assuming however that the adult with capacity does enjoy the basic choice to say yes or no, the threshold for capacity is crucial. In *Re C*[^36] (1994) there were, what Mason and Laurie[^37] went on to understate, ‘very interesting conditions [of the case – my brackets]’. C was a chronic paranoid schizophrenic and under detention in a specialist hospital. He was advised by doctors to have a severely infected leg amputated in order to preserve his life. C declined and despite C’s delusional state Thorpe J decided that C was competent enough to make that decision.

Thorpe J.:

…I am satisfied that he has understood and retained the relevant treatment information, …and that in his own way he believes it, and that in the same fashion he has arrived at a clear choice.^[38^]

In *Re C* the individual was told that without surgery he would die; die he did not but he had made his choice to refuse surgery and the courts respected that choice as they ultimately did in the case of Ms B in *Re B*.[^39] Ms B, a long term artificially ventilated individual, wished that the ventilator be switched off, with the inevitable consequence of her death. Finally after 18 months of psychiatric evaluation that satisfied the courts and the doctors, Ms B was deemed of full capacity, immaterial of the fact that her decision was at odds with the values of many who were treating her. Ms B got her choice, entered a unit that was prepared to remove ventilator support and died, as she had wished. And yet the same rationale did not apply in 2000 to Ian Brady, one of the so-called Moors Murderers[^40]. Brady was on hunger strike allegedly as part of a protest against what he saw as poor treatment at Ashworth High Security Hospital. In court Maurice Kay J authorised force feeding under Section 63 of the Mental Health Act 1983 on the basis that ‘the hunger strike is a manifestation or symptom of the personality disorder’; in effect a capacity issue.[^41] Notwithstanding that there may have been a political and perceived public interest issue in keeping Brady alive and in receipt of punishment, it is hard to see why C’s and Ms B’s choices were (finally) facilitated by the courts and yet Brady’s was not.

[^36]: *C (Adult: Refusal of Medical Treatment), Re* [1994] 1 WLR 290; [1994] 1 All ER 819.
[^38]: Ibid.
[^39]: *Ms B v An NHS Hospital Trust* [2002] 2 All ER 449.
Choice, consent and capacity therefore appear to be rather malleable concepts. Has the advent of the Mental Capacity Act\(^ {42}\) and its subsequent amendments (as a result of incorporating European Convention rights) with section 50 of the 2007 Mental Health Act\(^ {43}\) made any difference? \(^ {44}\) The MCA sanctions a ‘functional’ test, where function is deemed to be an ability to understand the options available to individuals. \(Re\ C\) above is a classic test of functional status now underpinned by the MCA, 2005; was C able to understand and continue to understand information about treatment proposals, was C able to have a belief in the treatment plan and could a decision be made on the basis that C was able to duly consider that information? Further it has been recognised that the functional capacity to make decisions, choices, if you will, can fluctuate over time\(^ {45}\) and the MCA requires sensitivity to this fact, at section 3(2):

> The fact that a person is able to retain the information relevant to a decision for a short period only does not prevent him from being regarded as able to make the decision.

The threshold of capacity enables the judges to override unwise choices. More recent case law may show something of a change in judicial approaches to choice and recognition that even in cases where capacity is questionable, patient choice is still to be valued. Two 2014 cases are illustrative in the sense that they give much more validity to advance decisions, that is, the choice of an individual to refuse a treatment. In the cases of \(Newcastle\) upon Tyne Hospitals Foundation Trust \(v\) \(LM\)\(^ {46}\) and of \(Nottinghamshire\) Healthcare NHS Trust \(v\) \(RC\)\(^ {47}\) the patients were Jehovah’s Witnesses, both had mental health issues and both declined blood transfusion in advance of requiring one. The courts upheld the choices of both patients, with Mostyn J stating in \(Nottinghamshire\) that ‘to impose a blood transfusion would be a denial of a most basic freedom’. In each of these cases the doctors had already decided that transfusions ought not to be given against the patients’ wishes and were seeking advice and possibly support from the courts in the matter of the choices that these patients had made. The courts agreed, signalling a definite shift to respecting the choice of the patient, however unpalatable others might find that ‘choice’. What the Mental Capacity Act continues to do is reinforce our negative choices; ‘you will not resuscitate me’. It does nothing for those who choose to say ‘you will resuscitate me’ as one Mr Burke found out with

\(^{42}\) MCA, 2005, n. 32 above.

\(^{43}\) Mental Health Act 2007, s 50, that resulted in Deprivation of Liberty safeguards.


\(^{45}\) Consider some dementias, toxic confusional states and psychotic conditions.

\(^{46}\) \textit{Newcastle} [2014] EWHC 454 (COP).

\(^{47}\) \textit{Nottinghamshire} [2014] EWHC 1317 (COP).
his demand for artificial hydration and nutrition not to be ceased prior to his death by natural organ failure.48

Patient choice has increasingly found a place in the judgments and language of the courts with regard to treatment consents and demands in association with autonomy yet stopping short of treatment demands. There is one other major category of health care provision where the recent policy rhetoric has placed an emphasis on the patient having a choice and that is over their medical information and the confidentiality and privacy or otherwise of its access, management and use by others; comprehensively addressed in Papers 2 and 3 later in this thesis.

2.3.2 Personal Medical Information Management and Choice

Patients tend to give freely of their medical information in the safe and sure knowledge it will be kept confidential.49 Confidentiality within the NHS and the information management and control policies therein also highlight issues and difficulties that the offering of and expectation of choice brings. Confidentiality and privacy issues have in the past generated medico-legal and ethical comment particularly in the field of the ‘new’ genetics50 and in relation to public health.51 I take a more pragmatic and less specialist approach and look at confidentiality in relation to handling our ‘every-day’ medical information. At the same time patient choice is so strongly endorsed in policy language, required changes in medical practice have undermined choices to ensure that medical information remained confidential.

In the early years of the NHS, or even before, a patient would be registered with one general practitioner, one person and quite possibly at one practice for life. The transfer of information, often in itself quite limited, would be illness and treatment based and would only be passed directly to a ‘relevant other’, as like as not a consultant at the local hospital. The form of the transfer was a handwritten letter from the GP, read by the consultant and then placed in a case file to be referred to again by that consultant or possibly one of his juniors, (the choice of gender is deliberate), and

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48 R (on the application of Oliver Lesley Burke) v The General Medical Council [2005] EWCA Civ 1003.
49 NHS Constitution, n. 13 above, ‘You have the right to privacy and confidentiality and to expect the NHS to keep your confidential information safe and secure.’ p. 8. See also X v Y [1988] 2 All ER 648 at 653 where Rose, J., stated that ‘…preservation of confidentiality is the only way of securing public health…confidentiality is vital to secure public as well as private health…’
where it would stay for time immemorial. Unlike now with electronic databases very few people had access to written patient information and any shared decision making was more likely to be between consultant and GP, rather than doctor and patient.

What happened however in the transitional period of 1989/1990 was a change that, unknown to the majority of patients and practitioners at least, began the process of nationwide NHS patient information management that we see today. It was the combination of some practices computerising medical records and referral letter writing, and a (then) new GP Contract that put the onus on health promotion and audit, and as such warranted the collation of large volumes of patient information without informing the patient. The results of such data gathering have gone on to have an impact on GP incomes and subsequently hospital earnings too via later fund-holding requirements. These all became contract based and the data was required in order to both audit and remunerate health activities and care provision. Developments such as the GP Contract of 2003\(^{52}\) went on to enhance all these elements of data extraction and sharing. While privacy per se appeared to be gaining more legal protection, health care privacy was becoming subtly undermined.

Some definitions may be useful:

Confidentiality\(^{53}\) from confidence; firm trust or belief,…trust in secrecy. Confide; to trust wholly; to tell with reliance upon secrecy… Privacy\(^{54}\); (one’s right to) freedom from intrusion from the public; avoidance of notice, publicity or display…

Confidentiality in health care remains a core concept in the NHS and for doctors\(^{55}\), although it is noteworthy that much of the most recent guidance is actually given over to information disclosure.\(^{56}\) Confidentiality is an expectation, albeit a relative right, and is underpinned by case law in England\(^{57}\)

\(^{52}\) British Medical Association and The NHS Confederation, *New GMS Contract 2003 Investing In General Practice* [www.bmas.org.uk](http://www.bmas.org.uk) [www.nhsconfed.org](http://www.nhsconfed.org)


\(^{54}\) Ibid., p. 1363.


and via European decisions. Statute is a significant influence, with the Data Protection Act 1998 (DPA) & Human Rights Act 1998 (HRA) affording some protections yet as many as fifteen other English Statutes (including the HRA) and regulations allow possible information incursion, without the benefit of judicial analysis and interpretation. Statute and case law do appear to protect our confidentiality but despite the protections, on reflection, choice over our medical information is largely illusory as I show in Papers 2 and 3. I go on to argue that this not necessarily wrong and that the choice talk around confidentiality and privacy has to be tempered with a need to access and utilise data for an efficient health service to function, promote new treatments and protect patients. In Paper 2 there is a more in-depth review and analysis of the current information systems, patient choice policy and confidentiality, and the law and our medical data; highlighting the need to limit confidentiality at times, despite the rhetoric, in favour of a functioning NHS.

Health care related information issues have already generated ethical and legal commentary; be this in the public health–private interest domain, in respect of clinical research needs and the individual and over the modern management of NHS systems. The law itself has undergone an evolution in the field of personal medical information control, be that as access or management of the data therein. A short 'look back' exercise on these developments brings us to an understanding of where we are today. There are many concerns expressed about breach of confidentiality and it may be that a more honest discussion about the demands and requirements of a functioning health system would explain those demands. It may be that it is the very state of confidentiality that needs questioning rather than more law developing.

61 Human Rights Act 1998, Schedule 1 The Articles, Part 1 The Convention, Rights and Freedoms. Specifically Articles 8 (1) and (20.
63 Brazier M., Harris, J., n. 51 above, 171-192.
English cases on confidentiality generally can be traced back to 1856 and as per Brazier and Cave took on a ‘haphazard’ formulation. Basic principles were established in *Coco v A N Clark (Engineers) Ltd* in 1969, and were developed further with *A-G v Guardian Newspapers* where it was determined that there was a public interest to be had in legally enforcing a protection of confidences received in a confidential arrangement. The medical/clinical scenario became a more distinct entity in the English system in *X v Y* with the attempts by the Press to name two HIV positive doctors. Rose J. considered but was not impressed by the public interest arguments submitted:

Confidentiality is vital to secure public as well as private health…I keep in the forefront of my mind the very important public interest in the freedom of the press. And I accept that there is some public interest in knowing that which the defendants seek to publish…. But in my judgment those public interests are substantially outweighed when measured against the public interest in loyalty and confidentiality…

Further, if we accept that there are occasions when patient record disclosure might well be in the public interest, such disclosure, while acknowledged, has also been limited and not absolute following *W v Egdell* as per Lord Goff:

It does not…follow that the public interest will…require disclosure to the media, or to the public by the media. There are cases in which a more limited disclosure is all that is required.

European human rights law has proved increasingly influential in the field of medical data control. Both the European Convention on Human Rights, in Article 8, and the Council of Europe’s

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67 Brazier, M., Cave, E., n. 57 above, p. 84.

68 *Coco v A N Clark (Engineers) Ltd* (1969) RPC 41 at 47 and 48.


71 Ibid.

72 Ibid.

73 *W v Egdell* (1990) 1 All ER 835.

Convention on Human Rights and Biomedicine, Article 10,\(^{75}\) acknowledge and endorse medical privacy, albeit as an unqualified right. The latter is not binding and remains unsigned and un-ratified by the UK.

The House of Lords endorsed the concept of medical privacy in the pivotal case of *Campbell v Mirror Group Newspapers Ltd.*\(^{76}\) From Baroness Hale:

…information about a person’s health and treatment for ill health is both private and confidential…\(^{77}\)

Whilst due reference was given to Article 8 rights, no tort of privacy was established. Ms Campbell claimed compensation under the Human Rights Act, 1998 (HRA)\(^{78}\) and the Data Protection Act of 1998 (DPA).\(^{79}\) The latter is a complex piece of (originally European\(^{80}\)) legislation that affords significant protections to data subjects, including consent(s) to information access and processing, while still enabling access without consent in the ‘substantial public interest’.

Supplementing the law on confidentiality and privacy, the General Medical Council (GMC) gives extensive guidance on confidentiality.\(^{81}\) Although not a focus of this thesis it should be acknowledged that there are what might be called ‘traditional’ exceptions that enable non-consensual disclosure when justified in the public interest. Choice is not a feature. Classically these disclosures will occur if the health care professional is bound by law to release information to a third party and where the doctor may ‘voluntarily elect’ to disclose.\(^{82}\) There have been few changes in this facet of health care law over recent years. However, the GMC have been much more explicit in their guidance to doctors over matters of compulsory and elective

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\(^{75}\) Council of Europe, ‘Convention for the Protection of Human rights and Dignity of the Human Being with regard to the application of Biology and Medicine: Convention on Human Rights and Biomedicine, Ch III Article 10, CETS No: 164, Oviedo. 4 April 1997.

\(^{76}\) *Campbell v Mirror Group Newspapers Ltd* [2004] UKHL 22.

\(^{77}\) Ibid., at para 145.

\(^{78}\) Human Rights Act, 1998, where the House of Lords undertook a ‘balancing exercise’ between Article 8 and Article 10.

\(^{79}\) DPA, 1998, n. 60 above, see s. 68 and 69.

\(^{80}\) European Directive 95/46/EC, Protection of Individuals with regard to the processing of Personal Data and on the Free Movement of Such Data. The Data Protection Directive.

\(^{81}\) GMC, n. 55 and n. 56 above.

disclosure, detailing both the specific circumstances and the manner or process to be undertaken. As guidance develops the GMC do seem to have endorsed more and more grounds for exceptions to confidentiality.\textsuperscript{83} However, the guidance has still to develop with specific regard to the major erosions of privacy, now taking place primarily electronically, for example, the General Practice Extraction System (GPES), in order to acquire and share data (see below). Here the rhetoric of patient choice is persuasive but the reality is rather different as I go on to show.

While several information technology\textsuperscript{84} projects have come and gone, it was the Connecting for Health NHS Care Records Service first mooted in 2002 that had the potential to facilitate distant information access with the aim of rapid information sharing. The intent of enhancing patient care appeared sound. However, the nature of the personal and medical information identified (and perhaps the margin for inaccuracy in medical records) might well attenuate the value to the individual whilst creating huge data sets for the Government. In itself this may not be problematic if the rationale is to assist a functioning health care sector and the situation is explained transparently and honestly.

Much of the personal medical information that is utilised for standard setting should be anonymised to one level or another and as such, since \textit{R v Department of Health, ex p Source Informatics Ltd.}\textsuperscript{85} (on appeal), should be free from confidentiality and privacy concerns and yet it is this very stance on anonymising date that started the process undermining privacy as is argued in Paper 2. One can only speculate as to the levels of anonymity ever achieved and who may profit. Does the HRA and the DPA, in effect, enable organisational intrusions? Further is it adequate enough in these days of data access and dissemination that employees of the NHS or research organisations are bound by employment codes of confidentiality only? Dr Z did not find such regulations supportive of either her confidentiality or her privacy.\textsuperscript{86} She had been ill in childhood with a disease that held research interests, but Dr Z had withheld any consent to participation in research and the inclusion of her information on any research database. The research happened to be conducted under the auspices of her own employing PCT and HA. And she had also objected to inclusion of other patients’ unconsented data in the same project. Yet she was subject to “uninvited, intrusive and

\textsuperscript{83} See GMC, n. 56 above.
\textsuperscript{84} National Programme for Information Technology (NHS CRS) includes the NHS Care Records Service, ‘Choose and Book’, Electronic Transmission of prescriptions (ETP), and IT supporting GP payments including the Quality Management and Analysis System (QMAS).
\textsuperscript{85} [2000] 1 All ER 786, CA.
\textsuperscript{86} Dyer, C., ‘Whistleblower who was excluded from work for five years wins apology’, \textit{British Medical Journal}, January, 2008, \textbf{336} [63].
upsetting” phone calls from unknown researchers and the data dissemination that also occurred adversely affected her employment. Dr Z was being excluded from work for five years with her fitness to practice in question. An unreserved apology was made to Dr Z by her employers in the High Court and they acknowledged that she had had ‘a long and distressing battle to preserve her medical privacy.’ The debate that resulted from this case was extensive despite the case itself being unreported and Dr Z subject to a gagging order. 87

With the Connecting for Health Care Records project, initially there was to have been absolutely no opting out facility for the patient. 88 Howls of concern, often from the medical profession, 89 resulted in a Ministerial Taskforce 90 and a Guarantee document, 91 with the latter stating that ‘usually [my emphasis] you can choose to limit how we share the information in your care records which identifies you’. Then, apparently, patients could choose to opt out, present limited information only or allow their data to enter the data ‘spine’ in entirety, if they did but know it. The Information Commissioner saw fit to comment 92 but again little publicity about the ‘privacy’ options was available and so whilst a choice of sorts was present, it was of limited quality and accessibility; and this too was of continuing and expert concern. 93 The Care Records project and associated Information Technology systems have gone on to be abandoned. 94

2013 saw the advent of GPES, managed centrally on behalf of the NHS by the Health and Social Care Information Centre (HSCIC) and described as follows:

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87 Rapid responses, British Medical Journal 336 [63-a],
90 Report of the Ministerial Taskforce on the NHS Summary Care Record, December 2006, pp. 15
91 DoH, Care Record Development Board, ‘The Care Record Guarantee Our Guarantee for NHS Care
92 Information Commissioner’s Office, ‘The Information Commissioner’s view of NHS Electronic Care
94 Lewis, M, ‘NHS electronic care records project fails to achieve aim, Computing 10 June 2011.
http://www.computing.co.uk/ctg/feature/2078110/nhs-electronic-ca See also Syal, R., ‘Abandoned NHS IT
system has cost £10bn so far’, The Guardian 18 September 2013.
http://www.theguardian.com/society/2013/sep/18/nhs-records-syste
GPES is a centrally managed primary care data extraction service that extracts information from GP IT systems for a range of purposes [my italics] at a national level.\textsuperscript{95}

The language underpinning GPES has been that of the market place. The policy views organisations such as the Department of Health, the National Institute for Health and Care Excellence (NICE), the Care Quality Commission (CQC) and the UK Biobank as ‘customers’ and the HSCIC considers data extraction requests from these ‘customers’. In time it is likely that there will many more organisations keen to access the patient data from both the public and private sectors. The HSCIC has been keen to point out that it does not function as a data warehouse and deletes all data once passed on to ‘authorised customers’.

More controversial still is the subset of GPES care.data\textsuperscript{96} which includes the extraction of identifying data such as NHS numbers, dates of birth, postcodes and gender, in addition to individual patient referral data and physiological indices such as blood pressure and lipid levels. Opt outs are few. For GPs to be remunerated they must remain in and adhere to GPES regulations. Data extracted via this pathway can be linked to personal confidential data from other sources such as the health and social care environments. Somewhat paradoxically with GPES as the extraction service and not a data storage facility, care.data information obtained via GPES will be warehoused at the HSCIC. For patients, a national mailshot and posters on the walls of practice premises advised people that they ‘may opt out of disclosures of confidential information….for secondary purposes other than….where justified in law.’\textsuperscript{97} A degree of emphasis was placed on how useful the patient’s data could be in improving health care; perhaps, however, not enough emphasis or clarity.

Medical confidentiality and potentially the broader scope of medical privacy have been given protection by the common law, statute and professional regulations. In English law the obligation of confidentiality is well recognised as limited in a number of cases by countervailing factors of public interest. Developments to facilitate information sharing in the NHS and the gathering of medical information are of sound intent, but, on balance, the powers of information access without individual choice prevail. The only choice is to opt out and many patients may not protest even if

\textsuperscript{95} See \url{http://www.hscic.gov.uk/gpes} The GPES is ‘developed and centrally managed on behalf of the NHS by the Health and Social Care Information Centre with the sponsorship and support of the Department of Health.’ \url{http://www.ic.nhs.uk/gpes} GPES - Questions and Answers.

\textsuperscript{96} See \url{www.england.nhs.uk/caredata}

\textsuperscript{97} NHS The Information Centre for Health and Social Care \textit{GPES Practice Newsletter} Issue 1 August 2012.
they know that they are able to. What seems less acceptable is the absence once again of pertinent and transparent information, either about the potential for access or when that access occurs. The NHS Act 2006 enabled medical data access, ‘in the public interest’\(^{98}\), and the HSCA 2012 has enhanced this, and yet how many patients realise that our choice to engage or not with the systems is for good or ill, limited at best? The HSCA 2012 Sections 254 to 259\(^{99}\) (preceded by the NHS Act 2006\(^{100}\)), regarding the acquisition and use of patient information, particularly impinges on the ability of the individual to retain control and thus choice over their medical data. As a consequence I argue we should be clear that choice over the handling of our medical information is at best limited, and in a collective and State funded NHS is this problematic?

Limitations on control and choice of medical information ‘in the public interest’ are not confined to NHS care. The health of one person, or rather ill health, may affect others and this is well recognised in the context of doctor’s health problems to the extent that self-disclosure is demanded by the GMC. In addition, fellow doctors are now under an obligation to report the ill health of an individual, whether as a colleague or as a patient, if ill health makes that colleague a risk to others. Paper 3 explores this situation in much more depth and argues that the model applying to doctors could and should be extended further to other professions and trades where health affects the wellbeing of others. The recent tragedy of the GermanWings pilot, thought to have committed suicide by crashing a fully occupied passenger plane, is a contemporary case in point.\(^{101}\) Paper 3 reviews matters of individual confidentiality and considers individuals, specifically politicians and civil servants, for whom health care information choices ought to be fettered beyond that required for a functioning NHS. We seem to have developed an interest in the information of certain types of individuals for example, doctors,\(^{102}\) and yet why just restrict the choice of doctors over their medical information; why not others in highly responsible jobs? This recommendation is less about the role of an individual’s choice, the necessary medical information requirements ought to be part of the job description; rather it is the lack of valid models on which to develop safe disclosure procedures that explain the reduction in personal choice. Thus far, and maybe out of necessity, it

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\(^{98}\) NHS Act 2006, n. 62 above, s. 251-252.

\(^{99}\) HSCA, 2012, n. 11 above.

\(^{100}\) NHS Act, 2006 n. 62 above, chapter 41, Sections 251 and 252.


\(^{102}\) My working example is the case of Dr Alan Banks, Medical Adviser to Tameside PCT and involved in The Shipman Inquiry in 2002, during the course of which details of his ill health were released in the public domain. Inquiry transcript at WB 14 00086 17 June 2002, The Shipman Inquiry, The National Archive [ARCHIVED REPORTS 2009] The Shipman Inquiry Reports, [http://webarchive.nationalarchives.gov/shipmaninquiry](http://webarchive.nationalarchives.gov/shipmaninquiry)
is the GMC who made the most progress on this front with a combination of codified guidance and revalidation.\textsuperscript{103}

Medical confidentiality no longer simply entails the giving of personal medical information over to one person, the doctor, who might share it with a small number of health care professionals. Health care is becoming increasingly complex and the demands for services continue to rise; the NHS is the prime example. Any efficient health care system needs access to information about the needs of its users whether that is for planning, practical or research purposes. Choice as applied to health care information policy is not representative of real events; choice is and should be limited, for some more than others and people need to know. The key to making this work in practice is to be transparent about the information requirements of the health care service, and the processes and outcomes involved in medical data access and use; in the spirit of shared decision making.

2.4 Ethical Themes

This section aims to provide an overview of the ethical background of the work in this thesis. It starts with an exploration of the ethical principle of respect for individual autonomy which is usually seen as the foundation of any requirement to uphold individual choice. However, this section also explores the central theme of this thesis which is the question of to what extent the reality of ‘choice’ in health care fits with this ethical notion of respect for individual autonomy. As such this section explains and explores these ethical principles and themes that are essential background to this research. While this section discusses the ethical background to the questions addressed by this dissertation, Chapter 4 will, after an applied policy analysis, explore these issues further to explain the particular approach I take to the ethical issues.

2.4.1 Why is Choice Important to Human Beings? The Principle of Respect for Individual Autonomy

The earlier sections of this chapter outlined how choice became a political issue and how gradually the law also adopted the language of choice. Neither law nor politics offer much help in understanding the value of choice. To consider that question some of the relevant ethical issues must be examined, beginning with autonomy. The principle of respect for individual autonomy is

\textsuperscript{103} GMC, \textit{Good medical practice working with doctors Working for patients}, [sic] (London: GMC, 2013) pp 11-12. See also GMC, \url{www.gmc-uk-org/doctors/revalidation.asp}
often seen as the most important ethical principle in modern health care ethics and more generally. Beauchamp and Childress define respect for autonomy as follows:

To respect an autonomous agent is, at a minimum, to acknowledge that person’s right to hold views, to make choices, and to take actions based on personal values and beliefs….respectful action, not merely a respectful attitude.104

John Harris explains:

Autonomy is, strictly speaking ‘self-government’, and people are said to be autonomous to the extent to which they are able to control their own lives…full autonomy and fully autonomous choices, are in a sense ideal notions, which we can at best only hope to approach more or less closely. This is because all sorts of things tend to undermine the individuals’ capacity for autonomy.105

All three authors regard autonomy as entailing the right to make choices. The idea here is that we must do what we can to respect the autonomy of individuals. This means allowing people to have control over their own lives by making decisions that are the right ones for them, even if we do not agree with those decisions. The central place of this notion of respect for the autonomy of the individual is now enshrined in the law around medicine and health care with requirements to ensure that those capable of consenting are only ever managed with their valid consent. This principle is so important because to do otherwise is considered to be against the interests of the individual. Traditional ‘doctor knows best’ attitudes are now usually considered to be unethical, outdated and against the interest of the adult, capable individual patient. Thus this focus on enhancing the autonomy of the patient appears to fit well with the policy mantra ‘no decision about me, without me’106

106 Delbanco, M.D., n.14 above.
The importance of giving patients choice about health care treatments and the access to and management of their own health care information is fundamental if we are to respect that patient's autonomy. Of course not all choices can be considered autonomous choices. Harris has identified certain defects where ‘autonomy is apparently undermined or diminished’.\textsuperscript{107} Furthermore, in an evaluation of freedom and autonomy Raz considers ‘autonomy based duties’\textsuperscript{108} that include enabling others to become autonomous by, as he puts it, ‘securing the background conditions’\textsuperscript{109}. Raz goes on to clarify one’s duties to include supporting cognitive functions such as the potential to gather, recall, utilise and reason with information. He also considers emotional and imaginative attributes along with health and physical skills/well-being, and the emotional and interactive side of relationships. Raz adds that there is a need for ‘creating an adequate range of options for a person to choose from.’\textsuperscript{110} This goes beyond the narrower traditional legal approach to autonomy because it respects and acknowledges the intrinsic needs and wants of the individual alongside extrinsic influences and pressures, from which the individual can be enabled, in this instance, in their choosing.

While respecting sufficiently autonomous choices is seen as important both ethically and legally, ensuring that a decision or choice is sufficiently autonomous entails determining that the individual has capacity, is not coerced, and has the necessary information to make this choice. Only if this is done can a decision be considered an adequately true reflection of an individual’s wishes. This process requires time, context, information exchange, shared decision making and the associated trust that these bring. Only then can the patient feel enabled to be substantially\textsuperscript{111} (or maximally\textsuperscript{112}) autonomous. There has been critique of the use and potential misuse in modern day health care and medical law of the term autonomy; encouraged perhaps by a consumer oriented society where people are directed towards having their wishes and wants fulfilled rather than restricted for whatever reason.

As Hope et. al.\textsuperscript{113} put it:

\textsuperscript{107} Harris, J., n. 105 above, pp. 195-200.
\textsuperscript{109} Ibid., 407-408.
\textsuperscript{110} Ibid., 408.
\textsuperscript{111} Beauchamp, T. J., Childress, J. F., n. 104 above, p. 60.
\textsuperscript{112} Harris, J., n. 105 above, p. 200.
\textsuperscript{113} Hope, T., Savulescu, J., Hendrick J., \textit{Medical Ethics and Law The Core Curriculum}, (London: Churchill Livingstone, 2003) p. 34.
If a desire, or choice, is not based on a rational evaluation then it is not autonomous.
This is one reason why respecting a person’s autonomy is not always the same as
respecting her choice.

Hope’s comment reinforces the potential for a lack of understanding and reality when choice policy
is seemingly conflated with autonomy. Further, from Gillon, ‘Autonomy is a subclass of freedom or
liberty, but not all freedom or liberty is autonomy.’114 In other words choice is a function of
autonomy but not a direct equivalent of same, and as ‘subclass’, of autonomy, paraphrasing Gillon’s
statement above, neither is choice about the person having what they want when they want it; that
would not be rational. Health policy in England has embraced the idea of individual choice with ‘no
decision about me without me’,115 seemingly an endorsement of autonomy as a cornerstone of
modern ethics. Does this mean that policy has embraced individual autonomy at its maximal
level,116 so limiting medical and political paternalism, and ought it to have done?

The informal conversations with medical practitioners that resulted in this thesis raised my
concerns. For all the talk of choice, autonomy and the ‘self’ there was the feeling that ‘choice’ was
in fact a tool of limitation and of health activity restriction. This is not necessarily a bad thing but
opaque choice talk without explanation, rationalisation around service delivery, time for
consideration and hence trust actually puts choice, ‘in conflict with autonomy’117 with Jonathan
Montgomery paraphrasing the (then) Archbishop of Canterbury, Rowan Williams, ‘making mature
choices involves closing down some opportunities as well as opening up others’, supporting the
notion that choice is neither unlimited nor unfettered.118 When people are made aware of the
rationale and consequences of enhancing or diminishing choices; that is a major step to autonomy
enhancement.

Policy documentation is light on the restriction of choice being ‘good’ perhaps for political reasons.
Some philosophers have spoken more openly about the justifications for limiting choices and that
respect for autonomy does not require that every choice can be honoured. Recognising that
choice talk is not all about allowing unfettered demand resonates somewhat with Onora O’Neill’s119

115 Delbanco, M.D., n 14 above.
116 Harris, J., n. 105 above, pp. 200-201.
118 Ibid.
development of principled autonomy and the desire to restore and enhance trust in, for example, the medical professions, at the same time as taking responsibility for one’s own choices in the spirit of self-determination. This is not, as perhaps the politicians might prefer, a way of apportioning responsibility and consequences for the health care choices made by the patient to the patient; the closure of service providers that are selected less frequently is one example. It is an attempt to balance the patient-consumer culture with recognition that the publicly funded NHS has limits and in order to use it we as patients have to accept certain limitations, be that what is available to us or about what happens to our information in order to enable the system to function, as Axtell-Thompson puts it:

…healthcare…ruled by managed care has raised a conflict between autonomy for the individual patient versus justice for the collective patient population.\textsuperscript{120, 121}

This sums up the real dilemma for those claiming to promote a policy of individual choice in health at the same time as effectively running a resource limited, publicly funded health care system designed for all to use.

As Dworkin (G.) points out:

…once I am aware that I have a choice, my failure to choose now counts against me. I now can be responsible, and be held responsible, for events that prior to the possibility of choosing were attributable to me. And with the fact of responsibility comes the pressure (social and legal) to make ‘responsible’ choices.\textsuperscript{122}

Is the patient responsible for the consequences of choices both taken and not taken, if the choices on offer have (maybe) necessarily been pre-arranged via the state or the NHS?\textsuperscript{123} Choice has the potential to become paternalism by another name, in part because what is offered is pre-set by


\textsuperscript{121} Justice is a complex topic with a number of associated competing and complementing ethical, political and philosophical approaches. See Beauchamp, T. L, Childress, J. F., n. 104, above, pp. 225-282.


others who are, in effect, determining what a person can pick from and then making those people responsible for that ‘choice’ and its consequences.\textsuperscript{124}

\textbf{2.4.2 Beneficence Meets Paternalism}

A further important ethical principle in this area and another expounded by Beauchamp and Childress is the principle of beneficence.\textsuperscript{125} This may, at first sight, appear to conflict with autonomous choice and suggests that doctors should focus on doing good and not sanction unwise choices. This principle of beneficence might be seen as a foundation of paternalism in health care as a result.\textsuperscript{126}

Hӓyry, H., had this to say about paternalism:

Practices and actions are paternalistic when those in positions of authority refuse to act according to peoples’ wishes. Or,… attempt to influence their behaviour allegedly in the recipient’s own best interests.\textsuperscript{127}

A softer definition and perhaps one that may be more applicable to health care practice where health care professionals have tended to act in a way they consider (rightly or wrongly) being in the patients’ best interests is provided by Beauchamp and Childress when they say:

Paternalism, then is, the intentional overriding of one person’s known preferences or actions by the goal of benefitting or avoiding harm to the person whose preferences or actions are overridden.\textsuperscript{128}

\textsuperscript{125} Beauchamp, T. L., Childress, J. F., n. 104 above, pp. 165-224.
\textsuperscript{128} Beauchamp, T. L., Childress, J. F., n. 104 above, p. 178.
Maclean\textsuperscript{129} gives a cogent analysis of the relationship between paternalism and beneficence saying:

> Beneficence and paternalism overlap, in that both involve acting for another’s benefit, but beneficence is constrained by the beneficiary’s will, while paternalism is not.\textsuperscript{130} 131

As in law and politics, it might be argued that ethical reasoning develops over time. O’Neill in collaboration with Neil Manson in \textit{Rethinking Informed Consent in Bioethics},\textsuperscript{132} appears to put aside the concept of principled autonomy\textsuperscript{133} in favour of what they call ‘a transactional model of informed consent.’\textsuperscript{134} This I interpret as an engagement model between patient and practitioner; a more equitable engagement than simply acknowledging the schemata around an individual’s autonomy yet not truly committing to it; and an inter-personal-professional transaction, in the non-business sense. O’Neill and Manson state that the advantage of their model is that:

> It provides a basis for deeper and more plausible justifications of informed consent than the autonomy-based justifications...that centre on disclosure-for-decision-making…A transactional account …also provides the basis for a convincing account of informed consent requirements and for a plausible and differentiated account of the standards they must meet.\textsuperscript{135}

This transactional method may help the individual in their choice making, where too many options are recognised as being potentially limiting in reality, and where making any choice at all is fraught with numerous intrinsic and extrinsic influences. As a model it may well enhance an individual’s relationship with and sense of responsibility to others because of a deeper sense of involvement. This applies to the processes involved in both matters of consent \textit{and} medical information access.


\textsuperscript{130} Ibid., Maclean, p. 51.

\textsuperscript{131} Of indirect relevance is the presence of paternalism in health care management. This from Mr Richard Popplewell, when Chief executive of the then Stockport PCT commenting on the loss of a memory stick that held the medical data of four thousand patients, ‘[There was]...a balance to be drawn between being open with patients and on the other hand avoiding unnecessarily upsetting them.’ Devine, P., ‘NHS Data Lost’ \textit{Stockport Times West} 24th January, 2008.


\textsuperscript{133} Ibid., p. 17-19.

\textsuperscript{134} Ibid., p. 69-96.

\textsuperscript{135} Ibid., p. 69.
management and use. Recent legal judgments\textsuperscript{136} enhance my argument about the need to respect an individual’s autonomy by engaging with them, sharing decision making, having a transparency about what is available and accessible, as well as affording people time and listening to preferences, even if the options on offer are necessarily constrained. Thus I would argue that the patient-practitioner relationship needs to be based on some form of transactional engagement.

\textbf{2.4.3 The Private and Confidential Health Record}

A core feature of the relationship between the patient and the medical practitioner is the telling of personal information with the expectation of confidentiality. This aligns itself with respecting an individual’s autonomy over the giving of that information and its use and dissemination. This is a core and longstanding component of medical ethics and is reflected in professional guidance and in health care practice. However, given the complexities of running an efficient resource constrained health system, such as the NHS, also allied closely with the private health care sector, and the need for health information to enable developments in medicine, access to (some) patient data becomes a necessity. In practice this means a limitation on the autonomy of the individual in order to respect the interests and autonomy of other service users, and without shared decision making and transparency might appear difficult for any one individual to understand. Manson and O’Neill state that:

An alternative approach, in line with our strategy for rethinking informed consent, is to shift our focus…in particular to the communicative actions and transactions by which knowledge is obtained and communicated, and to the norms and obligations most relevant to communicative transactions\textsuperscript{137}.

What they are saying is that the process and rationale underpinning the access and use of patients’ personal medical information needs to be an integral part of an interaction between the patient and the practitioner, as increasingly recognised in matters of informed consent.

One further question in relation to the confidentiality and privacy of our medical data is that of ownership. Who if anyone owns the information and does that afford property rights? It is out of the scope of this thesis to fully address in any detail the idea and concepts around whether our medical information is ours or someone else’s property. Laurie has undertaken a review of some

\textsuperscript{136} See Montgomery n. 2 above and Chester n. 27 above.

\textsuperscript{137} See n. 132 above, p. 123.
relevant commentaries and identifies ‘….the problems of trying to fit a concept such as information into an existing and rigid set of rules such as the law of property.’ Further, The Nuffield Trust, in a 2011 paper also debate the issue of patient data as property and conclude ‘that it may be not only legally but also conceptually mistaken to hold to a notion of patient ownership over health information.’

2.5 Conclusions

With choice talk are we dealing with little more than rhetoric but a rhetoric that alters depending on the environment in which it is used? The debate emerges as to whether choice is in fact about control and constraint; limiting and not enhancing autonomy. Politics and law now refer frequently to the choice of the individual, and this is usually assumed to be based on the ethical notion of the importance of allowing people to have control over their lives (the principle of respect for autonomy); but the reality of choice is rather different, and does not support the kind of unfettered choices that a true respect for autonomy might require. Politicians, I suggest, like choice because it adds a level of opaqueness to health policy that at first glance should in fact be transparent. Here lies the potential for true loss of choice and that apparently so valued self-determination.

Is Pollock right in saying?

When people are really sick they are seldom in a position to exercise rational choice…most people don’t know what health care they need…nor can they pick and mix…The supermarket model of health care as implied in the politician’s rhetoric is sham.

As I understand it what Pollock is highlighting is a belief that a state of being seriously ill is not helped by having to face (sometimes) numerous choices. The question should be not so much whether this statement is true, or whether the underlying policies are right or wrong. It is more about the transparency and quality engagement that is needed if choice is intended to respect the ill individual and allow a degree of self-determination, albeit necessarily limited, within the duly acknowledged resource-limited NHS, as Oliver and Evans note:

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138 See n. 50 above, pp.215-217.
140 Pollock, A., n. 7 above, p. 234.
Offering everybody a greater degree of choice over what they receive will thus create winners and losers…\textsuperscript{141}

There seems, therefore, to be an inevitability that patient choice advantages some individuals, the fitter, more articulate and the person with advocacy perhaps are more likely to access the so called choices on offer. For those without these benefits the difficulties in navigating the system may put them in the position of no or restricted access to the ‘choices’, potentially to their disadvantage.

Having choice and the ability to choose is a function of being a self-determining individual and thus manifests a respect for autonomy. Choice talk in health policy and law has to be about acknowledging the individual and their decisions; by being truthful and transparent about the options available and in a relationship of trust and a sharing of decision making. This includes respect for those who choose not to make a choice; with full knowledge and delegating that decision to someone else. If these elements are not present then choice risks becoming a smokescreen and tool behind which decisions are made about which the individual is uninformed and unware. That is not to say that health care choices ought to be an ‘a la carte menu’. ‘Prix fixe’ is acceptable, necessary and ethically justifiable as long as the rationale is clear.

Chapter 3 - Legal Approaches:

Choice, Information Disclosure and Treatment Demands

In an affluent consumerist society there is an illusion that we can have, and that we deserve to have, all that we desire; and that with the right consumerist stance by both provider and user it can be obtained.¹

3.1 Introduction and Background

In this thesis it is argued that although the courts have now embraced choice language, patient choices are limited in scope and application and what is meant by choice is far from clear. In Chapter 2, I examined choices to refuse treatment and control of personal medical information. I argued that the adult patient when of full capacity has unrestricted choice when it comes to accepting or refusing a treatment on offer. A malleable capacity threshold can be used to limit choice, but judges are now more willing to acknowledge choice in matters of treatment refusal. In addition, the patient, whilst expecting control over their own medical information if he listens to the policy rhetoric will find those choices limited.

This chapter focuses on two legal questions highly pertinent to how far English law endorses substantive patient choice rather than simply using the rhetoric of choice. I first examine information disclosure and choice, trace its history and assess the current law in the light of Montgomery v Lanarkshire Health Board² decided four years after the publication of my first paper. In that paper I concluded that 'the law...has resisted an opportunity to enhance decision making that would encompass positive choice or demand.'³ In this chapter I assess the impact of Montgomery on this argument. I examine both the substantive decision on information disclosure, which as Heywood notes, ⁴ while at least formally overruling Sidaway v Board of Governors of the

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Bethlem Royal Hospital and the Maudsley Hospital,\(^5\) does not, in practice, make any major changes to the law as understood in *Pearce v United Bristol Healthcare NHS Trust*\(^6\) and, analyse the language of consumer choice apparently endorsed by the Justices. While space does not allow for a comprehensive examination of the law I do look briefly at the extent to which the law gives force to positive choice allowing patients to go beyond refusing the option(s) offered by their doctor and demand the treatment of their choice. This is pivotal as despite the consumer oriented rhetoric of patient choice in health care policy, the law does not sanction consumer choice.

As was noted in Chapter 2 the term patient choice is now firmly set on any list of National Health Service (NHS) priorities, underpinning the ethos of the patient having choice in (their own) health care.\(^7\)\(^8\)\(^9\) A concept that one might presume is based on respect for the individual within the collectivist NHS and from which we should deduce that successive governments in recent years, as well the current leading political parties, are placing autonomy and self-determination as paramount features in health provision for the public. This has been the subject of debate from both a social and political perspective\(^10\)\(^11\) and given the recent evolution of medical law it should be a major interest as to whether it is possible for that law to (keep) ‘pace’ with these developments.

### 3.2 Choice – Consent and Demand; Can We Have It Every Which Way?

In Chapter 2, it is shown that there has been an evolution in English law and its judgements in relation to consent issues; agreeing to treatment. Adults with mental capacity may choose to reject treatment and judges expressly acknowledge patient autonomy. Consent is one thing, simply

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\(^5\) Sidaway v Board of Governors of the Bethlem Royal Hospital and the Maudsley Hospital [1985] AC; 871, [1985] WLR 480; [1985] 1 All ER 643, HL.


\(^7\) Department of Health (DoH) *The NHS Plan*, (London: The Stationery Office, 2000) Cm. 4818-I, 10.5-10.7, p. 89.


agreeing to what may sound like a good idea; yet the factors that affect our ability to consent and make an autonomous choice are many and various. At the very least consent needs to be informed, not just about what a procedure might entail but the potential risks that are associated with it. Otherwise there is no real choice. Further, in whose judgment should the balance of risk-to-benefit be made; the patient or the practitioner? If autonomy is to be given due regard and any sort of patient choice made, it must be via the judgment of the patient. Information is power and within a health care professional/patient relationship where does the power to choose lie? A respect for autonomy would suggest it should be with the patient. Does the present English legal system facilitate this? For many years it did not, allowing doctors to decide what information the patient should receive. Thus patients effectively lacked even the choice to decline treatment. Much has gone on to change, culminating in the recent Montgomery decision.

Judgments have developed since the (paternalistic) days of Hatcher v Black where Denning L.J. denied any choice for the patient and determined that:

…it was for the jury to say whether he (the doctor – my addition) told the plaintiff that there was no risk or merely prevaricated to stop her worrying.

…it he knew there was some slight risk, but he did it for her own good…it was of vital importance that she should not worry. In short he told a lie…

In subsequent years judges moved away from Lord Denning’s overt paternalism, making a number of statements pertaining to patient choice and the idea of an informed choice. Sidaway (1985) for example, as will be indicated, restricted patient choices by limiting doctors’ duty of information disclosure. Further, despite disagreements amongst the judges, holding subtly differing views regarding standards of care, there was agreement that a patient, in order to make a choice, has a right of [information] disclosure, and thus a doctor some duty to disclose. Lord Bridge said:

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16 Re C (Adult: Refusal of Medical Treatment) [1994] WLR 290; [1994] 1 All ER 819. Thorpe J., ‘...I am satisfied that he has understood and retained the relevant treatment information,...and that in his own way he believes it, and in the same fashion has arrived at a clear choice’.
17 Sidaway n. 5 above.
…that disclosure of a particular risk was so obviously necessary to an informed choice on the part of the patient that no reasonably prudent medical man would fail to make it.¹⁸

### 3.2.1 Choice and Information Disclosure: Moving Away From Sidaway?

Information disclosure is a significant issue – without it what choices can be made? And how much information is necessary or enough? Whilst patient choice as rhetoric and recommendation has been taken forward by a combination of NHS health policy and GMC guidelines, it was Sidaway¹⁹ that set a standard for pre-operative disclosure that held for thirty years, until Montgomery.²⁰ Mrs Sidaway suffered with chronic pain and was under the care of a neuro-surgeon, Mr Falconer. One operation had alleviated her pain but some years later it returned and Mrs Sidaway consented to surgery in order to relieve nerve root compression. There was spinal cord injury during the surgery and she was partially paralysed. Mrs Sidaway sued the hospital and surgeon on the basis that the surgeon had not warned her of the risk of spinal cord injury (quantified as a less than 1% risk). A long litigation process ensued finally reaching the House of Lords. They deliberated as Brazier and Cave have stated, on:

> What principle governed the doctor’s obligations to advise patients and warn of any risks inherent in surgery or treatment recommended by the doctor?²¹

Mrs Sidaway lost her appeal as the judges, via assorted rationales²² came to the conclusion that the so-called Bolam²³ test held and she need not have been informed of the risk of spinal cord damage. Of the four judges who gave judgment only Lord Scarman (dissenting) came near to acknowledging that the patient had a role in the decision making process, a choice if you will, yet the final judgment effectively stifled patient choice for years to come. Apart from Lord Diplock who mechanically applied the principles from Bolam, there was agreement that a patient has a right of [information] disclosure and thus a doctor the duty to disclose. Lord Bridge noted that:

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¹⁸ Sidaway n. 5 above, [1985] AC 871 (HL), at 663.
¹⁹ Ibid.
²⁰ Montgomery n. 2 above.
²³ Bolam v Friern Hospital Management Committee [1957] 2 All ER 118.
…although a decision on what risks should be disclosed for the patient to be able to make a rational choice...the disclosure of a particular risk might be so obviously necessary for the patient to make an informed choice...24

The judicial language was one of consent and 'ownership' of the self but there was yet to be anything said about the quality and circumstances of information disclosure and consent.

Over the ensuing years, although Sidaway did continue to 'lurk in the background'25, potentially stifling choice, although subsequent cases began to become much less doctor focused in favour of a 'prudent' and informed patient standard already established in transatlantic and Australian jurisdictions.26 Most significantly in 1998 at the Court of Appeal in Pearce27, Lord Woolf28 took a stance that rejected, or appeared to reject, a paternalistic view of information disclosure and recognised the need for a patient to have information in order to make a judgment on treatment if they, the patient, opt (choose) to do so.

Lord Woolf said this:

...where there is what can realistically be called 'significant risk'...the patient is entitled to be informed of that risk.29

And:

That if there is a significant risk which would affect the judgment of the reasonable patient...it is the responsibility of the doctor to inform the patient of that significant risk...so that the patient can determine for him or herself as to what course he or she should adopt.30

24 Sidaway n. 5 and n. 18 above, at 663
26 See Canterbury v Spence (1972) 464 f 2D 772, at 780 endorsing the ‘prudent patient’ tests in the United States, Reibl v Hughes (1980) 11DLR (3d) 1, where the Canadian Supreme Court preferred the ‘patient’s right to know’ over the prevailing ‘professional medical standard.’, as did the High Court of Australia in Rogers v Whittaker [1993] 4 Med LR 79.
27 Pearce n. 6 above.
29 Pearce, n. 6 above.
30 Ibid.
That notwithstanding, the decision was not found in favour of Mrs Pearce, with the debate seemingly hinged on the significance of risk rather than the patient’s entitlement to information and the enabling of their decision making. In other words it was still the doctors who determined the significance of risk and not the patient when told of the risks determining their significance.

The judiciary in England began to move away from the professional standard test in *Sidaway* and emphasise more the role of patient autonomy and choice. This shift became apparent in *Chester v. Afshar* in 2004 (albeit a non-NHS case and relating formally to causation, not the scope of the duty to disclose) with this from Lord Hope:

> For some [patients – my addition] the choice may be easy - simply to agree to or to decline the operation. But for many the choice will be a difficult one, requiring time to think, to take advice and weigh up the alternatives.

What is noteworthy here is that causation has been expanded to include not just the disclosure of surgical risk but the recognition that some people, some times, need more time to reflect and consider all the options (choices) open to them.

Lord Hope also commented:

> There were three possibilities [that Ms Chester could have opted for – my addition]...The choice between these alternatives was for her to take, and for her alone. The function of the law is to protect the patient’s right to choose.

The judiciary in this case were equivocating rather, a little uncertain of which way to jump, awarding damages anyway because what was lacking was a full choice; and imperatively, the time to choose.

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32 Ibid., at 86.
33 In *Chester v Afshar* the dissenting judges were not happy to link the timing of an operation to the injury sustained by Ms Chester. That issue remains for debate, not least in the clinical and medical indemnity worlds; the Lords finding in favour of Ms Chester by majority however.
34 Whiteman, I., n. 3 above, 155.

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A real shift towards the view that patients need information about the risk of a procedure, alternative procedures and the comparative risks came in *Birch v University College London NHS Foundation Trust*\(^ {35}\). The claimant had a stroke consequent upon cerebral angiography. It was found that in the event of the patient being ‘properly informed’ about any alternative investigations and their risk comparisons, she would not have opted for that angiogram. How could the patient have made a genuine choice? At first glance therefore it would appear that we have a legal system that does now evaluate and give due regard to a) the rationale for enabling the *informed* patient to make choices over their own treatment and b) the need to give individuals time in order to make those decisions. It says little if nothing yet about facilitating those decisions, particularly when difficult in nature or hard for an individual to understand; the use of independent advocacy for example rather than a reliance on the ‘reasonable doctor’ and ‘prudent patient’\(^ {36}\) equation, or indeed, the anything-but-patient-centred use of ‘therapeutic privilege’. \(^ {37} \) \(^ {38}\)

Closer scrutiny of the legal position as it has developed thus far reveals a certain pattern emerging. What seems characteristic is the enablement of the negative choice position; that is, the option to decline treatment and/or alter one’s decision (making) in favour of accepted alternatives, given the correct information at the right time. This formulation stretches as far as the option to decline even life prolonging treatment as with Ms B, in *Re B*\(^ {39}\), whose choice was to cease ongoing treatment (ventilator support) and die as a consequence. The circumstances of these cases vary greatly; yet information disclosure to the patient features throughout – without it what decisions can be made. There follows therefore the question of how much information? Mrs Sidaway lost her appeal even though choice was acknowledged; enough risk management had taken place apparently via the level of disclosure. *Sidaway* however, post *Montgomery*, has been relegated to the realms of history. Many years before *Montgomery*, in *Pearce*\(^ {40}\), Lord Woolf highlighted the patient’s entitlement to receive information on procedural risk; without which how can any of us make a choice and this forms a focus in my first publication.

\(^ {35}\) *Birch v University College London NHS Hospital Foundation Trust* [2008] EWHC 2237 (QB).
\(^ {37}\) Ibid., pp 188-189.
\(^ {38}\) *Sidaway* n. 5 above, 653.
\(^ {39}\) *Re B (Adult: Refusal of Medical Treatment)* [2002] 2 All ER 449.
\(^ {40}\) *Pearce*, n. 6 above.
3.2.2 Does Montgomery Finally Affirm Choice? Or Demand?

In this next section I consider how far the decision of the Supreme Court in Montgomery may affirm patient choice and challenge my initial hypothesis in Paper 1 that the law endorses only a limited form of patient choice in health care law. I shall suggest that while the decision strongly endorses the patient’s right to bodily integrity and negative autonomy, despite the language of consumer choice it does not affirm any concept of unfettered choice:

...the information about the risk in Montgomery was so crucial to the mind-set of the mother...that the failure to disclose it effectively meant that she was never afforded the opportunity to exercise her right of patient choice.41

In March 2015 the Supreme Court unanimously upheld the appeal of Mrs Nadine Montgomery on behalf of her now teenage son. In 1999, Mrs Montgomery, small of stature and diabetic, had a traumatic and instrumental vaginal delivery of a large baby that resulted in the child having permanent and significant neurological problems; cerebral palsy affecting all his limbs and a brachial plexus injury, Erb’s palsy, that effectively paralysed one arm. Given Mrs Montgomery’s stature and diabetes, that in itself gave risk to having a larger than average baby, having a vaginal delivery held a 9-10% chance of shoulder dystocia or impaction as well as the potential for umbilical cord compression with a risk in the order of 0.1% of cerebral palsy or death. What happened were known and identifiable potential risks and Mrs Montgomery’s argument was that she would have opted for delivery by Caesarean section (CS) had she received the necessary information about the problems a vaginal delivery might bring, information from the case consultant Dr Dina McClellan. Like the majority of women, Mrs Montgomery had hoped to deliver vaginally but this would not have been the case if she had already been made aware of the nature and risk this might bring in her specific case. Mrs Montgomery was not advised of the risk of shoulder dystocia or informed of the pros and cons of the alternative delivery method, CS.

The lower Scottish courts rejected the suggestion by counsel that Mrs Montgomery ought to have been both advised of the risks of vaginal delivery, and the CS alternative. Utilising the judgements from Sidaway42 the Lord Ordinary accepted the Board’s expert witnesses’ view in finding that Dr McClellan had not breached her duty of care in opting not to advise Mrs Montgomery of known risks to her baby and delivery options. The lower courts were firmly reliant on the approach advocated in Bolam, making the Board’s experts ‘a responsible body of medical opinion’, and in Bolitho, such

41 Heywood, R., n. 4 above, 459.
42 Sidaway, n. 5 above.
that the Lord Ordinary deemed that the expert’s evidence ‘could not be rejected as incapable of standing up to rational analysis.’

Further it was noted that:

Lord Eassie rejected the argument that there had in recent judicial authority (in particular, *Pearce*...), a departure from the approach adopted in *Sidaway*, so as to require a medical practitioner to inform the patient of any significant risk which would affect the judgment of a reasonable patient.

In *Montgomery* the Supreme Court as well the Scottish Courts dissected the judgements in *Sidaway*; and *Sidaway* was certainly a judgment of contrasts. Lord Diplock was a proponent of the medical paternalist when it came to information disclosure:

> The only effect that mention of risks can have on a patient’s mind, if it has any at all, can be in the direction of deterring the patient from undergoing the treatment which in the expert opinion of the doctor it is in the patient's interest to undergo.

Yet this from Lord Scarman:

> If, therefore, the failure to warn a patient of the risks inherent in the operation which is recommended does constitute a failure to respect the patients’ right to make his own decision, I can see no reason in principle why, if the risk materialises and injury or damage is caused, the law should not recognise and enforce a right in the patient to compensation…

And:

> …a patient may well have in mind circumstances, objectives, and values which he may reasonably not make known to the doctor but which may lead him to a different decision from suggested by a purely medical opinion.
The Supreme Court in *Montgomery* in effect endorsed the dissenting view of Lord Scarman and its later affirmation in *Pearce* by Lord Woolf:

…if there is significant risk which would affect the judgment of a reasonable patient, then in the normal course it is the responsibility of the doctor to inform the patient of that significant risk…so the patient can determine for him or herself as to what course she should adopt.48

And the Court reflected on judgements from *Chester v. Afshar*49 where Lord Walker noted ‘in making a decision which might have a profound effect on her health and well-being, a patient was entitled to information and advice about possible alternative or variant treatments.’50

Two key paragraphs in *Montgomery*, 75 and 76, focus on choice. At 75 the Supreme Court commented that not only are patients holders of rights, ‘they are also widely treated as consumers exercising choices’. Moreover the treatment that the health care professionals can offer are not just matters of clinical reasoning but also ‘…resource allocation, cost containment and hospital administration.’ This adds significant complexity to the doctor-patient relationship in comparison with its early days as a one-to-one engagement. Yet as the court points out in paragraph 76, patients can be and are much more informed on health related matters; hence ‘it would be a mistake to view patients as uninformed, incapable of understanding medical information…’

The Court went on to describe patients as:

…adults who are capable of understanding that medical treatment is uncertain of success and may involve risks, accepting responsibility for the taking of risks….and living with the consequences of their choices.51

In order to facilitate such an adult-adult relationship of shared decision making between the patient and the doctor there is an absolute need to engage with the patient, elicit their ideas, concerns and

48 *Pearce* n. 6 above.
49 *Chester* n. 31 above.
50 Ibid.
51 *Montgomery* n. 2 above, at 81.
expectations at the same as discussing treatment (or investigation) options, any alternatives and the known related risks, if this is what the patient wishes to be advised. The Supreme Court clearly acknowledged the cognitive complexity of the assessment of risk, the ‘dialogue’ that is required between doctor and patient rather than just the giving of information being sufficient to enable choice, and also clarified the place of the ‘therapeutic exception’\textsuperscript{52} such that doctors do not misuse the concept in order to block patients from making decisions with which the doctors do not agree.\textsuperscript{53} Similarly the Court introduced the individually-focused ‘particular patient’ concept:

\begin{quote}
...in the circumstances of a particular case, a reasonable person in the patient’s position would be likely to attach significance to the risk, or the doctor is or should reasonably be aware [my emphasis] that the particular patient would be likely to attach significance to it.\textsuperscript{54, 55}
\end{quote}

Given the liberal use of the word choice throughout the judgement, have the arguments in this thesis (and in particular in Paper 1) in relation to health care choices being limited, been demolished? Was the case endorsing the idea that patients can choose the treatments that they want, and in this case, open the door to Caesarean sections based on demand, not need? Had an era of unfettered ‘choices’ emerged as Mrs Montgomery’s obstetrician Dr McLellan implied in a series of non-evidenced based judgements.\textsuperscript{56} Dr McLellan considered that if the condition [shoulder dystocia – my addition] were mentioned, "most women will actually say ‘I’d rather have a Caesarean section'” And, “if you were to mention shoulder dystocia to every [diabetic] patient, if you were to mention to any mother who faces labour that there is a very small risk of the baby dying in labour, then everyone would ask for a Caesarean section, and it's not in the maternal interests for women to have Caesarean sections.”\textsuperscript{57}

This was a view that was seemingly endorsed by one of the defendant’s expert witnesses Dr Gerald Mason. Similarly despite Mrs Montgomery apparently articulating concerns about the size of the

\textsuperscript{52} Ibid., at 88 and 91.
\textsuperscript{53} Ibid., at 91.
\textsuperscript{54} Ibid., at 87. See also David Spencer v Hillingdon Hospital NHS Trust [2015] EWHC 1058 (QB), Collender J., (at 32) ‘Montgomery is clearly a decision which demonstrates a new development in the law as it relates to informed consent...the ordinary sensible patient would be justifiably aggrieved not to have been given the information at the heart of this case when appraised of the significance of it’. Mr Spencer developed a DVT and pulmonary embolus after a hernia repair but had not been warned of the potential for and risk of post-operative complications.
\textsuperscript{55} See also Brazier, M., ‘Patient autonomy and consent to treatment: the role of the law’, Legal Studies 7 (2), 1987 189-191.
\textsuperscript{56} Montgomery n. 2 above at 13 and 19.
\textsuperscript{57} Ibid., at 13.
baby and that she was worried it would be too large to deliver vaginally, Dr McClellan made the decision that Mrs Montgomery was too anxious to have a scan at 38 weeks gestation, implying that she, the doctor, knew that this would worsen the patient’s anxieties; a scan however that would have revealed more accurate data about the size of the baby. She also opined that ‘since I felt the risk of her baby having a significant enough shoulder dystocia to cause…damage... to the baby was so low I didn’t raise it with her, and had I raised it with her then, yes she would have no doubt requested a Caesarean section, as would any diabetic today’. 58

For Dr McClellan, the July 1998 GMC guidance of the time required:

That to establish and maintain trust you must...give patients the information they ask for or need about their condition, its treatment and prognosis...give information to patients in a way they can understand...respect the right of patients to be fully involved in decisions about their care...fully involved in decisions about their care...You must not allow your views about a patient’s lifestyle, beliefs…to prejudice the treatment you provide. 59

It is worth noting, that even prior to the Montgomery case, decided in 2015, obstetricians ought to have become familiar with the 2014 guidance from the GMC:

…give patients the information they want or needed in a way they can understand. Respect patients’ rights to reach decisions about their treatment and care. 60

There has hardly been a sea-change in the GMC guidelines between 1998 and 2014 and, I would argue, that unfortunately Dr McClellan may have put her own beliefs about patient demand above following those guidelines.

It is the National Institute for Health and Care Excellence (NICE) guidelines that might initially seem to be an affirmative response to demand, yet are, in fact, devised on the basis of shared decision making:

58 Ibid., at 19.
For women requesting a CS, if after discussion and offer of support (including perinatal mental health support for women with anxiety about childbirth), a vaginal birth is still not an acceptable option, offer a planned CS.61

It is Lady Hale who really focuses the *Montgomery* judgment. That it emphasises the enhancement of the patient–practitioner patient relationship; that of transparent information dissemination, the checking of understanding in a spirit of shared decision making. It is this that I believe acknowledges the need to present the options available and acknowledge and discuss the patient’s preferences, without caving in to choice as demand. This is about autonomy of the individual, as per Lady Hale:

…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… 62

Nor, it should be added, does the *Montgomery* judgment undermine ‘therapeutic privilege’, where doctors have a duty to protect the patient from recognisable potential harmful consequences of the information disclosure. Keywood points out, the case:

…paves the way for a *clearer exposition* [my emphasis] of the ‘therapeutic privilege’ that will, in exceptional cases, enable the clinician to withhold information from her patient, even if that information ought to normally be disclosed.63

As I have noted, with *Chester*64 earlier in this chapter, this level of patient-practitioner engagement requires time and often time beyond a first consultation in non-urgent situations. This is a point not lost on the medical profession, post *Montgomery*, engaged now in on-going debate about what the judgment may mean for patients and for clinical practice.65 Time of course was not on Mrs

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62 *Montgomery* n. 2 above, at 108.
64 *Chester* n. 31 above.
Montgomery’s or her baby’s side. However if risk based options and preference discussions had taken place well in advance of the birth, the outcome might have been very different.

### 3.2.3 Choice and Treatment Demands

Consumer choice in any real sense is not limited to the ability to refuse certain options but to select the option of your choice. In most instances (childbirth may be the exception, as delivery of the child is an inevitable event) English law rejects arguments that patients have a right to demand treatment of their choice. It should be noted that in English law generally consent alone is not sufficient to justify actual bodily harm. In the controversial decision of *R v Brown*,⁶⁶ in 1994 the House of Lords affirmed that an individual could not simply consent to or choose to have a physical contact or procedure that inflicted bodily harm. However the public interest was considered served in the context of ‘proper medical treatment and/or ‘reasonable surgery’.⁶⁷ It is a complex case and reasons of space prevent further development. However it does constitute a frontier on personal choice. In *R (on the application of Burke) v. General Medical Council*,⁶⁸ in 2005, Mr Burke had sought a declaration that as and when he became incompetent from his incurable disease, doctors would not be able to cease artificial feeding and hydration; that he is allowed to die a fully supported death until his heart stops of natural causes. This was to have been his positive choice, though the GMC and the Secretary of State for Health challenged this. Coggon commented:

> On the whole, judges talk of autonomy as being equivalent to self-determination. In English medical law, this allows patients to refuse any medical treatment or intervention, and to choose one of any treatments offered [my emphasis] by a medical professional. …The positive right is limited to one of choice between treatments offered [and the right to decline – my addition]: a patient may not demand that a treatment be provided…

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⁶⁶ *R v Brown* [1994] 1 AC 212, HL. In this case a number of men were convicted of violent offences despite the ‘victims’ having willingly engaged in sado-masochistic practices.


⁶⁸ *R (on the application of Burke) v The General Medical Council* [2005] EWCA Civ 1003.

Mr Burke\textsuperscript{70} hoped for life with the aid of artificial nutrition and hydration (ANH) until his own vital organs failed through the passage of time. He challenged the pertinent GMC guidance\textsuperscript{71} with Munby J. granting declarations based in part on autonomy/self-determination and, in part, on the ECHR\textsuperscript{72} that would have enabled Mr Burke to exercise his treatment choice. Mr Burke lost his case however, when on appeal\textsuperscript{73} the Court (critically) over-ruled much of Munby J.’s rationale,\textsuperscript{74} with the GMC this time assisted by the Official Solicitor on behalf of the Secretary of State for Health.\textsuperscript{75} The latter made much of resourcing issues - time and money, despite the case not overtly being about funding:

….Munby J purported to distinguish the case before him from those involving prioritisation of allocation of resources…he did so on a false factual basis…it is the Secretary of State who is best placed to make these points.\textsuperscript{76}

It would seem intuitive that capacity is a requisite for making health care decisions about oneself, including a demand for treatment. The Mental Capacity Act 2005 certainly ‘makes the right noises’ in seemingly reinforcing the self-determination of the individual, the presumption of capacity rather than lack of same and the need to disseminate information appropriately:

A person is not to be regarded as unable to understand the information relevant to a decision if he is able to understand an explanation of it given …in a way that is appropriate to his circumstances…\textsuperscript{77}

And yet note the citing of the MCA apropos \textit{Burke}, from the Official Solicitor:

…It [the Bill – my addition] seeks to clarify and codify the existing law by making provision for advance decisions to refuse medical treatment…including life-prolonging treatment, which will be binding provided that certain conditions are met. It makes no provisions for binding advance

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\textsuperscript{70} \textit{R (on the application of Burke) v General Medical Council} [2004] EWCH 1879 (Admin.)
\textsuperscript{72} \textit{Burke} n. 70 above, para 178.
\textsuperscript{73} \textit{R (on the application of Burke) v The General Medical Council} [2005] EWCA Civ 1003.
\textsuperscript{74} \textit{R (on the application of Burke)} [2004] n. 69 above, at 32.
\textsuperscript{75} Appeal No. 2004/2086, General Medical Council v Oliver Leslie Burke and others, Office of the Solicitor, DWP & DoH. \url{http://www.willtolive.co.uk/les_burke/main/the_government_interven} Accessed 26 June 2007 13.23.
\textsuperscript{76} Ibid., s. 16, p. 4.
\textsuperscript{77} Mental Capacity Act 2005, s. 3(2).
\end{flushleft}
decisions to require [my emphasis] medical treatment because, in the view of the Secretaries of State, such provision would be inappropriate and contrary to the existing law.\(^78\)\(^79\)

In other words you may make an advance directive when of full capacity but there is little point if you make a decision that requires/demands medical treatment from the NHS. Choosing, such as they are, are limited by Statute and not by capacity or ‘best interests’ or self-determination. This is a subject worthy of a separate work. To reflect, by Statute and case law, if you are of full capacity and your advance choice is for treatment refusal or cessation, under our current interpretation of autonomy your choice will be met; if you are of full capacity and that advance choice is for treatment continuation or demand, then under the same version of autonomy your choice will not be met; and if you are deemed incapable then autonomy is negated and ‘best interests’ prevail, i.e., medically (as in \textit{Re MB}\(^80\)). Capacity means autonomy only if we deem you capable of making the choices that we offer you.

It may be controversial to suggest that if there is no place for case-by-case reasoning as practised by Munby J., then we must accept that there is no place for individual autonomy. Biggs has been emphatic:

\begin{quote}
…Burke is about patient autonomy, decision-making and choice. …it [the Court of Appeal – my addition] has simply endorsed the view that the medical practitioner’s assessments of the patient’s best interests takes primacy…and that a patient may not demand a treatment not recommended by her or his doctor….Burke represents a dangerous endorsement of medical paternalism.\(^81\)
\end{quote}

\(^78\) Appeal No. 2004/2086, n. 75 above, s. 17.
\(^79\) \textit{...the Act does not provide that a patient can request treatment...An advance decision is not applicable to life sustaining treatment unless the person verifies that it applies to a treatment...However, basic care, including the offer [my emphasis] of oral food, water warmth and hygiene measures, may not be refused by advance direction.} From: Johnston, C., Liddle, J., ‘The Mental Capacity Act 2005: a new framework for healthcare decision making’, \textit{Journal of Medical Ethics} 33 (2007) 94-97.
\(^80\) \textit{Re MB (adult: medical treatment)} [1997] 2 FCR 541 [1997] 8 Med LR 217 (1997) 38 BMLR 175, CA. \textit{Re MB} was a patient who refused a Caesarean section. The procedure went ahead as MB was judged to be ‘temporarily’ incompetent as a result of a needle phobia.
\(^81\) Biggs, H., ‘“Taking account of the views of the patient”, but only if the clinician (and the court) agrees – \textit{R (Burke) v General Medical Council}', \textit{Child and Family Law Quarterly} 19 2 (225) (2007).
It should be noted that Mr Burke’s demand was based on a practice that the doctors themselves would rather not have engaged in and was contrary to guidance. There was an inevitable tension between what the doctors considered to be best for the patient, and the patient’s actual wishes.

3.2.4 Blurring the Boundaries: When Right To Refuse May Be Right To Demand

Respect for choice thus far had concentrated on information disclosure and the choice or the opportunity not to have received treatment. In other words respect for negative forms of choice-making. Burke appears to exclude any right to demand but the boundary may be less clear than it appears at first to be. In B v An NHS Trust, Ms B’s choice was to cease on-going treatment (ventilator support) and die as a result. Further:

…the absence of experience in the spinal rehabilitation unit clinic would deny Ms B, or any other similar patient, the right to choose whether or not to go on…

Was Ms B’s choice negative or positive? That rather depends on one’s perspective. Someone was in the position of having to actively switch off the ventilator. Arguably it is a negative form of choice to select treatment cessation and relinquish consent(s). So self-determination, autonomy, was given recognition in association with negative legal rights yet remained inconsistent and overtly over-ridden when considering positive choices. However the case of Montgomery may for analysts herald an era where patients begin to demand treatments; treatments that may be available but not on offer or even treatments not usually available. For example, there may be cases where a woman might request a Caesarean section for what may be considered more ‘social’ reasons but there is no significant evidence based data to support this hypothesis. Caesarean section rates are going up, and more so in more affluent areas of the UK but there are no definitive statistics to say why, only derivative commentary based on trial and study reviews. But in truth how many women will be asking for a CS in order to attend an appointment or event on a certain date? More likely we are looking at women who fear childbirth, ones who may have had poor past experiences or the older mother to be, where they believe a Caesarean section would minimise risks to the baby. However it should not be forgotten that the sharing of information as well as establishing the patient’s fears will also highlight the known risk of CS such as those that come from surgical intervention and anaesthesia, including infection, scarring and even death.

83 Montgomery n. 2 above, 1.
The GMC is clear in its guidance:

The doctor explains the options to the patient, setting out the potential benefits, risks, burdens and side effects of each option, including the option to have no treatment. The doctor may recommend a particular option but must not put pressure on the patient to accept their advice. The patient weighs up the potential benefits, risks and burdens of the various options...The patient decides whether to accept any of the options and, if so, which one.\textsuperscript{85}

As yet, post-Montgomery, this remains unchanged. If a woman in labour refuses all delivery options other than CS, on the basis that as the baby has to be delivered then a CS must be performed, as in Ms B there is a blurring of the boundaries between choice as consent and choice as demand.

### 3.2.5 Resources, Choice and Access to Treatments

English law now endorses the right of patients to choose to decline treatments on offer but not to choose treatment which professionals consider inappropriate. Negative choices are distinguished from positive choices even though in some cases the effect of refusing treatment X may result in an ability to require treatment Y. Choice is thus less than genuine consumer choice. One further limitation on choice within the NHS must be noted albeit due to space constraints this thesis cannot explore the full scope on resourcing issues and choice.\textsuperscript{86} I shall deal very briefly with 1) choice to access treatment abroad when such treatment is not available or much delayed in England and 2) choices to receive treatments that the NHS will not normally fund.


3.2.5.1 Access Abroad

Resourcing matters come to the fore in the case of Watts. Mrs Watts was a female in her seventies who needed bilateral hip replacements, without which she was wheelchair bound and in pain. Mrs Watts and her daughter were articulate and knowledgeable about the English and EU law, seeking NHS reimbursement for an operation that went on to be carried out in France having considered that the UK waiting times were too long; Mrs Watts exercised her choice by opting for treatment in the EU. Munby J featured once again (as did the Secretary of State), at first instance, with the Court of Appeal referring on to the European Court of Justice for clarification. Jonathan Montgomery and McHale gave insightful reviews of this case, with analyses of both relevant and emerging European jurisprudence and the background EU Articles. More specifically there is now a European Union Directive that ‘clarifies the rules on access to healthcare [sic] including reimbursement.’

Montgomery stated:

…allocating resources on demand undermines the opportunity for ethical decision making…The Watts case is…an illustration of the dangers of rights-based systems in threatening to distort priorities…It will benefit those skilled at using markets,…at the expense of distributive justice,…

Further, from Newdick:

…Munby J….assumed that,…if large numbers of people chose to go abroad for treatment, pressure on the service [NHS –my addition] would decline….“any medical incentive to travel abroad for treatment will simply evaporate.” However, the truth may be very different. Money lost from the “NHS loop” is no longer available for the NHS to invest….waiting lists will not decline.

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87 R v Bedford PCT v the Secretary of State for Health ex parte Watts [2003] EWHC 2228.
88 Secretary of State for Health v R, ex parte Watts [2004] EWCA Civ 166.
91 More specifically claims under Article 49 of the EC Treaty and Article 22 of Regulation No. 1408/71.
93 Montgomery, J., n. 89 above, p. 198.
What one could conclude therefore is that the offering of true choice in the NHS is contrary to its fundamental principles, and so one questions why it – choice – is apparently on offer at all; other than for politicking purposes. Government might argue that its choice agenda for patients obviates these inequalities but not all agree. What is on offer is limited, controlled and so managed that, in fact, the status quo may well be preserved. Jackson has provided a concise summary of near recent judicial reviews and European judgements in relation to patients seeking treatment abroad. Montgomery was concerned that spending scarce resources abroad will undermine UK based care. I worry too that the ‘money-follows-the patient’ policy in the UK will undermine care and care access here in the UK. The recent EU directive would appear to give legal endorsement to a limited extension of individual patient choice that is not necessarily beneficial to the NHS as a whole. The policy is likely to be embraced by the articulate, knowledgeable and supported person with the isolated, sick and possibly elderly patient neither wanting nor able to go abroad, still waiting.

3.2.5.2 Access to Treatment and NHS Funding

A discussion about access to treatment might seem pertinent in the debate about positive choices and demands for treatment. Access, I argue, is rather different. This is about the patient having the ability to engage with, choose and receive newer, often pioneering treatments and technologies. The law decided by the English courts says little about the provision of treatment by the NHS but focuses on decision making. It appears that early challenges were less successful than more recent endeavours and again this might reflect the European influence. At the time of writing there appear to be three prime areas where recourse to law via the courts is utilised in an attempt to assert some form of choice over treatment access. These are important areas but for space reasons are only noted in this chapter and thesis as a whole.

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97 See Newdick, C., n. 94 above.
100 Montgomery, J., n. 89 above, p. 198.
101 Klein, R., n. 9 above, p. 218.
102 Pollock, A., n. 10 above, pp. 228-234.
103 EU Directive, n. 92, above.
The first theme that emerges is that of the individual, or their representative, taking (legal) action, in the form of judicial review, and based not on the provision or refusal of treatments by the NHS, but rather the process of decision making that resulted in those blocks to access. Cancer issues are often and understandably headline leaders and so it was in *R (Ann Marie Rogers) v Swindon Primary Care Trust and the Secretary of State*[^104] and *R (Linda Gordon) v Bromley NHS Primary Care Trust*.[^105] An analysis by Newdick[^106] shows how the individual choice (in these cases for new and trial drugs respectively) brings the individual and their (guided) choice up against the institutions, such as the National Institute for Health and Care Excellence (NICE), the NHS, in the form of CCGs, and the involvement of the Secretary of State for Health. Politics undoubtedly affected organisational decision making but the courts focused on procedural failings and rationality in that decision making. On this approach choice in law is based more on the application of fair and consistent policy and practice. Without this:

Too little supervision is dangerous and may lead public authorities to ignore their duties to individuals. …too much intensity may encourage litigation and generate unrealistic expectations that courts can assist patients by increasing NHS funding.[^107]

Newdick is critical of the individualist approach taken by the European Court of Justice[^108] in *Watts*,[^109] believing it to be divisive and unethical, in favour of the wealthy and the articulate. I have sympathy with this view from an economic and moral stand-point and yet somewhere, somehow, the individual, often in dire straits, must have a vehicle to assert their own needs, and self-determine. In a communitarian ethos not all will get their chosen option but at least they should be heard.

Ford considered the policy of funding of cancer (in this instance) drugs on the basis that for some patients their situation will be exceptional and otherwise unfunded drugs resourced as a consequence. It is a detailed and comprehensive ethical and legal account of the, at times, erratic and illogical structures and processes in operation in the NHS that ends thus:

[^104]: *R (Ann Marie Rogers) v Swindon Primary Care Trust and the Secretary of State* [2006] EWCA Civ 392.
[^105]: *R (Linda Gordon) v Bromley Primary Care Trust* [2006] EWHC 2462 (Admin).
[^107]: Ibid., 243.
[^108]: Ibid., 244.
[^109]: *Watts* n. 88 above.
Funding patients on the basis of exceptionality, determined locally, is not the answer.\textsuperscript{110}

The case law above and other challenges to refusal of medical treatment in the NHS are, on the face of it, presented as claims for increased patient choice. This claim translates well to a second theme involving so called Big Pharma,\textsuperscript{111} and their undertaking of corporate legal challenges to the processes that have denied patients access to treatment, with other parties such as patient support groups declaring their interests.\textsuperscript{112} In a challenge to NICE ‘guidance’ on treatments for mild to moderate Alzheimer’s disease, Dobbs J found that the guidelines in part breached both Disability Discrimination and Race Relations legislation. Her judgment enabled in the order of 25,000 individuals access to anti-Alzheimer’s drugs that had previously been refused. Questioning the decision making procedures of an ‘arm’s length’ organisation such as NICE, can, in part, be successful although views on the taking of such actions are polarised.\textsuperscript{113} 114 It can be easy to forget that Big Pharma sells treatments to the NHS often at high prices; their agenda therefore is arguably about their share-holders and not the patient. The courts have avoided making decisions where the patient seeks a choice of treatment that the NHS cannot afford, preferring a right to be heard approach rather than one based on outcomes.

If you are very wealthy you can afford private treatment in entirety. In addition some people are able to exercise some degree of choice over their care that others cannot, not having the necessary financial resources. This third area involves the issue of co-payments for treatments, with patients paying for newer therapies that are limited or unavailable on the NHS, while still receiving adjunctive managements free at the point of delivery. Despite the ‘topping up’ system that already occurs with NHS prescriptions and dentistry, the DoH refutes any analogy\textsuperscript{115} and argues that co-payments should not apply to ‘clinical’ treatments, as this would initiate a two tier service (i.e. enhanced for those who can pay) in a communitarian NHS, a line of argument that Newdick might well support. One patient, Debbie Hirst, endeavoured to ‘top up’ her late stage cancer NHS treatments with a

\begin{itemize}
\item \textsuperscript{111} Defined as ‘large and successful pharmaceutical companies considered as a business group with important economic, political or social influence’, from \textit{Cambridge Business English Dictionary} \texttt{http://dictionary.cambridge.org/dictionary/english/big-pharma}
\item \textsuperscript{112} \textit{R (on the application of Eisai Ltd) v National Institute for Health and Clinical Excellence} [2007] EWHC 1941 (Admin).
\item \textsuperscript{113} Chalmers, I., ‘The Alzheimer’s Society, drug firms and public trust’, \textit{British Medical Journal} \textbf{335} (2007) 400.
\item \textsuperscript{114} Hunt, N., ‘Alzheimer’s Society replies to Iain Chalmers’, \textit{British Medical Journal} \textbf{335} (2007) 541.
\item \textsuperscript{115} Keen, A., House of Commons Hansard Debates for 18 December 2007: Column 718. \texttt{http://www.publications.parliament.uk/pa/cm200708/cmhandsard/cm0} Accessed 10/02/08 15.50.
\end{itemize}
Licensed but non-NHS drug. DoH guidance instructed localities not to permit this and if patients fund some of their treatment they have to self-fund it all. Legal action by judicial review was being contemplated.

Note the Parliamentary response of Alan Johnson, the then Health Secretary:

…A founding principle of the NHS enshrined in every single code of practice…is that someone is either a private patient or an NHS patient. …they cannot, in one episode of treatment, be treated on the NHS and then allowed….to pay money for more drugs. That way lies the end of the founding principles of the NHS.\textsuperscript{116}

However, Ms Hirst’s Primary Care Trust (of the time) undertook, at short notice, a special review and reversed its decision, thus purchasing the drug for her on the NHS.\textsuperscript{117} It would probably be too cynical to suggest that clinical need alone was insufficient influence but nationwide adverse publicity might have been, as perhaps was the threat of legal action? Interestingly the guidance was updated shortly after the Hirst case to allow patients to ‘co-pay’ for treatments not funded by the NHS without losing access to the rest of their care in the NHS.\textsuperscript{118}

3.3 Conclusions

I have indicated in Chapter 2 how the English judges refer to choice in health care matters on many occasions. The courts have honoured their approach to autonomy and thus choice to date, in so much as the negative choice of the individual is recognised. They stop short of extrapolating this approach to include positive choices. Yet state health care and the political agenda ‘markets’ choice for the individual while correspondingly strictly limiting the choices available.

Controversially perhaps, while the courts utilise autonomy as if it means choice and the State likens its choice policy to one of respect for the individual, they are acting in parallel and with a complementary rhetoric. Is there an alternative for the publicly funded and collective NHS, bearing

\textsuperscript{116} Johnson, A., Ibid., Column 723.
in mind, as detailed in earlier chapters, that cautions over this phrase now apply given the involvement of the private sector? Would it be reasonable to avoid the commercially and emotionally loaded word, choice, and talk instead of the treatment options available and patient preferences to be considered but not guaranteed? We are not then masking (deliberately or otherwise) the fact that those with resources might access a different level of health care to those without, and that those with positive needs and wants are less likely to be given their ‘choices’ than those with negative needs and wants; a situation currently perpetuated by the decisions of the English Courts and Europe.  

Choices, if that is what they are, become limited when services close or are centralised – the healthy, wealthy and mobile may not suffer but the ill, old and isolated certainly will; not much choice here. If Chester v Afshar promotes a concept of patient autonomy and thus choice, are Burke and Watts more about limiting autonomy, rather than the limited autonomy that many of us, like O’Neill, would accept is necessary for a collective system to function? Having perhaps indirectly and even inadvertently, with the aid of the Court of Appeal, castigated Munby J. for his advocacy of the individual in Burke, it would appear that the Secretary of State for Health is a powerful influence. The European arena has opened up a whole new dimension to the demand (and authorisation) for positive choice, including not just treatment per se, but the resources underpinning it. The Department of Health was quick to act, at least after the Watts judgment, and the process of gaining approval for treatment (in the EU) is not easy to navigate.

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121 n. 91 above, Article 49 EC, Regulation 1408/71/EEC.
127 See www.nhs.uk/...Healthcareabroad/plannedtreatment/Pages/Introduction.as
I would contend that at present the Courts respect autonomy and self-determination in the event of negative ‘choice’, yet have until recently avoided and even disregarded the need to apply the same scrutiny to positive ‘choices’. Judges have practically never confronted resourcing issues\(^\text{128}\) so it is only speculation that enabling individual positive choices has too great an implication for resourcing in our collective NHS. *Montgomery* does little to change this. In effect little has changed since my first paper; certainly *Sidaway* has perished but policy and *Montgomery* underpin my hypothesis that what you have is not unfettered choice.

One’s own free unfettered choice, one’s own caprice—however wild it may be….What man wants is simply **independent** choice, whatever that independence may cost and wherever it may lead.

*Dostoyevsky, The Brothers Karamazov*\(^\text{129}\)

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\(^{128}\) One notable exception is the case of *R v Cambridge Health Authority, ex parte B*, [1995] 1 WLR 898. See Jackson, E., n. 36 above, pp. 80-82.

Chapter 4 – Choice: Political and Philosophical Approaches

4.1 Introduction

One of the benefits of the doctoral programme in Bioethics and Medical Jurisprudence is that in the first semester all students participate in seminars focusing on bioethics, moral philosophy and medical law. Students were encouraged to consider whether some of the established philosophical approaches would facilitate their research questions. Thereafter students may focus on developing their research, preparing the published papers and the final thesis on law, policy, ethics or other disciplines as agreed. From my perspective philosophical approaches have informed my thinking but overall have played a lesser role within this thesis. This chapter explores some of the political and philosophical concepts and conflicts that exist with what intuitively seems to be an incongruous arrangement; the relationship between choice and the NHS. Oliver and Evans indicate this conflict exists when considering the individual and the collective NHS when they say:

The notion of choice and its individualistic underpinnings is fundamentally inconsistent with the collectivist NHS ethos.¹

The first part of the chapter summarises the development of patient choice from the diverse political standpoints that have contributed to choice policy. The second part of the chapter focuses on an applied analysis of respect for individual autonomy given the promotional rhetoric of individual patient choice in health care and the NHS in particular. Overall the chapter explains and develops the political and philosophical approaches in the papers that follow and demonstrates the complexities and complications in associating patient choice with an individual respect for autonomy.

4.2 Patient Choice and the Body Politic

Intuitively for me there is something almost contrary about considering central public funding along with individual patient choice. In the NHS example why would the system appear now to facilitate individuals in picking and choosing in matters of health care; the main concern might be considered the management of the service as a whole? Why should a resource-limited state and service

afford any choices to the patient? Perhaps it is unsurprising that the NHS remains unusual, not copied directly anywhere in the world, and whilst susceptible to whatever political dogma of the time, the aim remains fixed; care, ‘free at the point of delivery.’ For context purposes it was useful to look at the political history and evolution of the NHS up to the present day, and see how ‘choice’ has been factored in by successive Governments, utilising moral and political approaches to rationalise their decision making. The reality of patient choice in health care is very different from the policy and the theory.

There are many modern political theories, some complementing each other and others conflicting. Kymlicka appears to summarise what is, if not confusion, a lack of a satisfactory explanatory political philosophy. In a discussion on liberal egalitarianism and justice, the work of Rawls and Dworkin; with the latter believing that the welfare state can be ‘made more choice sensitive’, though presumably not necessarily offering *more* choice, Kymlicka pithily states:

Most people view liberal egalitarianism as providing a philosophical justification for the …liberal-democratic welfare state…the most common way of describing the welfare state… was to view it as an ad hoc compromise between competing ideals. Libertarians on the right believe in liberty, Marxists on the left believe in equality and liberals in the middle believe in a wishy-washy compromise of liberty and equality.

On this basis it is hard to see how any political party in the United Kingdom could agree with each other on what patient choice could and should mean.

For those in government post World War II, including Labour-Conservative coalitions, Labour Governments, followed by Conservative Governments, a sweeping change to Labour, then the politics of the Conservative-Liberal Democrat Coalition and now pure Conservatism, the NHS became a pawn or tool in the debate between socialist ideology and concessions towards Conservative policies, towards decentralisation and local, rather than central control. Klein saw UK health care policy stagnating in the 1970’s:

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5 Ibid., p. 88.
By the end of the 1970’s, the NHS was more than ever a paradigm of British society as a whole: the stalemate society.\(^6\)

There was as much inertia and lack of development in the NHS as there was in other public services and the private sector of the time. But then in the 1980s the political scene changed with the advent of ‘Thatcherism’,\(^7\) and ‘…the change in the NHS mirrored wider political, social and economic changes.’\(^8\) Klein reviews the years since the inception of the NHS in blocks of time and with a degree of creativity; as the politics of consolidation, followed by technocratic change, then disillusionment, on to value for money, the big bang, the third way, reinvention, ending with transition just before the general election of 2010. Reinvention encompassed some ten years under the leadership of Tony Blair and the latter three under Gordon Brown; reinvention became transition and both were core to so called New Labour ideology.\(^9\)

On reflection it seems that throughout the pre New Labour years the role, influence and impact of the key players, the politicians, civil servants, medical professionals (a powerful force until very recent times), and administrators, waxed and waned according to policy and political dictats. Thatcher’s Britain endeavoured to bring market forces to bear in all aspects of life and the NHS was not spared. Apparent libertarian policy however, with devolution to the localities and the commissioning (of health care) bonanza, with purchaser-provider splits, could well be considered to be one of the greatest Utilitarian command and control operations in the public sector. Responsibility for locality spending was at a locality level yet the DoH was strictly in control of what could be spent. The Department of Health never really let go at any time of finances, but responsibility for financial governance was firmly local. Policy claimed an NHS culture no longer based on trust, but based on contract,\(^10\) apparently a preferable option. The promotion of individual autonomy, freedom of the individual really took off and yet little did we see how controlling and paternalistic it could become, by making the individual responsible for the consequences of their decision making. And was there choice? Arguably a libertarian Thatcherite would consider decentralisation and local provider purchasing powers enabled a form of choice, largely for the

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\(^8\) Klein, R., n. 6 above, p. 106.

\(^9\) Ibid.

\(^10\) Ibid., p. 156.
commissioning organisation or practitioner though and not the patient; somewhat ironically a policy that so called New Labour went on to develop and devolve.

New Labour was swept into Government on a wave of enthusiasm and optimistic national fervour not seen since war time. They promptly adopted policies towards the NHS that were so similar to those of the Thatcher years one could be forgiven for thinking that little had or has changed. In fact, via the so-called Third Way\textsuperscript{11} influences of Anthony Giddins\textsuperscript{12} and other Labour think tank advisers, Labour commenced a health reform programme that the Tories could only have dreamt of but would never had dared initiate; no libertarian laissez-faire, nor for that matter any Rawlsian distributive justice\textsuperscript{13} or the top down redistribution of Socialist Labour\textsuperscript{14}. There were different names for organisations, more emphasis on ‘co-operation’ and funding with the private sector, monies moved out to the localities in the name of choice and yet a DoH that, via a target driven programme, returned to a tight central control of operations.

Further significant NHS reforms resulted from \textit{The NHS Plan}\textsuperscript{15} and \textit{Delivering the NHS Plan}\textsuperscript{16} and ‘consolidated the idea of market principles…’\textsuperscript{17} and patient choice became core rhetoric. In 2003 the Health Secretary, Alan Milburn, gave a seminal speech to NHS Chief Executives and the state claim became ‘to put the patient and their choices first across a spectrum of NHS provision.’\textsuperscript{18} ‘Choose and Book’ policies were expanded as was the policy of ‘Free Choice’;\textsuperscript{19} surely not named by accident. The independent sector was enrolled in providing NHS care via independent treatment centres. The system was difficult to navigate and then as now individuals or their advocates needed to be confident on the telephone and the internet to take advantage of the choices on offer. Patients could continue to rely on the referral advice of their GPs but given the

\footnotesize{\textsuperscript{11} Ibid., p. 188-190.  
\textsuperscript{14} Edwards Poole, K., ‘Arguments for income redistribution’, Encyclopaedia Britannica,  
\textsuperscript{18} Milburn, A., Speech to Chief Executives, ‘Choices for all’, 11 February 2003.  
\textsuperscript{19} See Thorlby, R., Gregory S., ‘Free Choice at the point of referral’, Briefing (London: The King’s Fund, March, 2008) 5pp.}
pressure on the GP, for example, to utilise the private sector at guaranteed levels of activity meant the patient was often led down pre-set referral pathways. GPs were rewarded for producing a reduction in referrals\(^{20}\) and referrals made were scrutinised at practice level and externally for ‘appropriateness’ before the patient had the opportunity to make a choice. Gordon Brown took on the Premiership in 2007 having previously declared some scepticism over patient choice. As Ham points out:

Disagreement was particularly apparent in the wake of the 2001 election when the Prime Minister [Blair – my addition] in association with…Alan Milburn, developed policies to increase patient choice and competition between hospitals and other providers. The policies were resisted by the Chancellor [Brown – my addition].\(^{21}\)

The patient entered a period that Klein describes as an ‘era of transition from political stability to political uncertainty’.\(^{22}\) The much vaunted, then latterly abandoned, so called ‘Darzi Report (2008)’\(^{23}\) talked at length about patient empowerment but for some this was a vehicle by which choice and the responsibility to choose was a method by which policy could be implemented. The Government signed the NHS Constitution in 2009 with its talk of rights to choice and the information to support choice.\(^{24}\) It was an odd move for a Prime Minister who had not embraced patient choice but, as Klein\(^{25}\) says, he may have been pre-empting Conservative Party policy. Brown’s Premiership coincided with a global financial crisis and an NHS financial crisis that led the then NHS Chief Executive demanding in 2009 savings of 20 billion pounds in the NHS by 2013/14; the so called Nicholson Challenge.\(^{26}\) Klein notes that ‘choice was trumped by clinical authority and the imperative of financial pressures.’\(^{27}\) Choice and competition\(^{28}\) policies did survive however and went on to be inherited and massively developed by the Conservative-Liberal Democrat Coalition that took power in 2010.

\(^{22}\) Klein, R., n. 6 above, p. 254.
\(^{23}\) DoH, High Quality Care for All NHS Next Stage Review Final Report, June 2008 92pp., Cm 7432.
\(^{25}\) Klein, R., n. 6 above, p. 266.
\(^{27}\) Klein, R., n. 6 above, p. 256.
The Conservative led Coalition comprehensively embraced patient choice talk and rhetoric. The then Health Secretary Andrew Lansley had had eight years in opposition as Shadow Health Minister to plan and prepare for more reform; reform that resulted ultimately in the Health and Social Care Act, 2012; with Lansley stating that:

We will put patients at the heart of the NHS, through an information revolution, choice and control.  

There should be a presumption that everyone should [sic] have choice and control over their care and treatment…We expect choice of treatment and provider to become the reality in the vast majority of NHS-funded services…

From this the patient might finally see themselves at the centre of, and with control over, their own health care-related decision making. By now the language of patient choice was firmly associated with competition and the fiscal market, and choice was an instrument in negotiating that market. The patient had become the consumer and might somewhat understandably, given the rhetoric, have the perception and expectation of health care wants being met rather than (just) needs.

The pace and scope of Andrew Lansley’s health reforms proved unpopular and he was replaced as Secretary of State for Health by Jeremy Hunt – the incumbent at the time of writing this thesis. Mr Hunt has carried on and expanded the Lansley reforms. Under the latest NHS Chief Executive Simon Stevens, in October 2014 NHS England and five other health-related organisations released the latest proposals for the NHS entitled ‘Five Year Forward View’. It is in this document that there has been a notable change in the language of patient engagement. Partly in response to health care scandals such as that at Mid-Staffordshire NHS Trust and in all likelihood as a result of persistent criticism, the talk has become less of choice and competition and more of health

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31 Le Grand, J., n. 28 above.
quality and integration; integration of health and social care. Patient ‘choice’ and competition policies remain intact however, whatever their intent or the language used.

4.2.1 A Note on Other Key Players

This thesis is primarily concerned with concepts around patient choice. It would be remiss however not to acknowledge, albeit very briefly, the other key agents in the NHS; medical practitioners to whom the affording of choice falls, given the nature of the patient-doctor relationship, and the NHS organisation itself, given the nature of its publicly funded role and the Government setting of its policy.

4.2.1.1 The Health Care Practitioner

In this instance the HCP in question is the doctor and Oakley and Cocking state that this is a person:

…whose training and expertise conferred upon them a special authority to give and withhold diagnoses and treatment.

This statement summarises what seemed be the prevailing medical attitudes in the first thirty years of the NHS; few concerns for the intrinsic nature and beliefs of the patient and more about the values, applications and egocentric, yet self-sacrificing, attitudes of the practitioner. Furthermore I believe that this generation of practitioners were expected to show a degree of paternalism (without malevolence) towards the individual patient. The patient was only made aware of the existence of any choices if the practitioner deemed that this was good for the patient to know.

Something changed in the 1980s with the advent of ‘Thatcherite’ Britain. As society, politics and the NHS emerged into the market economy of the 1980s and early 1990s doctors were not immune to the ensuing changes that affected the system as well as the professional and personal lives of the practitioners. Doctors, no longer prepared to be so self-sacrificing, were expected to deliver to a tight market oriented health care agenda with a ‘client’ base that was evolving into a self-oriented consumer culture. Choices were beginning to be expected by the ‘consumer’ patient and ‘some’

35 NHS England, n. 33 above, pp. 3-5.
choices were on offer as doctors followed a central health policy. It was the turn of the state to be paternalistic as much, if not more so, than the professional: ‘Individuals may have an impact, but under conditions not of their own making.’

The background conditions to health care choice such as accessibility and availability are, necessarily perhaps, pre-set by those in control of the funding; the individual-consumer-patient will have little if any influence at that policy level. Health care in England has become a complex mix of social change, policy, practice and professional ethics, supposedly engaging with the patient but often not doing so in reality. There is a view that this is where doctors’ (in the United Kingdom) confusion over moral values began, and dissatisfaction with practice started to set in; a clash of practitioner virtues with state principles perhaps?

A good example comes with financial incentives for doctors; basic schemes put forward by the Conservatives in the 1980s and early 1990s became very active policy and are now an entrenched feature of English health practice. Whatever the top-down organisational pressures, a bottom up financial inducement strategy must surely confuse personal and professional moral values even more. Turn a doctor into a technician via tasks, targets and practise may become more one of utility than one of principles. Of interest is that commentary expressed concerns that some, in managerial positions of governance, were instrumental in these changes, demonstrating a ‘soft coercion’ towards their own colleagues.

Those concerns have continued to be articulated and may be worthy of further research.

4.2.1.2 The Organisation: The NHS

The NHS aims and needs to be utilitarian in form and function no matter who has been or is governing; utilising market forces now in order to deliver this choice agenda but still failing to match costs with demand. The naivety behind any early analysis of the impact of establishing an NHS was simplistic and well intentioned and I would add continues to apply; Ham comments:

One of the assumptions that lay behind the NHS, …was that there was a fixed quantity of illness in the community which the introduction of a health service, free at the point of consumption,
would gradually reduce...expenditure would soon level off and even decline...In fact the reverse happened.\textsuperscript{42}

If the NHS were an individual, one could feel a degree of empathy with its predicament. As intended and predicted management of the NHS has been devolved further to the localities, managed as arms-length bodies, apparently independent, yet accountable to central government,\textsuperscript{43} so independent of what remains unclear.\textsuperscript{44} What better way to garner support for a thriving health service when resources are abundant, and shift blame to doctors and patients\textsuperscript{46} for making ‘wrong’ choices when the service lapses in to deficit. Factoring in the practitioner and an organisation with multiple stakeholders into this patient focused thesis is an added complexity and although not developed further here it provides an illustration of how what seems to be such a simplistic concept of patient choice becomes anything but straightforward. As a result the next section re-focuses on the patient and develops a view on some of the thinking that underpins autonomy and that patient.

4.3 Autonomy and the Patient – Pertinent Principles and Philosophical Approaches

Having established that the reality of choice in the NHS is, and probably always will be, very different from an ideal notion of choice, it is important now to consider the ethical principle of respect for individual autonomy in this context. Whilst most mainstream ethical theories will prioritise respect for autonomy, and thus patient choice, because the notion of choice in the NHS is a rather different concept, I found it difficult to locate this discussion into established philosophic al theories. I endeavour to show that although there was a great deal of insight gained from the exploration of ethical theory, my approach in this area is a much more applied and practical one of critical thinking with consideration of pertinent philosophical principles and issues, rather than applying a particular theoretical approach. The focus of the ethical approach is the association between choice and respect for individual autonomy.

\textsuperscript{42} Ham, C., n. 21 above, p. 16.
4.3.1 A Return to Autonomy

The concept of patient choice and choice in any publicly funded service is a modern phenomenon. In general terms and until recent times a person got what they were given from the State and had little to say in that decision. Similarly in health care, doctor knew best. Yet modern health policy, law and ethics literature is full of terms such as patient choice and patient autonomy. Few medical practitioners in the United Kingdom are expert in the philosophical concepts that might underpin an analysis of patient choice, however it is exactly these philosophical concepts and their perceived ethical importance that underpin this emphasis on patient choice. Chapter 2 considered the important and central role that respect for individual autonomy has in ethical thinking, and how this is often considered to be the ethical basis for prioritising patient choice. In this section I will examine further the concept of respect for autonomy and how and why it underpins the modern notion of choice. In doing so I raise the philosophical elements that affected my thinking towards choice and its association with respect for autonomy, and make reference to a number of philosophical approaches that influenced my early development work in this area. I explain why I concluded that attempting to apply a particular ethical approach such as utilitarianism was not likely to be very fruitful given the complexity of the political, legal and practical issues under consideration. Rather, a straightforward critical analysis approach of the ethical principles involved and the language around choice and its association with choice in health care was, I came to believe, the most appropriate method, of investigating my question. This enabled an evaluation of the questions to be addressed in the papers that follow in a critical and reasoned manner.

4.3.1.1 The Importance of the Ethical Principle of Respect for Individual Autonomy

Autonomy originates from ancient Greek political theory with ‘autos’ meaning self, and ‘nomos’, self-government or self-rule. It related to the self-government of the ancient Greek city states rather than the individual. 47 In the Middle Ages there was no place for individual autonomy – self-rule was God’s domain, as people were ‘relegated to a place within a religious and metaphysical hierarchy…’. 48 Immanuel Kant 49 (1724-1804) argued for individuals to be considered as rational beings, able to make their own decisions in a spirit of self-governance within the laws of the time. By the 1800s Liberal thinkers like John Stuart Mill considered that the individual ought to be free to decide for themselves; a freedom from interference unless one’s

48 Ibid.
actions pose a threat to others; a negative freedom, not based on demand. The Utilitarian philosopher Mill was of the view that individuals themselves are the best judges of what will be to their benefit; the implication being that the more free the choice that a person has then in turn this would lead to a maximisation in well-being. Respect for autonomy is ‘a norm of respecting the decision-making capacities of autonomous persons.’ It is perhaps unsurprising then that such respect features in the law over matters of consent and information handling. It may not be happenstance that one of the early NHS choice policies was entitled ‘Free Choice.’ The ‘sound-bite’ is very much one of respect for the autonomy of the individual as the author of one’s own life in a flourishing democracy that has developed an NHS for the greater good.

4.3.1.2 What is the Importance of Choice in Ethical and Philosophical Traditions?

Mark Sheehan comments that ‘patient choice, we may think is the popular version of the ideas of informed consent and the principle of the respect for autonomy.’ Such a statement articulates the way choice has become almost analogous with self-determination. Choice itself appears to be a relatively modern day phenomenon and it is interesting to abstract back a little on how more traditional thinkers might have conceived the concept. Jackson, in an analysis of the ethics of Aristotle, talks of choice as being ‘a kind of conduct’ and ‘...a reasoned conduct’ which does resonate with the definitions of choice in Chapter 1.

Further, the 2nd formulation of Kant’s Categorical Imperative, for instance, would indicate an intrinsic requirement for, and respect of reason, free will, self-determination and the ability to choose. If respect for autonomy is important then it seems clear that enabling individuals’ choice is

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53 Thorlby, R., n. 19 above.

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important for the same reason and this has been reflected in the philosophical literature.\(^{57}\) Time, thought and reason have enabled people like O’Neill\(^{58}\) to develop Kantian theory almost to a point of extrapolating what Kant would have really meant ‘if…?’; that is, how would Kant himself analyse the modern use of health care choice. Kantian theory is taken beyond that of the individual per se and into the realms of principle:

Principled autonomy requires that we act only on principles that are principles for all; it provides a basis for an account of universal obligations and rights that can structure relationships between agents.\(^{59}\)

What this means in practice is that arguably unlike pure Kantianism, which may leave the door open to a degree of paternalism or worse (harmful coercion and/or covert deception), because it is ‘not relational’,\(^{60}\) a principled (so-called) neo-Kantian method with its concerns for rights and duties at least narrows undesirable consequences. I have found it useful to focus on O’Neill’s conception of principled autonomy for the reasons that while O’Neill does draw upon some traditional notions of autonomy and choice, she develops further the idea that respect for autonomy, if it is to be trust based, and I would add relational as applied in health care, has developed beyond the individual alone. For O’Neill, principled autonomy favours trust with its ‘obligations’ to reject deception; individual autonomy if held in higher regard than trust can make trust ‘elusive’.\(^{61}\) To extend this argument further, trust, when validated, enables a belief in the reality of choices on offer; lack of trust should make one suspicious of the so called choices on offer – appealing as they might to notions of individual autonomy and yet eroding that very concept. In terms of arguments over patient choice in health care, elements of this approach are compatible with the way this thesis develops, in that it matches that my contention that a fully functioning patient-doctor relationship that incorporates shared decision making, and information dissemination, is based on trust not choice. Having said that, whilst O’Neill’s theory complements my hypothesis regarding law and policy; that whatever choice, it is not unfettered consumer choice, the theory does not appear to identify the justifiable restrictions on choice corresponding with Mills’ harm principle which I hold to


\(^{59}\) Ibid., p. 96.

\(^{60}\) Ibid., p. 83-84.

\(^{61}\) Ibid., p. 192.
be equally essential.\textsuperscript{62} I will argue that in line with the harm principle, in practical terms the individual cannot and should not have what they want from the health care system if that is detrimental to another and particularly if that other is vulnerable and lacks a voice or advocacy.

4.3.2 Is Choice in Health Care Enhancing Autonomy?

The affording of health care choice to the individual in the English health care system has the essence of having a respect for that individual's self-determination; an enhancement of the respect for their autonomy even. In this section, and by considering some recent and near recent commentaries, I look at how true this might be. Gerald Dworkin in \textit{The Theory and Practice of Autonomy} (1988)\textsuperscript{63} states that:

Arguments for the value of choice may rely on the instrumental value of choices or on the intrinsic value…either the value that attaches to choices because having more contributes causally to the obtaining of other good things or the value that attaches to having more choices for its own sake.\textsuperscript{64}

Again this interpretation resonates well with one of the definitions of choice as cited in Chapter 1. Instrumentally then, in for example health care, would be the belief or hope that with extra choice in treatments available, there would be one choice that would be preferable to the others on offer; the preferred or best part. Alternatively, and again from Dworkin, would be the belief that if a choice holds value just because it is a choice then it has intrinsic value and thus more choices must bring more value. Dworkin, I should add, actually states that neither the instrumental nor the intrinsic value of choice means that more choice is better or more preferable than less: 'In the realm of choice,…we must conclude – enough is enough.'\textsuperscript{65} In other words the value of choice comes from having options, but not unlimited options. Moving more specifically into the health care arena, whether there is a choice to be had and whether that is a good thing is a relative issue, depending on the social model of the times. On the latter point I would develop this further and say choice in matters of consents to treatment, information disclosure and information protection and

\textsuperscript{62} Mill, J., S., in Warnock, M., n. 50 above.
\textsuperscript{64} Ibid., p 78.
\textsuperscript{65} Ibid., p.81.
management also depend upon on the norms chosen; norms that are not decided by the patient, as per Chris Ham, above.\textsuperscript{66}

The medical model of health/ill health/illness\textsuperscript{67} is core to the NHS raison d’etre, and health policy is directed towards putting the patient at the centre of their own health care, what is it that respecting the individual’s autonomy and offering them choice is expected to achieve?:

Health, which is a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity, is a fundamental human right and that the attainment of the highest possible level of health is a most important worldwide social goal whose realisation requires the action of many other social and economic sectors in addition to the health sector.\textsuperscript{68}

The implication is that in order to achieve the best possible health there has to be autonomy promoting input from external agencies that facilitates the individual in, for example, making choices about their own health. The expectation on the system therefore is high. Are we then given to expect that the NHS can and should deliver what is apparently rightfully ours? Schlesinger notes that the term choice is ‘redolent with positive associations’\textsuperscript{69} and patient choice policy is integral to the NHS Constitution\textsuperscript{70} and health legislation. And so what of us all as patients; are we given to expect that the NHS can and should deliver what is apparently rightfully ours? Given the advances in medical science and major investment programmes in health (and social) care would it be any surprise if there was a mismatch between patient expectations and what is on offer? So how might the modern NHS patient view the ‘choice’ on offer? Iona Heath, a GP who has chaired both the British Medical Association and Royal College of General Practitioners ethics committees, identified that:

Most people want good healthcare services from their local NHS hospital and are not interested in shopping around, yet the rhetoric around choice is all about just doing that. There are clear limits to officially sanctioned choice and the word itself becomes corrupted.\textsuperscript{71}

\begin{flushright}
\textsuperscript{66} Ham, C., n. 21 above, p. 5.
\textsuperscript{68} WHO and UNESCO Declaration of Alma Ata, 1978.
\textsuperscript{70} NHS Constitution, n. 24 above.
\textsuperscript{71} Heath, Iona, ‘The growing gap. Collusion between the state and the market is at odds with the idea of free choice for patients’, \textit{British Medical Journal} 334 (2007) 670.
\end{flushright}
Yet empirical evidence has been clear that the offer of choice to patients has an intrinsic value, and that despite choice being on offer it is the value and being valued that has meaning, not necessarily the choices on offer themselves. This is one explanation as to why many people given a choice of different hospital for treatment perhaps with lower waiting times than their local facility, the patient still goes to the local hospital. Respecting a person’s autonomy would necessarily involve engagement with them and interacting and understanding sharing the decision making.

Speculatively in both the public and private sectors the promotion of patient choice as a method of placing the patient central to their own care, and its association with respecting their autonomy, is ill guided. In spite of and despite the sophisticated and yet inefficient health delivery models such as ‘Choose and Book’, the evidence shows that what patients want are clean local hospitals and to be treated with dignity, not necessarily a choice of place, practitioner or treatment. Some of the heaviest critique of (current) ‘choice’ policy comes from HCPs, who are of course themselves patients at one time or another. What unnerves these commentators is the collusion element of the choice agenda. Practitioners are being discouraged from sharing with patients what they cannot, but perhaps should, have in health care, in favour of (only) what is on offer. It is not transparent. And the consensus seems to be that ‘choice’ enables the healthy, wealthier and better supported to access alternatives within the system, with the ill and the old and those with no advocate getting what is left. In the current NHS the money follows the patient and if local services do not attract the mobile and relatively fit, services will fail. This is hardly respectful of autonomy. In summary therefore the sort of choice that is talked about theoretically in relationship to autonomy, is different from the reality of choice in the NHS. Is it then ill advised to associate choice in English health care with autonomy, and in this system does choice have the potential to erode autonomy?

75 Marcus, Robert, ‘Should you tell patients about beneficial treatments that they cannot have? Yes’, British Medical Journal 334 (2007) 826. Note that this commentary is part of a head to head debate in print.
4.3.3 Diminishing Choice as Autonomy in Health Care?

In disentangling the rhetoric and polices of patient empowerment, ‘no decision about me without me’, it becomes clear that choice in health care risks undermining the very autonomy that the choice talk purports to enhance. Brazier challenged the ‘notion’ of respect for individual autonomy in the patient-health care arena:

Just as autonomy has gradually but inexorably extended to become a claim of a right to health care, and the health care of your choice [my emphasis] so it is to be used as a template for decision-making in circumstances where it may be mythical because the purported choice is by no means an autonomous choice.

The association of autonomy with an individual’s choice and demand-led decision making can be fallacious as there are times where choice itself seems to have little relationship with autonomy; for example, the ‘choice’ might be the only option and the options may be pre-set by others. To use an extreme example, the full term pregnant woman might endeavour to try and choose a Caesarean section as a method of delivery. What she cannot choose is not have the baby at all, whether she wants it or not. Nor does everyone favour the enhancement of autonomy approach and although not developed further in this thesis for reasons of space, this is worthy of note. Conly, for example, makes an argument for what is called ‘coercive paternalism’, in preference to autonomy. Notwithstanding preventing individuals from harming others, she feels there is a strong case, ‘obligatory’ even, that ‘when individuals engage in behaviour that undercuts their…happiness, state interference may be justified.

At first glance such a proposal might well find a place in the field of public health, smoking bans provide a good example. It is harder to argue for such an autonomy diminishing principle when considering individual patients and their health care choices. The government is in effect already determining the choices that are on offer in state-funded health care. Attempts to alter the choices that a patient is able to make, for example, with the aim of saving resources, without being transparent about the rationale, does risk lapsing in to a form of state coercion, rather than paternalism. This is an interesting area for research but for reasons of space is not considered further in this work.

77 See DoH, Liberating the NHS No decision about me, without me Government response, Gateway Reference 18444, December, 2012, 42pp.


79 Conly, S., ‘Against autonomy: justifying coercive paternalism’, JME Online First December 12, 2013, 10.1136/medethics-2013-101444, 1.

80 Ibid.
The situation exists where the vocabulary of health care in both policy and practice is taken from the language used in the service and consumer-based industry. Choice becomes equivalent to having wants and demands met; choice becomes a demand in itself. Yet as Brazier says, this right to have what we want, when we want, is anything but a manifestation of autonomy; not if one incorporates the ‘self-determination’ and ‘self-control’ of O’Neill into the definition. Being a maximally autonomous person presupposes that there are no ‘apparent defects’ in an individual’s control, reasoning or the information available to them; and sound information and reasoning must enable people to acknowledge what we cannot and should not have in a resource limited public service; it is not about unlimited claims.

Kenneth Veitch also makes a crucial point about the patient choice agenda and patient empowerment; all is not what it might first seem to be for the patient:

By deepening the role of choice of provider within the NHS – with resources following patients’ choices…the government renders the decisions and opinions of patients the means of managing costs…

Patient empowerment also provides crucial political functions…it offered the government the possibility of deflecting potential criticism of public expenditure…by passing responsibility….for this onto patients and the choices they have made.

Arguably engaging patients in matters of responsibility for their health choices ought to enhance autonomy. However that can only be true if the patient is actively informed that this is their role in the patient choice agenda and that there are consequences which might include loss of service provision. Veitch in referencing David Harvey recognises how the subtle use of choice language and patient empowerment ‘appeals to our intuition and instincts’ and this becomes ‘embedded…and to be taken for granted and not open to question’. This feels less and less like a policy that enhances a genuine respect for autonomy.

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81 O’Neill, n. 58 above, p. 22.
84 Ibid., p.320.
85 Ibid.
It is well recognised that having choices can itself be problematic even for the fit and well. Newell et al. state that ‘so much choice makes decision-making increasingly complex.’\textsuperscript{87} Schwartz notes as our experience of having choices and apparent control increases, our expectations for same elevate as a result and we become less, not more, satisfied. In addition, he postulates that more choice can bring with it a sense of loss of control, and inability to cope or decide. Again in terms of respect for self-determination, the choice agenda becomes increasingly unappealing.\textsuperscript{88} Levy talks in terms of ‘increasing patient autonomy by constraining it.’

Since we know that human beings, unaided, are subject to a dizzying variety of pathologies of reasoning….we ought not to expect patients to make crucial decisions unaided. Rather they should be helped and supported to make their choices…We should tell patients when we think their decisions are distorted …we should do this in the service of protecting their values…To refrain from doing these things is not to respect autonomy, it is to decrease it.\textsuperscript{89}

In other words in this era of apparently extensive patient choice to not take the time to share decision making with the patient or discuss their ‘choices’ realistically and honestly, disrespects an individual’s autonomy far more than having only a limited range of options or perhaps even having no choice at all. The suggestion is therefore that philosophical theories and political policies address choice and autonomy in very different ways.

\section*{4.4 Conclusions}

Exploring some of the philosophical arguments and principles such as respect for autonomy has proved useful as they have aided my understanding of the ideal of autonomy and choice and given a structure around which I could compare these with the realities in and of health care, and do so in a critical and reasoned manner. The analysis has exposed the reality of choice in the NHS; it is as if theory and practice are at some degree of variance. The reality of choice in, in this instance, the NHS, is so removed from the ‘ideal’ that no one single ethical theory is used in the papers. What was utilised was this background knowledge of the ideal that is often alluded to by policy makers resulting in an analysis based on critical thinking.

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\textsuperscript{89} Levy, N., ‘Increasing patient autonomy by constraining it’, \textit{Journal of Medical Ethics} \textbf{40} 2014 293-300. 
\end{flushright}
Increasingly I have found myself arguing that the emphasis on patient choice in health care when associated with an apparent respect for autonomy is less about enabling self-determination and more a guise under which policy and practice might legitimately be developed; ‘you chose it’. Perversely the ‘choice agenda’ is predetermined for you, the patient, so what choice is that? This along with recognition that patients are not unsophisticated and do have to be treated as adults with all the responsibilities for others as well as self that this brings, led me to develop Paper 1 and beyond, along the concepts of patient engagement and shared decision-making. This requires a change in the language of health care in matters of choice; delineating options available and why, and acknowledging but not guaranteeing patient preferences and why, in matters of consent or confidentiality. In addition it needs time for discussion and an altered model of the patient-practitioner relationship; something that can be problematic given time constraints. Alternatively, it needs the advent of ‘third part’ advisers, as piloted elsewhere and already basically modelled in the NHS. This however requires resources. The true respect for autonomy comes with being honest and transparent with the individual about what is and is not available and accessible and why this is so. Therein lies trust that is such a crucial part of the relationship between patients and their advisers.

Choice is important; it is underpinned by philosophical principles and applied ethical approaches in favour of self-determination, control, well-being and responsibility; respect for an individual’s autonomy. It does not ally well with the use of choice rhetoric in the NHS and health care at a wider level. The ‘choice’ under consideration here is not one that can be said to enable maximally autonomous choice because the latter is necessarily restricted in the NHS and beyond. Transparency and trust is manifestly the way to demonstrate respect for individual autonomy of the adult, capable person.

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90 Schlesinger, n. 69 above, p. 378.
91 Ibid.
Chapter 5 - Choice: Research Questions and an Introduction to the Papers

“When I use a word,” Humpty Dumpty said in a rather scornful tone, “it means just what I choose it to mean, neither more nor less”.¹

“There is now ample evidence from scholars…people who have choice and take control over their lives tend to be healthier and to live longer….So we are introducing choice to give more power to the patients.”²

5.1 Re-setting the Scene

The first two chapters of this thesis indicate that patient choice would at first glance appear to be a core feature of a modern and progressive health care system and National Health Service (NHS) policy. Choice as a concept also appears to have been endorsed, albeit with certain limitations, in English case law and statute. This parallels developments in contemporary ethics where choice can be associated with a respect for autonomy, the recognition of an individual’s self-determining status. Closer reflection however questions this choice rhetoric. Does choice really exist in health care especially that which is publicly funded and resource limited and, perhaps more to the point, should it? What is meant by choice? The following papers, which form the core of the thesis, seek to answer those questions in part and investigate the reality of patient and individual choice in health care. Initial research revealed a huge potential area of study and choices had to be made about which questions to focus on. The speed of change in NHS policy and the law also meant that in the course of the research change and modification took place rapidly, and from almost the moment of publication or completion, some aspects of each of the papers were affected. The main areas of inquiry within the three papers include choice and consents to treatment, choice as treatment refusal and demand, and the field of individual choices involving medical confidentiality and information management. I shall contend that much less true choice is on offer than the rhetoric suggests and that in itself is not necessarily wrong. Rather it is a lack of transparency about what really happens and needs to happen that becomes disrespectful to the patient and undermines endeavours towards patient autonomy.

It might be argued therefore that a collectivist, welfare oriented system such as the NHS ought not to offer the patient, the client and the user choice, or rather need not have to. However, to a greater or lesser extent, some form of ability to select care elements has always been inherent in NHS provision albeit perhaps little known about or exercised. What did change from the mid-1990s was the political outlook on NHS management with the introduction of patient choice, the promotion of which really took off in 2000 with *The NHS Plan,* and was enhanced subsequently via the Health and Social Care Act, 2012. The rhetoric itself is now on the wane; the policies remain the same. Furthermore, and almost in parallel to policy, there has been a shift from a position of judicial deference (as in *Bolam* to judicial questioning of health professionals (from *Bolitho* through to *Chester v Afshar*) and now with *Montgomery v Lanarkshire Health Board.* At the same time social attitudes have altered also from a position of deference to challenge of those delivering health care. Despite developments in consumerism, apparent choice policies and something of a legal shift towards the patient-as-a-consumer, choice in health care and law is rightly a restricted and limited notion. Furthermore de-emphasising the term choice in favour of advising on what health care options are genuinely available and acknowledging but not guaranteeing patient preferences in a spirit of transparency and patient engagement says more for patient autonomy than a dubious use of choice.

At the start of this research there was little to find in the literature with regard to patient choice and how that might be interpreted. From both a patient and practitioner perspective there appeared to be a need to fill that void. I was open-minded as to what the research might determine despite the original concerns that I had as a result of conversations with former colleagues. In developing the papers and approaching the work I adopted a desk based critical doctrinal analysis of law, ethics and policy, and the relationship between the three. The analyses also made recourse to established and evolving works in the legal and ethical literature including journals (legal, ethical, philosophical, professional and service policy), professional guidance, texts and relevant conference proceedings via thematic and literature reviews. Internet and library based research

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4 Health and Social Care Act, 2012.
5 *Bolam v Friern Hospital Management Committee* [1957] 2 All ER 118.
6 *Bolitho v City and Hackney HA* [1997] 4 All ER 771.
7 *Chester v Afshar* [2004] UKHL 41.
was undertaken as necessary.\textsuperscript{10} In addition, empirically acquired data when available and applicable was referenced; this proved more specific to health care policy and practice.

The title of this thesis evolved into \textit{Choice and Health Care – Fact or Fallacy}. It is based on policy claims for individual choice even from a system that must be designed to facilitate a greater overall, collective function, \textit{if} choice is what is on offer. Chapter 1 noted that an accepted definition of choice is:

\begin{quotation}
...the act or power of choosing...the preferable or best part...\textsuperscript{11}
\end{quotation}

If we presuppose that individual patient choice as promoted within health care and law is a Fact; then it should be ...a truth; truth; reality; or a real state of things...\textsuperscript{12} If however it is Fallacy, we have ...an apparently genuine but really illogical argument; deception...\textsuperscript{13}

\section*{5.2 The First Paper}

My first paper published in 2011 (‘The Fallacy of Choice in the Common Law and NHS Policy’, \textit{Health Care Analysis}, DOI 10.1007/s10728-011-0198-4) derived from an interest in seeing if there was real connectivity between how the English courts and health care, particularly NHS care, had developed in the use and interpretation of patient choice talk; given that the rhetoric sounded like an enhancement of self-determination (in one’s own care). From a reflective and deductive viewpoint, until very recent times, with a judiciary that indicated deference to the medical professions, the law operated in effect in parallel streams to NHS policy and practitioner activity. There was little, if any, ‘coming together’ of these parallel streams and thus the development of a disparity and lack of clarity in interpreting and using choice.

The result was a paper initially entitled ‘Parallels in Practice’, and subsequently published in Health Care Analysis entitled ‘The Fallacy of Choice in the Common Law and NHS Policy’. Why the change of title? It became apparent during the research period that the term choice and its

\textsuperscript{12} Ibid., p. 601.
\textsuperscript{13} Ibid., p. 605.
interpretation varied widely across health care provision and health care law when used in the context of patient consent. This seemed a rather vulnerable situation to be in from a patient and a practitioner perspective; was choice all that it might seem?

A clarification in terms was followed by a number of sections that analysed the (then) law in England and its relationship to choice in terms of accepting treatments on offer, looking at the potential for a lack of choice to equate with harms, (my) choice to reject treatments on offer and to demand treatment that can be available but is not offered. The paper went on to identify the place of choice in background health policy and the English NHS not forgetting the implications for medical practitioners, as already ‘guided’ by the General Medical Council (GMC).

In summary this paper identified a need for a shift in the terminology in order to co-ordinate meaning, process and outcomes of health care treatments; favouring patient preferences, available and accessible options for treatment instead of the use of the word choice, with its heavily loaded expectations of wants as well as needs. To do so would require a more transparent and engaged form of patient–practitioner decision making.

Subsequently four years after the production of the first paper, law and policy had moved on. The Supreme Court in Montgomery v Lanarkshire Health Board [2015] UKSC 11 might appear to endorse consumer choice undermining my argument in the first paper. In Chapter 3 of the thesis the decision in Montgomery is analysed and it is argued that important as that decision is, it does not as such embrace unfettered choice.

5.3 The Second Paper

The second paper published in 2015 (‘The decline of medical confidentiality – medical information management: The illusion of patient choice’, Clinical Ethics OnlineFirst doi: 10.1177/1477750915591293) addresses the presence and use of choice talk in matters of confidential and private information and medical information access and management. Confidentiality carries a certain gravitas in the NHS; that is, the confidentiality of an individual’s medical information has been central to a trust based patient-doctor relationship. This concept has
been taken further, allied to privacy given the language used in the NHS Constitution.\textsuperscript{14} By looking at this area of NHS choice, policy and practice, I intend to argue that from an English legal perspective, that is, case law and statute, choice is restricted and at times rightly limited, thus choice and confidentiality talk is not all that it might seem to the individual patient.

The thinking and formulation that underpinned the conclusions to Paper 1 led neatly into a developing idea for my second paper. I have had a long time interest in patient confidentiality and data management both as a patient and a practitioner. Again, at the inception of the research major changes were taking place in the access to and use of our medical information. Increasingly there were concerns in my mind about the use of the language of patient choice in this field. I set out to look at the reality of the legal relationship with our personal medical information and its acquisition and its use and dissemination by the NHS; information management and its control and the rights and wrongs therein.

In a short review of the historical background the paper critically outlines a health care environment that has rapidly changed from one where patients’ details were limited to a small number of doctors through to now where there are numerous points of data access, facilitated by IT changes, audit and quality assurance requirements. It was helpful to review these areas in brief, noting but not pursuing the public health and research components as well as the clinical requirements. Furthermore, there have been a number of NHS and public agency data loss incidents,\textsuperscript{15} \textsuperscript{16} and intrusions\textsuperscript{17} and state authorised data selling\textsuperscript{18} that arguably flout any notion of choice.

With a health care culture that is apparently confidentiality oriented and also collectivist, just how much choice does and should an individual have over their data? What influences and effects does the law have and should the law have in this regard, given that case law had developed with talk of privacy but not endorsed a tort of privacy (\textit{Campbell v Mirror Group Newspapers Ltd}\textsuperscript{19}). Nor

\textsuperscript{14} DoH, \textit{The NHS Constitution the NHS belongs to us all}, (DoH: London, March 2013), p. 8.
\textsuperscript{16} Morris, N., ‘Ministers face embarrassment over stolen laptop and further data losses’, \textit{The Independent} (19\textsuperscript{th} January 2008) 11. Referring to the loss of a laptop containing the personal details of 600,000 benefits claimants; the laptop was found later by a roadside.
\textsuperscript{17} Dyer, C., ‘Whistleblower who was excluded from work for five years wins apology’, \textit{British Medical Journal} \textbf{336} (2008) 63.
\textsuperscript{19} [2004] UKHL 22.
can the Human Rights Act 1998, be relied upon to prevent and protect against intrusions, despite its talk of a right to private life.

The first part of the paper reviewed the concepts and rhetoric around this apparent idea of patient confidentiality, and then reflected on how this appeared to be sited in the case law and statute of recent times. The second section went on to support the notion that any fiduciary relationship between patient and practitioner over confidential information is no longer viable in modern health care; particularly when it is publicly funded and almost by definition resource limited. Rather than concentrating on the rhetoric of individual patient choice over data management matters, a shared and transparent discussion needs to take place between the patient and front-line practitioners about the system requirements for personal medical information.

It should be recognised that the NHS Constitution is an ever evolving document and while the 2013\textsuperscript{20} and 2015\textsuperscript{21} versions of same do not vary in their wording apropos patient rights and expectations of data confidentiality, privacy and choice, the Handbook to the 2015 Constitution\textsuperscript{22} is much more detailed in terms of sources and nature of the relevant rights and pledges as well as suggesting that patients, by virtue of their information, have a role, responsibility perhaps, in the care of others. For example, as a pledge:

The NHS commits to anonymise the information collected during the course of your treatment and use it to support research and improve care for others.\textsuperscript{23}

\textbf{5.4 The Third Paper}

The research for Paper 2 (concentrating on the NHS) highlighted that efficient and effective health care requires information, our health care data, \textit{and} that we needed to be told and involved in the processes that facilitate this rather than being somewhat infantilised by the suggestion that we have a choice. Confidentiality becomes less about the need and requirement to access this data and more about being open about its acquisition and use, at the same time as reducing opportunities for misuse. Individual choice must sometimes cede to the public good and I then began to question whether for some individuals, in particular professions or roles, their medical data ought to be

\textsuperscript{23} Ibid., p. 65.
available and accessible in a broader domain than that usually required or expected in health care, even if they access that care outside the NHS. The resulting third paper is entitled "Medical Privacy: Health Professionals and Ministers"; (currently submission pending).

The origins of this paper pre-date my PhD research and stem from a Master’s thesis undertaken in 2002/03 and based on a case study, this engaged with the idea that for doctors a different value system appeared to be in operation apropos their medical information, and there were potential consequences that included premature departure from the profession. However, some people in our society (including but not exclusively doctors) by virtue of the roles they hold do carry a considerable weight of responsibility for others in this society. Impairment in their performance be that for physical, psychological or social issues, has the potential to cause harm, sometimes to the few and sometimes to the many.

The clearest approach was to compare two professions that both carry an expectation of trust and the potential for harm; doctors and politicians. A brief historical review of some of our eminent politicians revealed substantive health issues that arguably influenced their decision making. The paper looked at the regulatory systems in place for doctors when they have performance-affecting health issues. It goes on to propose a regulatory model that senior politicians and civil servants would be expected to ascribe to. This kind of model has the potential to be applied to other highly responsible occupations. Such schemes not only place a duty on the individual to disclose health issues but require information to be disclosed whether or not the individual in question gives permission. This is a necessary diminution in ‘choice’ in a health care system where, in truth, the options for medical secrecy are already rightly limited.

In summary, this thesis seeks to indicate that the lack of clarity in the use and meaning of the word choice by the legal system, the state and providers, practitioners and inevitably the patients, results in confusing arrangements and a lack of clarity. Despite the greater recognition of autonomy, patient autonomy still has its limitations; English law for the most part endorses only the negative treatment choice. The positive treatment choice is, and may always be, unacceptable. Arguably, in a collective and State funded system such as the NHS, efficient and cost effective function is an absolute requirement. This cannot be achieved without organisational information including that of the system users, the patients. It could be considered a necessity therefore to forego confidentiality in order to facilitate function. As a consequence there should be limited choice for the individual over their own data; as underpinned as it is by case and Statute as well as policy.
What is troublesome is less about the rights and wrongs of collating information and more about the lack of transparency about what is being collected, by whom and for what purpose. Without that information the NHS user is unable to make a choice. This I argue is more of a compromise to our autonomy than the data access and collation itself; the latter corresponding more with a ‘principled’ approach and patients’ responsibilities within the system as well as their rights. I see this as a complicating and maybe confounding or contradictory issue. Rapid changes in NHS policy and the evolution in legal decision making may have altered the place of the health care practitioner in terms of health care delivery to that more suited to the collective agenda. The patient still expects and is encouraged to be treated as an individual however and assert their choice.
6.0 Chapter 6 - Paper 1 - The Fallacy of Choice in the Common Law and NHS Policy

6.1 Abstract

Neither the English courts nor the National Health Service (NHS) have been immune to the modern mantra of patient choice. This article examines whether beneath the rhetoric any form of real choice is endorsed either in law or in NHS policy. I explore the case law on ‘consent’, look at choice within the NHS and highlight the dilemmas that a mismatch of language and practice poses for clinicians. Given the variance in interpretation and lack of consistency for the individual patient I argue for a semantic change that obviates the use of ‘choice’, focusing instead on the options for treatment that are available and accessible, with due acknowledgement of individual preferences, without raising unfettered and false expectations.

6.2 Keywords

Choice, Demand, English Medical Law, English National Health Service, Fallacy, Options, Preferences
6.3 Introduction

Until recent times both the law relating to patient care in England and National Health Service (NHS) policy were heavily paternalistic, in contrast to the position in the USA. Today patient choice is often invoked both in the judgments of English courts in cases relating to consent to, refusal of and even demands for treatment and in the provision of health care within the ‘modern NHS’. The rhetoric is impressive. Lord Hope in Chester v. Afshar\(^1\) opined that: “The choice between [these] alternatives was for her to take, and for her alone. The function of the law is to protect the patient’s right to choose.” The Department of Health has also been clear: “Choice matters because it is at the heart of the Government’s public service reform agenda to empower patients, reduce inequalities in access to healthcare and improve health outcomes for patients”.\(^2\)

In this paper I analyse some of the medico-legal dimensions of judicial decisions apropos choice and the patient and explore the vogue for proffering ‘choice’ in the English NHS. I shall show that in neither arena is any form of real choice fully endorsed. I hope to demonstrate that choice, an apparently simple notion that appeals to the individual, becomes a complex concept with the potential for flawed understanding. Choices, as we commonly understand them, are neither available to nor accessible by all in a publicly funded health system like the NHS. There is no presumption of choice being inherently good in this paper. Rather, in common law there are boundaries to patient choice that are less apparent in policy and practice making the term neither accurate nor useful. The analysis is Anglo centric, as the devolved administrations of Scotland and Wales have not engaged in choice policy.

This paper is organised into six sections. Following this introduction the next section looks at definitions and interpretation of choice, indicating room for confusion at even this basic level. Choice can be associated with other concepts that are also open to interpretation; ‘autonomy’, ‘consent’ and ‘equity’ for example. The third section concerns itself with the interpretation of choice by the English courts; the developing rhetoric is illuminating. I will argue that, at least until Re T,\(^3\) patient choice was rarely taken into account in the face of judicial deference to medical practitioners’ decision making. For three to four decades choice was not on the agenda of either

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the NHS, or the common law as it touched on issues of consent. The fourth section addresses and reviews choice as an NHS policy, its recent evolution and practical application, with reference to relevant external policy analyses. In the penultimate section I look at the place and influence of the General Medical Council (GMC), given its relationship with the health care professional, in this instance the doctor tasked with advising the patient. I conclude with a recommendation for a semantic change that more fully represents what the patient can expect from law and health policy in England at this time. Instead of the language of choice we should focus on respect for preferences. There is a hint of this in the NHS Constitution with an association between needs and preferences.

Why should replacing the word choice with preference make a difference? While the law and policy are weighted towards ensuring that patient preferences are usually met in the area of consent, there is little if any enforcement of patient demand. Thus an abandonment of the term choice, in favour of presenting the options for treatment that are available and accessible requires a transparent engagement and enablement process that allows the patient to express preferences or preferred options, recognising that there are no treatment access assurances in the public sector. It is important to note that preferences may also include the refusal of, as well as the request for, treatment. Both the law and the NHS present a concept of choice that is neither determinative nor unfettered for the individual; yet the impression given to, and potentially expected by, the patient can be the reverse.

6.4 Choice: Definitions and Associations

‘Choice’ is a word that has, arguably, become near-ubiquitous in United Kingdom political discourse. It has an air of simplicity in meaning, ingrained in casual use and yet the word is value-ridden. The term ‘choice’ in the context of health care and beyond has become an extension of expressing (or choosing) preferences. To have choice implies that there is the opportunity for an individual to have what they want, when they want it; demand if you will. The most basic dictionary definitions highlight the complexities in using the term with meanings that include, “choice: the act or power of choosing…the preferable or best part” as well as “the opportunity or

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6 Notwithstanding that certain preferences may be seen as so bizarre as to trigger a manipulation of the capacity test.
power of choosing…’¹⁻⁸ It is this notion of ‘power’, as well as opportunity that implies a control of outcomes by the individual rather than being merely an expression of preference.

That the individual should be enabled to select his preferred health care treatment would appear to be more than implied by the language of choice. This suggests that choice, in whatever context, is an exercise in self-determination and to be applauded. However, such a conclusion is too simplistic. The definition of choice given above is not indicative of choice equating with demand, though current interpretations of choice in health care suggest otherwise. Choice has become a ‘soft’ term, open to interpretation. Health care is promoted to the patient-as-consumer, as in the NHS Constitution,⁹ Lord Darzi’s NHS Next Stage Review Final Report¹⁰ and via the Coalition Government’s White Paper Equity and excellence; liberating the NHS.¹¹ It is unsurprising that patients interpret choice as meaning that their requests and demands can be met. Fotaki et al¹² have noted that “Choice is a many-sided, diffuse and value laden concept…the term choice invokes assumptions…”.¹³ The problem can be seen in the way the law, health care policy and related commentaries each take a different slant on the process and outcome of patient choice. The same word bears different meanings.

Consider what an English trial judge said in up-holding one Mr Burke’s claim for the continuation of artificial nutrition and hydration:

the personal autonomy which is protected by art 8 embraces such matters as how one chooses to pass the closing days and moments of one’s life, and how one manages one’s own death.¹⁴

The Court of Appeal did not agree but the judge’s language illustrates a growing legal association between the idea of choice and the concept of personal autonomy or self-determination. But the

¹⁰ High Quality Care For All, NHS Next Stage Review Final Report CM 7432 (Norwich, The Stationery Office, June 2008) 84pp. Known informally as ‘The Darzi report’, after Lord Darzi of Denham who was commissioned to undertake this review by the Government of the day.
¹¹ DH Equity and excellence; Liberating the NHS, (London: The Stationery Office, July, 2010) Cm 7881. Note that this document is applicable to the NHS in England only.
¹⁴ R (on the application of Burke) v General Medical Council [2004] EWHC 1879 (Admin) at 62.
appeal court decision set clear limits on personal choice, limits that conflict with the rhetoric used by policy makers and sometimes judges today.

In terms of NHS policy choice is, or has been, associated closely with equity as much as self-determination. Choice is said to be a tool that enhances equitable health service use, as indicated by Alan Milburn stating when Secretary of State for Health that “greater choice can mean greater equity…making choice more widely available on the NHS so that it is extended to the many not just the few”.\footnote{Milburn, A., ‘Choices for all’, the Rt Hon Alan Milburn MP, Secretary of State, addresses NHS Chief Executives. 11 February 2003, (London: Department of Health, 2003) \url{http://www.dh.gov.uk/enNews/speeches/Speecheslist/DH_4000782} Accessed 19 September 2009 12.17.} He went on to counter this with what may well prove to be a key comment in the future of the NHS: “There are of course limits to choice in the health service…no health care system…can provide unlimited choice”.\footnote{Milburn, A., Ibid.}

On the issue of choice and equity, however, there are powerful arguments to counter any positive association and as indicated by Fotaki et al, “how at the very least, choice policies have the potential to increase inequity”.\footnote{Fotaki, M et al., n. 12 above, p. 118.} Further, NHS policy documents stop short of advising people what might be unavailable to them or perhaps less popular still, inaccessible.

In a separate work Fotaki notes:

The role that individual patient choice occupies in government designs…shifts the balance of power from professionals and the NHS itself, in favour of the user-consumer while self-appointing itself as a guardian of patients'/users' rights to healthcare…redefined in terms of a consumerist commodity.\footnote{Fotaki, M., ‘Choice is yours: A psychodynamic exploration of health policymaking and its consequences for the English National Health Service, Human Relations 59 (12) 1732.}

Efforts to enable individual or consumer choice are perhaps further confounded when at times "A paradox may arise: the patient chooses not to choose",\footnote{Fotaki, M., et al., n. 12 above, p. 26.} a subject worthy of further, separate discussion.

\begin{itemize}
\item \footnote{Milburn, A., Ibid.}
\item \footnote{Fotaki, M et al., n. 12 above, p. 118.}
\item \footnote{Fotaki, M., ‘Choice is yours: A psychodynamic exploration of health policymaking and its consequences for the English National Health Service, Human Relations 59 (12) 1732.}
\item \footnote{Fotaki, M., et al., n. 12 above, p. 26.}
\end{itemize}
Information dissemination and the time to consider that information in order to make meaningful choices are now accepted in English law. At this time it appears that the law is at least in parallel with the thinking of the health care analysts:

For policy makers, the main message is that giving information needs to be a specific priority if patients are to exercise meaningful choice. Providing information in a way that is useful to patients is not straightforward…a key issue if the provision of choice is not to increase inequity.  

Maclean and Veitch have both addressed many of the complex legal issues that arise from the association between choice, health care law and policy and by default, it could be argued, the resulting clinical practice. Maclean raises a counter-argument to that of expanding information disclosure to include options not open to the patient. For example, if a treatment is not ‘available’ to the patient then knowing about its existence becomes ‘irrelevant’ to consent. Extending this further raises the question as to whether imparting knowledge about a treatment that is available but inaccessible to a patient ought also to be restricted; the choice that may be available to some becomes no choice for another. The obligation to provide information in such a case becomes a matter of professional ethics and duty of care. Veitch, in presenting the consumer choice health policies of the 2005 Labour Government, envisaged increasing litigation based less on clinical negligence claims and hinging more on a lack of choices available or, in the case of resource limited treatments, accessible. Choices that may be available and accessible to some, but inaccessible for others are hardly conducive to equity and may bring the law into conflict with health care policy and practice.

The consequences of the latest proposals in *Equity and excellence* and its supporting documents have yet to be determined. Commissioning responsibilities involving eighty per cent of the NHS budget in England are to be devolved largely to general medical practitioners in association with secondary care colleagues and a lay membership forming clinical commissioning consortia. Doctors will have to learn to say ‘no’ to patients on purely fiscal grounds. Some patients will have access to information and be educated about their treatment options, many will not. Will the virtuous professional disseminate information about treatments that the same professional will have to refuse or be unable to commission, or will utility prevail and the patient no longer be told about treatments they cannot ‘choose’?

20 Ibid., p. 121.
6.5 Choice: The Law in England

Choice (in English law) has developed in an incremental manner that can be classified into three phases. What may be called ‘old’ law made no real reference to choice at all. This led to a phase where the rhetoric of choice could be heard although rarely did decisions favour the patient. Most recently there are judgments that give some (but not necessarily full credence) to the choice of the individual. Paradoxically some recognition of the significance of choice and consent in medical law decision making pre-dates the founding of the NHS, by almost two hundred years. Yet within six years of the NHS’s inception, in *Hatcher v Black*, Denning L.J. determined that:

> it was for the jury to say whether he [the doctor] told the plaintiff that there was no risk or merely prevaricated to stop her worrying…he knew there was some risk, but he did it for her own good…In short he told a lie.

This judgment in 1954, supportive as it was of medical paternalism, intimated that doctors might utilise their privileged position over information and its dissemination in the consent process. Perhaps this is because the NHS and its doctors could be seen as benevolent and something for which the patient should be grateful. Subsequently there were infrequent legal challenges to what can be considered paternalistic medical decision-making and its lack of involvement of patients in their own care. Skegg in 1999 highlighted the emphasis on so called informed consent, rather than choice, with regard to treatment alternatives. He noted both the complexity inherent in the term ‘choice’ when used in parallel with consent, and intimated that choice in the guise of consent may be less about the patient and more about (protecting) the health care practitioner:

> It is the overwhelmingly great emphasis on consent (even ‘informed’ consent), rather than on choice. Consent does, of course, involve choice. However the choice is usually a matter of whether or not to consent to a particular proposal. The role of consent is often seen to be that

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23 *Slater v Baker* (1767) 2 Wils 359, 95 ER 860. ‘...it was improper to disunite the callus without consent, ...it is reasonable that a patient should be told what is about to be done to him, that he may...put himself in such a situation as to enable him to undergo the operation.


of protecting a practitioner from a risk of legal proceedings: information is disclosed to ensure that consent is legally effective.\textsuperscript{26}

In \textit{Re W} \textsuperscript{27} Lord Donaldson saw consent as analogous to a “legal flak-jacket”, protecting doctors from litigation and thus not necessarily favourable in the handing over of power from the patient to the professional via consent. Yet in \textit{Re T}, as I will amplify later, Lord Donaldson advocated strongly for consent; consent as choice, firmly associating the patient’s interests in the language of rights.\textsuperscript{28} At the present time following a series of recent cases recognising damages for violation of autonomy, judges have moved towards giving some significance to the negative patient choice compared with earlier years. This is not, and may never be, full and unfettered, as positive choices are by no means allowed to be demands.

6.5.1 My Choice is to Accept the Treatment on Offer

In 1981 the first of a series of claims in England relating to what came to be called ‘informed consent’ was heard. English law seemed to be concerned less about individual patient choice as such and more about claims relating to adverse consequences of treatment. Such injury, accompanied by an apparent lack of information disclosure, might be litigated either in battery or in negligence. If considered in negligence, as most such claims are, the central question is more concerned about the appropriate standard of care for doctors advising patients rather than choice. This was articulated by Bristow J., in \textit{Chatterton v. Gerson}, “once the patient is informed in broad terms of the nature of the procedure…the cause of action on which to base a claim for failure to go into risks and implications is negligence, not trespass”.\textsuperscript{29} Negligence requires proof of harm in physical terms and until recently English law has largely held that lack of choice \textit{per se} is not a legally recognised harm. Although it may occasionally have been open to a patient who feels denied of the opportunity to make an informed choice to pursue a claim in battery instead; an

\textsuperscript{26} Skegg, P. D. G., ‘English Medical Law and ‘Informed Consent’: An Antipodean Assessment And Alternative’, \textit{Medical Law Review} 7 (Summer, 1999) 135-165 and 149. See also General Medical Council (GMC), \textit{Seeking Patients’ Consent: the Ethical Considerations} (1999) Note the statement ‘…take appropriate steps to find out what patients want to know and \textit{ought} [my emphasis] to know about their condition and its treatment.’

\textsuperscript{27} Re W [1992] 4 All ER 627, at 635.

\textsuperscript{28} Veitch, K., n. 22 above, p. 79.

inherent presumption of harm arising from violation of bodily integrity might have been a more favourable way of both acknowledging and protecting choice.\textsuperscript{30}

Recognition that the patient had a \textit{substantive} role in treatment decision making can be traced to the United States and \textit{Canterbury v. Spence}\textsuperscript{31} in 1972, a claim framed in negligence. The judicial language used was firmly oriented towards the patient having choice:

True consent to what happens to one's self is the informed exercise of a choice…to evaluate knowledgeably the options available and the risks…

Academic comment in the UK went on to advocate a ‘transatlantic’ approach to the disclosure of risk within the context of negligence.\textsuperscript{32} Brazier made the point that trespass as a means to endorsing patient autonomy, ‘a right to choice’, had been in retreat anyway.\textsuperscript{33} Further, Brazier’s commentary noted that there was “an absence in general of a consumerist approach to medicine…”\textsuperscript{34} That can no longer be considered the case.

In \textit{Sidaway v Governors of Bethlem Royal Hospital}\textsuperscript{35} Lord Bridge talked more specifically in terms of risk disclosure enabling a rational and informed choice:

although a decision on what risks should be disclosed for the…patient to be able to make a rational choice…the disclosure of a particular risk…might be so obviously necessary for the patient to make an informed choice.

\textsuperscript{33} Ibid., 180.
\textsuperscript{34} Ibid., 191.
\textsuperscript{35} \textit{Sidaway v Board of Governors of the Bethlem Royal Hospital and the Maudsley Hospital} [1985] AC 871; [1985] WLR 480; [1985] 1 All ER 643, HL.
Sidaway, a case involving neurosurgery to the cervical spine, has resulted in much academic discussion summarised by Maclean.\(^{36}\) Despite disagreements between the judges regarding standards of care there was a degree of consensus that the patient has a right of (information) disclosure, and thus a doctor the duty to disclose.\(^{37}\) In order to make a choice the patient has that entitlement or rather, the *enquiring* patient. Their Lordships considered that this did not apply to the un-enquiring individual for whom unsought information had (apparently) the potential to be detrimental. Lord Bridge tempered a full shift in favour of the patient, finding that disclosure enabling ‘rational’ choice was “primarily a matter of clinical judgement”.\(^{38}\) The argument became rather circular back in favour of acceding to medical opinion; the necessity of informed choice by the patient essentially allowed the medical professional to define the boundaries of the choice(s) available.

Mrs Sidaway’s claim that a lack of complete\(^{39}\) risk disclosure constituted negligence was rejected, in spite of Lord Scarman’s adoption of a prudent patient standard that appeared more oriented towards the individual patient’s choice.\(^{40}\) Thus Mrs Sidaway had no choice as, perhaps unsurprisingly at this time, for the majority of their Lordships the ‘reasonable doctor’ standard from *Bolam*\(^{41}\) (albeit modified) still prevailed despite the dissent of Lord Scarman.\(^{42}\) It is noteworthy that Lord Scarman himself, whilst utilising a pro-patient choice of language, found against Mrs Sidaway and did not endorse a situation of unfettered choice, protecting the concept of (medical) professional ‘therapeutic privilege’ on the basis that:

> a reasonable medical assessment of the patient would have indicated to the doctor that disclosure would have posed a serious threat of psychological detriment to the patient.

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\(^{36}\) Maclean, A., n. 21 above p. 162-169.

\(^{37}\) Sidaway n. 35 above, at 905, Lord Templeman. See also Lord Diplock at 895 and 898.


\(^{39}\) Mrs Sidaway alleged that the neurosurgeon (Mr Falconer – deceased) whilst having warned her of possible damage to the cervical nerve roots, had failed to warn her of possible damage to the cervical cord itself.

\(^{40}\) Sidaway n. 35 above, at 654.

\(^{41}\) *Bolam v Friern Hospital Management Committee* [1957] 2 All ER 118 at 122. See also Jackson, E., *Medical Law, Text, Cases and Materials*, [1st edition] (Oxford: Oxford University Press, 2006) p. 123. ‘…this judicial deference to medical opinion is partly due to the complexity of the medical evidence, but might also be explained by a sense of professional solidarity, and by the high regard in which the medical profession has conventionally been held.’

For many years Sidaway prevailed and there continued to be uncritical judicial acceptance of the views of a responsible body of medical opinion, per the so called Bolam test. That the level of information disclosure was a matter for the medical professional to determine came with strong judicial endorsements in 1987 in Blyth v Bloomsbury Health Authority\textsuperscript{43} (not reported until 1993) and Gold v Haringey Health Authority\textsuperscript{44} in 1988. In both cases even the enquiring patient was subject to the Bolam standard and medical paternalism was preserved. Not until 1994 however when a 28 year old man developed impotence after rectal surgery did a claim that a patient had not been warned of such a risk prove to be successful. The judge in Smith v Tunbridge Wells Health Authority\textsuperscript{45} found that the common practice of not warning patients, as noted by the expert witnesses, should not be considered ‘reasonable or responsible’, implementing Lord Bridge’s 1985 recognition of choice.

Subsequently in Bolitho v City and Hackney HA (1998)\textsuperscript{46} the judiciary reasserted the power of the court to question expert medical opinion. The expectation of logical medical decision making derived from the Bolitho case was applied in Pearce v United Bristol Healthcare NHS Trust.\textsuperscript{47} The claimant was pregnant with child number six and 14 days past her expected delivery date. Her request for Caesarean section was refused on safety grounds. A fetal death \textit{in utero} occurred five or six days later with a stillborn baby being induced after a further twenty four hours. Mrs Pearce claimed that the obstetrician had not disclosed the risk of still birth, a risk of 0.1 - 0.2 percent, by waiting for natural labour to begin. Lord Woolf recognised the paternalism inherent thus far in information disclosure \textit{and} that a patient needs information in order to choose:

that if there is a significant risk which would affect the judgment of the reasonable patient…it is the responsibility of the doctor to inform the patient of that significant risk …so that the patient can determine for him or herself as to what course he or she should adopt.

Read literally, Lord Woolf seemed to suggest that the doctor now owed a duty to the patient to disclose risk; risk that any ‘reasonable’ patient would require in order to consider their decision, and

\textsuperscript{43} Blyth v Bloomsbury Health Authority [1993] 4 Med LR 151.
\textsuperscript{44} Gold v Haringey Health Authority [1987] 2 All ER 888, CA.
\textsuperscript{45} Smith v Tunbridge Wells Health Authority [1994] 5 Med LR 334. It is notable that Morland J found that a failure to give a risk warning (impotence in this case) could be considered ‘neither reasonable nor responsible.’ Judicial views were shifting.
\textsuperscript{46} Bolitho v City Hackney Health Authority [1998] AC 232. In \textit{Bolitho} their Lordships defined the requirement for any professional opinion, including a body of opinion, to ‘withstand logical analysis’. That analysis is judicial analysis.
\textsuperscript{47} Pearce v United Bristol Healthcare NHS Trust [1998] 48 BMLR 118 (CA).
so make a choice. And yet still the decision did not fall in Mrs Pearce’s favour, hingeing more on significance of risk as determined by the medical profession, than an entitlement to information in order to make or support a choice. So while Lord Woolf associates risk significance with information disclosure, he appeared to trust the doctor’s view as to what actually constituted a significant risk:

the doctors called on behalf of the defendants did not regard that risk as significant...

In practical terms, as Jackson points out, Mrs Pearce’s own judgment as to whether a risk was sufficiently material for her to have her choice endorsed, was over-ridden by virtue of a reliance on the doctors’ assessment.

Pearce also raises another question not fully explored previously. Mrs Pearce was not just in a position to consent to or refuse treatment; she was placing a demand on the health service, a demand for Caesarean section, the treatment of her choice. This aspect of the case has not been addressed and yet to place a demand on the system opens up a new aspect on patient choice considered later in this paper.

6.5.2 Lack of Choice Equals Harm?

So far the courts had been ascribing relatively little value to choice but a series of decisions relating to failed sterilisations brought about some change. By 1999 the courts were giving consideration to infringements of claimants’ autonomy, which by default had influenced their choices or rather a lack of the same. In two wrongful pregnancy cases, McFarlane v Tayside HB in 1999, and developed further in 2003 in Rees v Darlington, modest damages were awarded in acknowledgement of the harms resulting from such a breach of an individual’s autonomy, even though the substantive harm was found irredeemable. Do these judgments reflect a robust endorsement of patient autonomy and choice at last? Coggon, in an insightful reflection on the position of English law, opines that judges do not treat autonomy with a ‘full intellectual rigour’ and equate it with self-determination and bodily integrity despite it being ‘a concept of unspecific scope

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49 Jackson, E., n. 41 above, p. 277.
50 McFarlane v Tayside Health Board [2000] 2 AC 59.
51 Rees v Darlington Memorial Hospital NHS Trust [2003] UKHL 52, HL.
or meaning."  Perhaps the same is true when endeavouring to equate choice with autonomy. However, from 1999 the jurisprudence relating to consent gives credence to patient choice in two ways. The first is via the violation of autonomy route and secondly, as I will show, by a ‘mauling’ of the law on causation.

_Chester v Afshar_ 53, emanating from the private health care sector in 2004, has the potential to alter both choice seeking and affording behaviours inherent in the consent process. In addition it resulted in a judgment that introduces a significant cognitive element to consent and hence choice. Miss Chester underwent spinal surgery that resulted in a paralysis known to occur in 1-2 per cent of such cases, with the facts of the case bearing similarities to _Sidaway_. The statistical risks were not disclosed to Miss Chester pre-operatively and on this occasion the defence acknowledged the materiality of that risk. Lord Steyn54 makes an association between choice and autonomy citing Dworkin’s _Life’s Dominion_:

> The most plausible [account] emphasizes the integrity rather than the welfare of the choosing agent… the value of autonomy. Recognizing an individual right of autonomy makes self-creation possible.55

It was found that Miss Chester would have been subjected to the same risks if she had consented to the operation at a later date by a different surgeon. The majority in the House of Lords agreed to a modification of the principles of causation. In moving the reference points for conventional causation, Lord Hope seemed clear, that:

> For some [patients] the choice may be easy – simply to agree or to decline the operation. But for many the choice will be a difficult one, requiring time to think, to take advice and weigh up the alternatives. The duty is owed as much to the patient who, if warned, would find the decision difficult, as to the patient who would find it simple and could give a clear answer to the doctor one way or the other immediately.56

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54 _Chester v Afshar_ Ibid., at 18.
56 _Chester v Afshar_ n. 53 above, at 86.
The decision has not been without subsequent academic legal comment. Maclean puts this apparent shift in causation succinctly:

Following Chester...claimants will succeed if they can show that disclosure of risk would simply have altered their decision. Claimants no longer need to show that they would have refused consent to the proffered treatment.

The structure and resourcing of the NHS rarely enables repeated visits from patients whilst they consider issues around a particular treatment. Can the courts ever really differentiate between decisions made in the NHS and the private health system? That notwithstanding, it is noteworthy that causation has now been expanded. The concept no longer includes (just) the disclosure of treatment information and risk, but rather there is a recognition that some people, some times, need more time to reflect and consider all the options (choices) open to them. In his analysis of the 2006 case *Al Hamwi v Johnston and another* Miola further enhances this cognitive and temporal element:

the notion that what is important about risk disclosure is that the facts are imparted rather than communicated effectively [my emphasis] should be resisted.

Emily Jackson acknowledges that whilst the competent adult (usually) has a right to decline a treatment that they do not want, the decision has to be made having considered the appropriate risks and benefits of any 'available' treatment. In turn this requires the dissemination of information: "...whether or not patients will get this information still generally lies within the doctor's discretion". These are valuable points given recent developments in health care policy and practice, as this paper will show.

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58 Maclean, A, n. 21 above, p. 188.

59 See *Wilsher v Essex Area Health Authority* [1988] 1 All ER 871, HL and subsequently *Fairchild v Glenhaven Funeral Services Ltd.*, [2002] UKHL 22 at 60; Lord Hoffman acknowledges the 'political and economic' consequences of litigation on the NHS perhaps implying that there is the potential shift in causation rules dependent upon whether the cases emanate from the public or private health care sectors.


Chester may have resulted in a shift in judicial thinking. The individual once in possession of information and given the time to consider that information, may refuse or defer medical treatment even when their advisers consider proceeding to be in the patient’s best interests. Furthermore, the enablement of a choice over one’s treatment enhances both the protection of one’s own bodily integrity,63 and respect for self-determination, as illustrated in *Birch v University College London Hospital NHS Foundation Trust*64 where the claimant had suffered a stroke following cerebral angiography. It was found that had the patient been ‘properly informed’ about alternative procedures and the comparative risks, she would have declined the procedure that ultimately resulted in that stroke; her choice was impaired.

### 6.5.3 My Choice is to Decline the Treatment on Offer

The patient’s preference may be to refuse a recommended treatment. Any discussion of treatment refusal does risk focusing on patient capacity rather than patient choice. However, it is illustrative how a patient’s choice in such cases becomes a malleable entity depending on the prevailing norms and mores. The influence of medical opinion and the judicial interpretation or manipulation of mental capacity thresholds still have a bearing on the individuals’ opportunities to decide for themselves, to have their preferences given force. Choice is not just about accepting or agreeing to treatment.

In *Re T*65 there was a complete rejection of the patient’s choice. The pregnant Ms T, having agreed to a Caesarean section following a road traffic accident went on to decline any blood transfusion on faith grounds. Following a stillbirth Ms T haemorrhaged and became comatose. Ms T’s father, supported by her partner, applied to the court seeking a declaration that it would not be unlawful for a transfusion to be given. An interlocutory order was made and the transfusion given before a full hearing took place. Subsequently, in the Court of Appeal Lord Donaldson utilised choice language and argument. He commenced his judgment thus:

> This appeal is about the right to choose how to live...even if the choice, when made, may make an early death more likely.

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63 Priaulx, N., ‘Rethinking Progenitive Conflict: Why Reproductive Autonomy Matters’, *Medical Law Review Advance Access* (April 15, 2008) 1-32. See p 11; Priaulx recognises that bodily integrity can be considered a basic physiological need, and the ‘critical importance of bodily integrity to one’s sense of self.

64 *Birch v University College London Hospital NHS Foundation Trust* [2008] EWHC 2237 (QB).

65 *Re T* n. 3 above.
Further stating that:

…the patient’s right of choice exists whether the reasons for making that choice are rational, irrational, unknown or even non-existent.

Lord Donaldson addressed ‘the conflict of principle’, that is, the conflict that exists between the individual and their society:

Society’s interest is in upholding the concept that all human life is sacred and that it should be preserved...  

This highlighted the difficult equation of meeting the choice of the individual when the choices made can be hard for others to accept and leading to what Maclean calls, “a sliding scale risk related standard of competence” derived from Lord Donaldson’s belief in Re T that “…capacity…was commensurate with the gravity of the decision.” Recall Lord Donaldson’s ‘flak-jacket’ analogy in Re W, where consent was seen as a mechanism for protecting the practitioner from the patient. Correspondingly, it could be argued that an emphasis on having offered the patient a choice, acknowledging same but not exploring or enabling it, would a priori suggest that choice talk serves much the same function. The affording of an apparent choice may serve to protect the health care professional from lapses in engagement with the patient and any critique or potential litigation that might ensue.

66 Re T Ibid.
67 Maclean, A., n. 21 above, p. 156. See also Foster C., ‘It should be, therefore it is’, New Law Journal 154 (2004) 7151, as cited by Jackson E., n. 41 above, p. 299.
68 Re W [1992] 4 All ER 627 at 635.
A person’s capacity appears to feature more in situations that involve the consequences of choosing to decline treatment rather than the risks of agreeing or consenting to interventions, where capacity will rarely be questioned. Brazier and Cave summarise the three areas that led the Court of Appeal to determine that T’s choice was not autonomous and whilst due acknowledgement was given in this case to the notion of individual autonomy as a function of choice, the sanctity of life argument was the final determinant.

In case of doubt, that doubt falls to be resolved in favour of the preservation of life for if the individual is to override the public interest, he must do so in clear terms.

In 2002 there was a further development in Re B. Again the consequences of accepting the choice of this competent adult patient would result in her dying, but to allow her choice required that doctors act to switch off the ventilator. Ms B’s wish, her choice, after years of severe disability and artificial ventilation, was that treatment cease. Those health care professionals whose own choice was not to participate in the cessation of Ms B’s ventilatory support were able to decline, and a unit was then found that accommodated her needs and wants. One can only speculate on the consequences for clinical conscience, medical duties and patient responsibilities if no such unit had been available, or there was no vacant bed. The patient may not be the only arbiter of choice. Ms B had to go through some eighteen months of psychiatric assessment in order to convince doctors and the courts of her capacity, and achieve her wishes; it took time to prove the validity of her choice.

The issue of capacity and the choice to decline treatment is challenging despite the decision in Re B. The difficulty remains, once an assessment of capacity is deemed necessary (and to paraphrase Glover-Thomas), in how to tease out what is a rational mental state from mental illness.

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69 See Rochdale Healthcare (NHS) Trust v C [1997] 1 FCR 274. Note the somewhat paradoxical decision where during the time C was refusing consent to a Caesarean section she was challenged as lacking capacity, yet once the courts became aware that C had changed her mind in favour of consent, her competency to consent was no longer in doubt.

70 Brazier, M., Cave, E., Medicine, Patients And The Law, [4th edition] (London: Penguin Books, 2007) p. 102. A multi-factorial situation that included the effects of injury and medication, a lack of credible information apropos the consequences of treatment alternatives and extrinsic family (maternal) pressures making Ms T’s decision ‘less than independent and voluntary.’

71 Re T n. 3 above.

72 Ms B v An NHS Hospital Trust [2002] 2 All ER 449.

personality disorder or incapacity. If refusal of treatment is seen as demonstrative of a compromised capacity then treatment can take place despite the choice of that individual. This was demonstrated both in *R v Collins ex parte Brady* where Brady challenged being force-fed, and in *NHS Trust v T (Adult Patient: Refusal of Medical Treatment)* with T’s advance refusal of blood transfusion. There is a blurring between competency and enabling irrational and bizarre decisions, versus incapacity and preventing irrational decisions being carried through.

What then for that individual whose choice is a positive one: a request or demand for treatment? The above apparent respect for autonomy and hence choice would suggest that these people too should be afforded the same opportunities to access treatment as those who decline. Is this the case? It would appear not to be so however, with a further and controversial development apropos choice and consent.

### 6.5.4 My Choice is to Demand Treatment that is Available but not on Offer

Mr Burke also argued that his preferred treatment choice should be met. He suffered with an incurable degenerative neurological disease that in all likelihood would leave him sentient but totally immobilised and dependent on others. He would be unable to feed himself or take fluids naturally. Mr Burke sought to choose artificial nutrition and hydration (ANH) until his own vital organs failed. Just as Ms B chose to die and the law endorsed her preference, he chose to live as long as he could. Mr Burke’s preference was based on a claim that he could demand treatment. The Court of Appeal however was clear that Mr Burke should receive the treatment that he sought but on clinical grounds and not through his own demand preference.

Mr Burke challenged the 2002 General Medical Council (GMC) guidelines for doctors on withholding and withdrawing treatments that may prolong life:

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76 *NHS Trust v T (Adult Patient: Refusal of Medical Treatment)* [2004] EWHC 1279 (Fam), [2005] 1 All ER 387.
77 *R (on the application of Burke) v General Medical Council* [2004] EWHC 1879 (Admin).
it is your responsibility to make the decision about whether to withhold or withdraw a life-prolonging treatment, taking account of the views of the patient or those close to the patient.\textsuperscript{78}

Further:

Adult patients who have the capacity to make their own decision can express their wishes about future treatment in an advance statement.\textsuperscript{79}...However, where a patient wishes to have a treatment that – in the doctor’s considered view – is not clinically indicated, there is no ethical or legal obligation on the doctor to provide it.\textsuperscript{80}

Mr Burke endeavoured to utilise Articles 2, 3, 8 and 14 of the European Convention on Human Rights (ECHR), to assert there was incompatibility between this guidance and his human right to remain alive with the aid of ANH, having already made an advance directive detailing his choice.

Munby J. performed a critical and comprehensive analysis of the ethics, common law and Convention law\textsuperscript{81} that underpinned the case as well as engaging with the medical professional issues raised.\textsuperscript{82} The issue of health care resourcing was notably absent.\textsuperscript{83} The judgment might have been seen as moving from a situation where the patient could expect to be able to refuse medical treatment once in possession of enough information and given the time to consider the consequences, to the position where a patient could demand an established medical treatment, ANH.\textsuperscript{84} It is noteworthy that Munby J. rarely mentioned choice himself, being content to cite preceding cases that utilised choice language.\textsuperscript{85} There is one exception when he refers to:

\textsuperscript{79} Ibid., Part 1, para. 13, p. 9.
\textsuperscript{80} Ibid., Part 1, para. 16, p. 10.
\textsuperscript{82} R (on the application of Burke) n. 77 above, at 213 and 214.
\textsuperscript{83} Ibid., at 26 and 27.
\textsuperscript{84} There is a semantic argument to be had that treatment is at variance with management and that ANH is no more than management.
\textsuperscript{85} R (on the application of Burke) n. 77 above, at 42, 55, 56, and 62.
…the personal autonomy which is protected by article 8 embraces such matters as how one chooses to pass the closing days and moments of one's life, and how one manages one's own death.86

Munby J. considered that Mr Burke had reflected on his situation and his judgment indicated a cogent analysis of what could be considered universal principles, underpinned by the European Convention. This could have been another pivotal moment for patients, practitioners and medical law alike. The Court of Appeal did not agree87 and ensured that the boundaries, as far as patient choice in their own treatment is concerned, remained where they had been pre-Burke. Choice does not include a claim to demand a treatment:

Where a doctor offered a patient more than one possible treatment but with a particular recommendation for one of them, the patient's right to refuse that one appeared to give the patient the positive option to choose an alternative treatment. However that choice was nothing more than a reflection of the doctor's duty to provide a treatment considered to be in the best interests of the patient…88

Furthermore:

Autonomy and the right to self-determination do not entitle the patient to insist on receiving a particular medical treatment…Insofar as a doctor has a legal obligation to provide treatment this cannot be founded simply upon the fact that the patient demands it.89

The patient does not have the power to choose certain options, just the power to refuse treatments and express certain preferences. Mr Burke's 'demand' for his choice to be met was a step too far and firm limits on apparently autonomous choice now appear set. Gurnham comments similarly:

86 Ibid., at 62.
87 R (on the application of Oliver Leslie Burke) v The General Medical Council [2005] EWCA Civ 1003.
88 Ibid., see headnote.
89 Ibid., at 31.
…it makes good practical sense to allow doctors some legal leeway when a patient demands resources that cannot justifiably be provided to the detriment of other’s needs.⁹⁰

It might be argued that any such ‘leeway’ ought to be part of an overt and transparent process that involves the patient in understanding NHS limitations.

Veitch analyses both the reasoning of Munby, J. and the Court of Appeal highlighting the tension that has emerged in health care law as a result of human rights talk. There is a tension between the stance taken by Munby J., and that which involves an “avoidance of judicial engagement” in ethical dialectic issues in favour of a ‘case-by-case’ approach based on a standard legal rationale.⁹¹

Were there extrinsic influences upon the Court of Appeal decision-making given the involvement of the Secretary of State for Health because of the wide ranging implications for policy and practice had the decision of the court of first instance prevailed? For the GMC after Burke perhaps it is unsurprising that their guidelines for doctors on seeking patient’s consent were revised in the light of recent case law, into a document that aims to address both consent to treatment and demand for it.⁹² Note the following statement apropos Burke:

…for the purposes of this guidance, the key point is the court of appeal’s opinion that doctors are under no legal or ethical obligation to agree to a patient’s request for treatment if they consider the treatment is not in the patient’s best interests.⁹³

Now questions can be raised with regard to Pearce which classically is considered in terms of informed consent and thus choice. Mrs Pearce like Mr Burke was actively choosing a specific treatment rather than refusing an intervention. Perhaps like Mr Burke, it could be argued that she had no right to demand treatment of her choice, but what she was denied was the information needed to enable her to express her preferences or seek a second opinion. More controversially perhaps, had Mrs Pearce demanded Caesarean section based on personal choice rather than concerns about risk, would the GMC and/or the Secretary of State for Health be involved as

⁹¹ Veitch, K., n. 22 above, pp. 123-127.
⁹³ Ibid., p. 39
interested parties, and would those interests be based on medical concerns or financial and resource limitations?

In English law what choice the patient can have is currently based on what may be called intrinsic and cognitive factors; the receiving of information and being given the time to assimilate that information. This has led to a right to say no, and even then constraints may be in place on a choice that could be perceived to be a flawed preference. A tension has emerged as demonstrated in *Burke* that centres on the acceptance of negative patient choices that may favour the patient. Allowing the individual patient to state what treatment they want and receive it as a (self) determinative option remains unavailable and potentially unacceptable.

As English law has developed incrementally in favour of acknowledging that the patient has a form of choice, albeit limited, does English NHS policy and practice have a similar accord?

### 6.6 Choice and the English NHS

Patient choice, the where and when you can be treated, not what treatment you may want or can have, has been core government strategy. It has developed a high profile in English National Health Service policy, focusing on the individual and their health care choices. Lord Darzi, in his 2008 report, *High Quality Care For All*, talked specifically of patient empowerment allied with choice: “empower patients with greater choice, better information, and more control and influence”.

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97 *High Quality Care For All*, NHS Next Stage Review Final Report CM 7432 (Norwich, The Stationery Office, June 2008) pp. 84. Known informally as ‘The Darzi report’, after Lord Darzi of Denham who was commissioned to undertake this review by the Government of the day.

98 Ibid., Section 3 para. 25 p. 38. See under ‘Empowering patients: more rights and control over health and care’.
The change of Government in the UK has reinforced this philosophy. The July 2010 White Paper ‘Equity and excellence; Liberating the NHS’, which remains to be implemented in the controversial Health and Social Care Bill, states that “Patients will have choice of any provider” and for the first time in writing, “…and choice of treatment”. A subsequent consultative document ‘Liberating the NHS: greater choice and control’ translates the White Paper rhetoric further by attempting to illustrate what is meant by phrases such as “choice of any willing provider” and “we will introduce choice of named consultant-led team”.

Such statements need to be placed in the context of the major changes in NHS care commissioning. In the order of eighty per cent of the NHS budget is to be transferred to locality based clinically-led commissioning consortia. These will have the power to negotiate service provision with any ‘qualified’ (formerly ‘willing’) provider and only a limited number of services and care conditions will be centrally managed. Contracts may be made with providers from the existing NHS and from the private sector. Some of the latter are likely to be large and experienced overseas-based health management organisations (HMOs); others are already established as alternative providers in the United Kingdom. It is plausible that in time HMOs and experienced clinical commissioners may find the proposed national tariffs designed to expand patient choice unprofitable to work with and in time may develop the economic market force to amend the list of choices on offer. Clinical commissioners will be expected to run lean and efficient services at

101 Ibid., p. 3.
102 DH Liberating the NHS: Greater choice and control A consultation on proposals (London, DH, October 2010)
103 Ibid., pp. 6-7.
104 Ibid., pp. 9-10.
105 DH Equity and excellence; Liberating the NHS n. 100., p. 28. An NHS Commissioning Board will be responsible for commissioning dentistry, community pharmacy and ophthalmic services, as well as national specialised services such as transplantation.
consortia level at the same time as offering this choice mantra to the individual patient. The consultative document talks in terms of:

people should be offered choice of treatments as a matter of course. This is not just about whether to have treatment, but also which treatment to have.

From a consumer point of view this would seem a significant step in the new market economy of the NHS, yet the same statement also talks in terms of choice not being offered ‘where clinically inappropriate or unfeasible’. There is an inherent tension within the statement because it becomes a case of who decides. Is the choice ultimately still one made by doctors? If a lack of feasibility is determined to be a consequence of commissioning and contracting decisions, there is a risk that choice as such is a function of availability not patient preference or need. This seems at odds with the earlier ‘free choice’ rhetoric.

Choice, per se, was never part of the original NHS vision. A patient choice programme sounds like a complication in the fine balance between the individual and general utility, in favour of the individual (autonomy). This would suggest that the best any public service can and should offer is the acknowledgement of individual preferences from a limited list of services on offer. Yet the NHS Constitution might suggest otherwise:

You have the right to make choices about your NHS care. The options available to you will develop over time and depend on your individual needs.

The NHS Constitution of 2009 appears to place patient choice firmly in the language of rights and is barely countered by the statement that:

You have the right to drugs and treatments recommended by NICE…if your doctor says they are clinically appropriate for you.

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This statement did have the potential to become redundant with Coalition government plans to remove the role of the National Institute for Health and Clinical Excellence (NICE) on mandatory matters of medicines approval and cost, in favour of centrally organised value based drug pricing, with clinical commissioners then making the decision as to whether their locality can afford the chosen treatment. This raised fears of internal health tourism between consortia boundaries. A recent policy U-turn that allows value based drug pricing but retains NICE in its drug approval role has not however removed the present ‘postcode lottery’. Consortia will still have to balance their books and as with the current PCT system they may decline to fund some treatments at a locality level. Patients of one commissioning group may be able to access or choose a treatment, yet a patient in a neighbouring area under a different clinically-led commissioning consortium potentially may not.

Does the NHS Constitution give patients like Mrs Pearce or Mr Burke the right to demand treatment as their individual needs develop over time? Could the Constitution underpin legal challenges on the basis of patients’ positive choices-as-demands, such as those argued for in Burke and given the legality that the Constitution has acquired by the Health Act of 2009? Alternatively will the health White Paper and any resulting primary legislation underpinned by the NHS Constitution lead to an increase in judicial review cases? These are likely to be challenging the decision making of clinically-led commissioners engaged in the difficult equation of managing locality demands with those of the patient and their individual choices and preferences.

There exists a wide spectrum of opinion about the rationale for a choice agenda within NHS policy, ranging from cost containment through to promoting enhanced quality initiatives, and concerns about equality and quantity rather than quality. Consumer organisations have raised concerns about the new health market economy having the potential to restrict patient access

112 Health Act 2009, Chapter 21, Part 1, Chapter 1. See para. 2, ‘Duty to have regard to the NHS Constitution’.
rather than enhancing such access for all patients.\textsuperscript{116} Veitch\textsuperscript{117} makes a case for this, asserting that affording choice to the patient makes them an unwitting tool in the political manoeuvres of cost containment and resource management. If someone needs hospital treatment and the local hospital downsizes or closes as a result of efficiency measures then the only ‘choice’ available to them is to travel. Thus if patient choice results in a service closure, the patients have themselves to blame. The responsibility for a particular policy becomes that of the patient and patients have already been told that with rights come responsibilities.\textsuperscript{118} This may be restrictive to those who are most in need: the immobile and the vulnerable. It remains unclear whether choice is always what the patient actually wants, preferring clean, local and accessible health care facilities instead.\textsuperscript{119} Currently, all patients when referred for non-urgent treatment under the free choice policy can choose to have that treatment at any hospital listed in a service directory, a list that includes NHS and independent (private) sector service providers.

Results from the King’s Fund collaborative on how patients choose a provider and how their providers respond are unsurprising if complex to interpret. Almost half the patients did not recall that they had been offered a choice. For those who did so, the majority of patients chose their local provider. The reasons cited again included (as perhaps could be expected) care quality, hospital cleanliness and the standard of facilities, along with a lack of transport to more distant providers. Previous poor quality care in the locality seemed to be the rationale for selecting a non-local provider.

But the recent research by the King’s Fund,\textsuperscript{120} as summarised by Coulter\textsuperscript{121} notes that an “offer of choice has an intrinsic value to patients”, regardless if their intention or action involves changing from one health care provider to another. This has a resonance with the present English law on treatment consent and refusal. There is an emphasis on the intrinsic or cognitive nature of choice rather than on an extrinsic policy structure purporting to deliver choice.


\textsuperscript{118} Milburn, A., n. 15 above.

\textsuperscript{119} Carvel, J., ‘Hospital choice irrelevant, say patients’, Picker Institute research on behalf of The Healthcare Commission, \url{http://society.guardian.co.uk/health/story/0,,20788971,00.html} Accessed 18\textsuperscript{th} May 2007 15.30.


\textsuperscript{121} Coulter, A., ‘Do patients want choice and does it work?’, \textit{British Medical Journal} 2010; \textbf{341}:c4989 \url{http://www.bmj.co/content/341/bmj.c4989.full} Accessed 15 October 2010 08.30.
Pollock, in 2005, raised concerns about the introduction of competition between health care providers:

The new financial system creates conflicts between the interests of patients and the interest of hospitals…the new incentive system has nothing to do with need and everything to do with the supermarket model of care.\textsuperscript{122}

The recent health reform proposals enhanced the place of competition in commissioning. Subsequent protests have resulted in amendments that at first glance dilute the role of the market; time will tell.

The King’s Fund endeavoured to establish if the competitive element between providers aimed at creating efficiencies and enhancing quality had been achieved. The results indicated a variety of purchaser models primarily working to retain and enhance their reputations rather than being in significant competition for new patients. Providers complained about GPs ‘giving little attention to quality’ and GPs complained about the actual structures and processes in place such as the electronic appointment booking facility ‘Choose and Book’.\textsuperscript{123} The study identified that GPs were enabling the patient to choose a provider should a referral be deemed routine, yet were ‘more directive’ in the event of feeling that more specialist services were needed. How this might now change will be interesting.

In England for both the patient and the doctor there are two parallel streams of activity utilising choice language. There is a need to navigate a legal system that more or less endorses negative patient choice and a policy and practice that says a lot about where and when a person can be treated. Yet despite recent and enhanced choice rhetoric it does not in reality permit the patient to demand treatment or necessarily improve accessibility to care.\textsuperscript{124} It is not clear from the Health Bill or its proposed revisions how, if at all, equitable access will be seriously considered. Is ‘choice of treatment’ an extrinsic economic tool that perhaps fortuitously (for health policy) appeals to the intrinsic values of the patient.

\begin{flushright}
\textsuperscript{124} Given the release in July 2010 of \textit{Equity and excellence: Liberating the NHS}, n. 11 above, it remains to be seen how devolving ‘power and responsibility... to GPs and their practice teams working in consortia’ in a primary care commissioning format will influence the concept of patient choice.
\end{flushright}
6.7 Choice: Practitioner Perspectives and the General Medical Council (GMC)

If Mr Burke or any other patient with a positive treatment choice feels let down by the legal system, health policy or both, it leaves the doctor facing that patient demand and acting as a linchpin when the two streams converge. From the perspective of the medical practitioner in the front line for the delivery of NHS care and its choice policies, and mindful of the English legal expectations, they may look to their regulatory body, the GMC, for guidance on managing this era of patient choice, the mismatch of patient expectations and the reality of law and policy. Linking back to the doctor’s duty to impart information, Miola indicates that the recent GMC guidance expects the doctor ‘to communicate with the patient rather than just list the risks inherent in the treatment’. In this context communication does not just mean listing the choices on offer and risks attached, but engaging in a much more holistic manner in the patient’s ideas, concerns and expectations as well as the practicalities of clinical management. This must include dealing with patient demand for treatment, now potentially perceived as not just a choice but their right.

The decision in *Burke*, encapsulated in best interests, was not restricted to just Mr Burke himself, but the wider concept of the doctor-patient relationship where patients are deemed unable to demand treatment that doctors feel is not in (any) patients’ interests. Patients need to be made aware that there may be treatments that the doctor does not believe will be effective despite the patients’ own desires. And patients will need to be aware of treatments that the doctor thinks will be effective but are not or no longer available via the NHS.

The GMC guidance following *Burke* is very specific about managing a patient’s positive choice or demand:

Doctors are under no legal or ethical obligation to agree to a patient’s request for treatment if they consider the treatment is not in the patient’s best interests.

It is less clear whether the doctor has to be open about the reasons for turning a request a down when the argument remains in the realms of ‘best interests’. GMC guidelines also remain less

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than specific on advising patients about the treatment options that may be in their interests but are not accessible to them, including those not obtainable via the NHS. Furthermore they may need to be reviewed and changed in the light of current health reforms. For example, in the context of the White Paper proposals patient A should be able to choose between treatments offered by any consultant led team (or similar) that their doctor believes will be effective. These may be provided via the NHS (e.g., a Foundation Hospital Trust) or by private health care companies with whom the patient’s consortium has an NHS contract. That sounds equitable. However, what if the patient’s commissioning body has decided against a contract with the organisation that offers the chosen service for whatever reason? Further, there may be situations as already demonstrated in contracts with the private sector in recent years, where provider companies have been able to ‘cherry pick’ the patients to whom they are prepared to offer treatment. Patient A chooses the treatment; his GP endorses his choice but the chosen provider turns him down. A fit patient may be seen for a routine hip replacement but is it possible that another individual who happens to be elderly and immobile and diabetic may be excluded from the contract terms, not just for reasons of clinical risk management but also to contain the risks of costly follow up?

Does GMC guidance assist the doctor in knowing how far he must inform individuals of what treatments they cannot choose, or in considering how to manage the case of an individual for whom a listed choice is not accessible, for reasons of health, distance, personal finance or public resourcing perhaps? If not this would support the potential scenario described by Maclean earlier, that is, the possibility of withholding information from patients when options are not available, or accessible.

GMC guidance does develop a model of patient centred care that seems to overtake anything that English case law has developed. Miola allies the GMC guidance more to an antipodean model, specifically the New Zealand Code of Health and Disability Consumers’ Rights (1996) in that patient-doctor discussion needs to include ‘unsolicited’ information. In practical terms there is a question about how applicable such guidance can ever be, in a resource limited service such as the

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131 See also GMC, Treatment and care towards the end of life n. 78 above. Detailed professional guidance on the complex issues that arise at the end of life/near end of life (including resource constraints) that also emphasises involvement of the patient, their partners/family/carers and the health care team in decision-making.
132 Miola J., n. 126 above, 106.
NHS, although the same GMC document is specific about giving patients time to reflect on treatment information\textsuperscript{133} and obliges practitioners to raise concerns with their own employers/contractors should that time be restricted.\textsuperscript{134} This raises a further question for the practitioner-patient relationship. Are there genuinely the resources available to facilitate a patient-doctor alliance in the way recommended, such that the individual can genuinely state and make their choice? Concurrently and not yet codified, as part of the guidance on ‘a relationship based on openness, trust and good communication’\textsuperscript{135}, the doctor should, I argue, be able to advise or refer on for advice about the potential methods by which a patient can challenge decisions that decline their ‘choice’ of treatment. This would need to include challenging decisions at local consortia level through to the more complex challenges of process as in judicial review.

The White Paper supporting document \textit{Liberating the NHS: An Information Revolution}\textsuperscript{136} is concerned with the structure of health care information strategies and the outcomes from the use and dissemination of the resulting data. It is sketchy on the process element that includes engaging the patient with the practitioner and vice-versa. The following statement does hint towards a shift in the language away from ‘choice’:

A genuine dialogue in which each brings an important perspective to bear: the health care professional brings knowledge about conditions and treatment \textit{options}; the patient or service user brings individual needs, protected rights and values, \textit{preferences} and personal circumstances. [My emphases].\textsuperscript{137}

In context it is expected that many of these interactions will be via remote internet based methods as well as with face-to-face conversations. The implications for patients, not all of whom will be comfortable or able with newer technologies, and for the GMC with its self-stated role of ‘Regulating doctors Ensuring good medical practice’,\textsuperscript{138} have yet to be determined. The GMC response to the White Paper proposals has so far been limited.\textsuperscript{139} This is largely because the GMC reports that its existing guidelines are able to cover the challenges posed by the reforms and are 'strongly aligned

\textsuperscript{134} Ibid., p. 25.
\textsuperscript{135} Ibid., p. 7.
\textsuperscript{137} Ibid., p. 22.
\textsuperscript{138} GMC publications carry this phrase as a tagline.
over matters of the doctor-patient relationship.’ The consequences intended or otherwise for patients of GP-led consortia and for commissioning itself will become clear if the White Paper proposals are implemented and given time to operate. It seems likely that given the so called information revolution, the meshing of the private and public health care sectors, and complex contracting arrangements that still have to afford choice, the GMC may need to develop and expand its guidance further to encompass the specifics of availability and access.

Using a word like ‘choice’ in health care law and health policy/practice might imply that there is a gold-standard (a best part) to be achieved. Just as there are now (many) models of the optimal patient-doctor consultation\textsuperscript{140} so too are there models of consent to medical treatment.\textsuperscript{141} The reality may be different. The ability of professionals to communicate with the patients in an extensive enough manner to permit an informed choice may well be restricted by the administrative constraints of the choice agenda, the choices may not be available or accessible; that is, not choices at all. This leaves the good practitioner frustrated and the under-performing practitioner potentially shielded behind a method that allows them to state that they have followed the role expected of them by policy. In which case is it ever a choice or merely an expression of preference?

From the policy and practice perspective choice as a term might be abandoned as it becomes a construct fraught with confusing messages. Instead, illustrating what treatment options are really available and, importantly, accessible (by whom and by what method) is more genuine. Further, there needs to be a detailing of why particular options are on offer or otherwise. The result would be that the patient is in more of a position to express realistic treatment preferences. This is a semantic argument perhaps, but these are important semantics if transparency is to be recognised as part of the engagement process that should take place between patient, provider and practitioner.

6.8 Choice: Conclusions

Two systems, of health care law, and policy with practice in health care, can be seen to operate in parallel at the present time. The law has established a boundary at which negative patient choice

is usually safeguarded, if open to interpretation in the context of contested capacity, *and* has resisted an opportunity to enhance decision making that would encompass positive choice or demand. Further disputes on this facet of the law may yet arise but for now a limited and limiting form of choice prevails in law.

The NHS in England is delivering a limited and limiting form of health care, under the guise of patient choice, focusing on where and when care is delivered. The choices offered can impact on the lives of almost all by being part of a modernisation and rationalisation policy in the NHS. The problem centres not on the need to promote the shape and function of the health service, but rather to ensure that the boundaries to any treatment on offer that are necessarily in place are clear and transparent to the user. Without such transparency and despite the clarity at law that now exists, further legal challenges to health services and care seem inevitable.

There must be a tension in any system where the choice that you can have is only the choice that that system or your particular GP can offer, and is not necessarily that which is available. It is a concept that is neither unfettered nor determinative and how those preferences are enabled, or otherwise, remains a function of the health care professional and/or the courts, risking being rhetorical. Further, if the choice on offer is available but not accessible, is it choice at all? I believe that it is this element that is unclear to the modern patient who is encouraged even by the NHS Constitution to behave as a consumer.142

Engagement is a popular term in health care,143 engagement between patients, practitioners and policy-makers; a therapeutic alliance.144 Any engagement process must stretch beyond just materiality of risk. To facilitate this, ambiguities in language need to be reduced and choice as a

142 See also *High Quality Care For All*, NHS Next Stage Review Final Report CM 7432, n. 10 above, Section 2, para. 8, p. 26.
term should be abandoned. Terms such as ‘treatment options available’ and the acknowledgement of patient preferences set a clear line on the interactions that take place in health care, without encouraging any perceived guarantees that an individual’s choice can be met. This is more than mere semantics. A greater transparency in both policy and practice is required within a process that ensures accessibility to both information and available treatments. This would go a long way to dispel any illusion of unlimited and unfettered choice in favour of reasonable options.

6.9 Acknowledgements

I am grateful to Professor Margot Brazier, Dr José Miola, Dr Anne-Maree Farrell, Dr Rebecca Bennett and Dr John Coggon for their comments and thoughts on drafts of this paper. Also, grateful thanks to two anonymous reviewers for their helpful commentaries. All errors remain my responsibility.
7.0 Chapter 7 - Paper 2 - The Decline of Medical Confidentiality
Medical Information Management: The Illusion of Patient Choice

You have the right to privacy and to confidentiality and to expect the NHS to keep your confidential information safe and secure\(^1\) (NHS Constitution, 2013)

7.1 Abstract

It is reasonable to consider and trust that information taken from us about our medical health and history will be protected by rules on confidentiality and consent. Apart from very rare cases, perhaps of major public interest or for public health reasons, this information will not be shared with others without our consent. However both a number of reforms in National Health Service patient data management policy (now enshrined in legislation) and developments in the general law on privacy challenge this traditional view of our control and choice over our medical information, as this article will show. In doing so it analyses the question as to whether in spite of the rhetoric do any of us now really have choice over the access to and use of our medical data? In reality our choices are limited and in any relationship of trust and shared decision-making this ought to be transparent.

7.2 Keywords

Choice, confidentiality, privacy, trust, health care law, human rights, fiduciary, shared decision-making

7.3 Introduction

Recent National Health Service (NHS) operational reforms in England and the data management systems that underpin them continue the patient choice theme so promoted in the White Paper *Liberating the NHS*\(^2\), summarised by the mantra ‘no decision about me without me’\(^3\) and subsequently incorporated into legislation in the NHS Constitution above and the Health and Social Care Act, 2012 (HSCA, 2012).\(^4\) Most people have a sense of what is meant by medical confidentiality. In line with this, at first glance, many patients might be of the belief that no information about them would be shared with others save with their own consent or individually justified by a major public interest concern, for example that a patient posed a risk of harm to others. Some readers might then be surprised and unhappy to learn that data about them and sometimes data identifying them may now be subject to data extraction. That is to say NHS organisations and private companies are able to access his medical information. What can be called a ‘traditional’ idea of medical confidentiality has been altered and now confidentiality and patient choices associated with it are limited.

Rather late in the day, a furore\(^5\)\(^6\) has emerged over two related data extraction systems that are being based in general medical practice.\(^7\)\(^8\) They are intended to take a combination of health care activity information and personal confidential medical information with the intention of ‘supporting—my addition—a diverse range of services and initiatives that aim to improve the diagnosis, treatment

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3 Ibid., p. 3.
4 Health and Social Care Act, 2012, Ch. 7.
5 Typical of many of the coalition Government’s health reforms, it has taken time for a groundswell of opinion to form and raise concerns, in this instance about the unconsented sharing of patient information that could be considered confidential. A loose collaborative of the British Medical Association (BMA), the Royal College of General Practitioners (RCGPs), privacy campaigners such as medConfidential became vociferous in their critiques of the NHS England information policy. The latter organisation describing the history of same as ‘hellishly convoluted’.
http://medconfidential.org/2014/section-251-to-be-amended/
6 I have shamelessly used the word from the following, Torjeson, I., ‘Furore over data could jeopardise research’, *BMJ* 2014; 348:g1761.
7 See [http://www.ic.nhs.uk/gpes](http://www.ic.nhs.uk/gpes) ‘and [http://www.hscic.gov.uk/gpes](http://www.hscic.gov.uk/gpes) ‘GPES is a centrally managed primary care data extraction service that extracts information from GP IT systems for a range of purposes [my italics] at a national level.’
8 See [www.england.nhs.uk/caredata](http://www.england.nhs.uk/caredata) ‘The care.data dataset includes confidential medical information such as NHS numbers, dates of birth, postcodes along with prescription details and physiological indices. Data extracted along this pathway can be linked to personal confidential data from elsewhere such as hospital and social care environments.”
and prevention of illness\textsuperscript{9}, as well as facilitating payments to practitioners and service commissioning organisations.

The General Practice Extraction System (GPES) is already in operation and its more controversial element, care.data [sic] has been piloted by general medical practice; the service highlighted in this paper.\textsuperscript{10} At the time of writing there has been a six month delay imposed on the implementation of the latter; a so called ‘public awareness’ period. Concerns have arisen over the potential for identification of individuals as well as the potential for the selling of personal information to third (non-NHS) parties.\textsuperscript{11} In addition the manner in which patients are being advised about these systems and their options concerning opting out have provoked further debate as will be shown. The policy and practice rhetoric however is to afford the patient a choice over their own data.

This controversial episode hides the reality of existing case law and statute relating to individual patient confidentiality and privacy, and the reality inherent in running a communitarian NHS. I argue that case law and legislation as well as health care policy provide gateways to data access often disguised by talk of a right to patient choice and the right to privacy. The relationship of trust and confidence between patient and doctor, in this instance General Practitioners (GPs), has facilitated the discussion and protection of sensitive and personal issues within a ‘safe’ place. Case law appears at first glance to protect this but as a result of the 2001 decision in \textit{R v Department of Health ex p. Source Informatics Ltd.},\textsuperscript{12} that ‘safe place’ began to be undermined. At the same time and perhaps controversially I would contend that the fiduciary nature of the patient-GP interaction relating to confidentiality has become eroded as changes in health care policy and practice have been implemented, becoming less fiduciary\textsuperscript{13} and more technical in nature. It is tempting to assume that confidentiality is complementary to privacy and as such rights to privacy prevail. Certainly of late judges have talked more of privacy, albeit where there is no

\textsuperscript{9} See \url{http://www.hscic.gov.uk/article/2226/GPES-overview}
\textsuperscript{10} These datasets are managed by the Health and Social Care Information Centre (HSCIC) whose establishment role and duties (and potential conflicts) are well described elsewhere. See Grace, J., Taylor M.J., ‘Disclosure of Confidential Patient Information And The Duty To Consult: The Role Of The Health And Social Care Information Centre’, \textit{Medical Law Review}, 2013, advance access 0, 1-33.
\textsuperscript{12} \textit{R v Department of Health, ex parte Source Informatics} [1999] 52 BMLR 65, CA.
\textsuperscript{13} See \textit{Montgomery v Lanarkshire Health Board (Scotland)} [2015] UKSC 11 [75-76]. [75] Their Lordships (Lord Kerr and Lord Reed) stated ‘...patients ...are widely treated as consumers exercising choice....a wider range of health care professionals [other than doctors – my addition] now provide treatment...The treatment which they can offer is now understood to depend not only upon their clinical judgment but upon... such matters as resource allocation, cost-containment and....administration: decisions that are taken by non-medical professionals.’
classic relationship of confidence. However the defences provided for by Articles 8(2) and 10 of the European Convention on Human Rights (ECHR), enable further statutory intrusions to take place beyond those already enacted via Schedule 3 of the Data Protection Act 1998, Section 251 of the 2006 National Health Service Act, Section 9 of the Health and Social Care Act, 2012 (HSCA) and now the ‘deficient amendments’\textsuperscript{14} to the HSCA via the 2014 Care Act.

The core funding of the NHS is rarely discussed in the same forum as individual patient data management. The key however is that this tax funded service is available for individual members of the public to use. Is it reasonable therefore to expect (our) patient data to be accessed and utilised to the benefit of that NHS; be that as a way of optimising efficiency or improving patient management? Data sharing (our) individual patient information throughout the NHS and beyond to its supply sectors such as the pharmaceutical industry might well be seen as a reasonable trade off in terms of utility and also a necessary reality in a resource limited environment, despite the veiled rhetoric of patient choice. The key is less about the access use of such data but its potential for misuse. Current and proposed regulations\textsuperscript{15} do not easily address the risks inherent in what are already large\textsuperscript{16} and will become enormous publicly held databases.

The first part of this article undertakes an analysis of the concept of individual medical confidentiality that is apparently well underpinned by existing case law and statute. In reality, however, it is far removed from this. Then, having looked at how confidentiality is branded within primary care in particular, the second part of the article considers whether the traditional fiduciary (Patient–GP) relationship in this regard is anachronistic. I consider that efficient and rational data access and management of individual health data are an imperative when utilising a resource limited NHS. Further as established case law and statute over-rides traditional concepts of the doctor keeping our secrets safe from others, what is required is an open discussion about the rationale for data

\textsuperscript{14} Pollock A., Roderick, P., Booth, P., \textit{Parliamentary control over the Health and Social Care Information Centre Proposed amendment to the Care Bill and Briefing Note} Centre for Primary Care and Public Health, Queen Mary University of London and medConfidential. (March, 2014) 3-4.

\textsuperscript{15} After the submission of this article for publication (Nov 2014) in February 2015, The Nuffield Council for Bioethics published a comprehensive detailed analysis of the ethical issues associated with data management in health care and biomedical research. This put forward a number of ‘recommendations and precepts’ on the topic. See Nuffield Council for Bioethics ‘The collection, linking and use of data in biomedical research and health care: ethical issues’, (London: Nuffield Council, 2015) 198pp.

\textsuperscript{16} For some twenty years there has been the clinical patient research data link (CPRD), until recently called the general practice research database. This encompasses in the order of 5 million longitudinal records at first obtained from general practice and now including hospital records. As well as being used for NHS purposes, the data once ‘anonymised’ (names, dates of birth and postcodes removed) has long been sold on to the pharmaceutical industry.
sharing and management; not a faux strategy of offering patients choice, when beyond a certain practical level there is none. The relationship should now be one of trust but not guaranteed confidence. Patients benefitting from the NHS should accept responsible information sharing; a more technical yet truth based relationship.

7.4 Perception and Protection in Information Management

7.4.1 Problems of Interpretation

Information management health policy literature is liberal with its use of terms like confidentiality, privacy and choice. The NHS Constitution is a prime example as is the forward in the Government’s response to Dame Fiona Caldicott’s information governance review (to be called Caldicott II throughout) that contains statements such as:

…it is vital that we respect people’s privacy and put them more in control of how their information is used.19

As well as:

…health and care organisations should do more to increase people’s understanding of how their personal confidential data is used and the choices they can make…20 21

What is less clear is the interpretation of such terms and as such their consequences.

McHale drew a distinction between confidentiality and privacy as far back as 1993:

17 DoH, n. 1 above.
18 Caldicott, F., et. al., Information to share or not to share The Information Governance Review, (London: Department of Health [DoH], March 2013) 142pp.
20 Ibid., p. 22.
Having identified a number of definitions of confidentiality, privacy and security, Cambridge Health Informatics opted to treat confidentiality and privacy as synonymous, ‘since authors may not have made consistent distinctions between the terms’.
An obligation of confidence arises in a situation in which one person gives information to another expecting that person to keep that information ‘confidential’ by not disclosing it to third parties. The person who imparts the information binds the recipient by an obligation of confidentiality. Issues of privacy however may arise whether or not we regard the information as ‘confidential’. The right to privacy relates to the right of the individual to control access to his own personal information and this does not simply cover information which he has passed to others expressly or impliedly expecting them to keep it in confidence. It applies to all personal information.\textsuperscript{22}

On reflection, this statement is prescient. Much of a patient’s medical information is no longer just shared with one other person, a health care practitioner. Computerisation and data distribution means that data can be shared with other IT systems and distant third parties. Arguably therefore the existing law on matters relating to an individual’s medical confidentiality will no longer be enough as the obligation of confidence is subsumed into matters of privacy, and medical privacy becomes ever more qualified by common law and statutory exceptions.

\textbf{7.4.2 Confidentiality – Traditional Legal Analysis}

In the early years of the NHS care was largely carried out in the individual’s locality, letters between practitioners written like personal conversations. Doctors had no need to provide data about the activities they were undertaking in order to be remunerated. Change came in the late 1980s and more rapidly with the 1989/90 GP contract that saw a rapid expansion in the computerisation of patient notes and the beginnings of the downloading of computerised information to more distant sites, for payment and audit purposes. It was not just the NHS that could access such information. Interrogative systems were developed that could batch download, often overnight, apparently anonymised patient data for use by commercial (usually pharmaceutical) companies. With some systems the practitioners were remunerated for those downloads.\textsuperscript{23}

Nonetheless, there remained something familiar, comfortable and unique about the relationship between patient and ‘his’ NHS GP. Despite recent changes involving ‘choice’ of GP surgery,\textsuperscript{24} the process of patient registration prevents the individual from moving from practice to practice

\begin{itemize}
\item \textsuperscript{22} McHale, J., \textit{Medical Confidentiality and Legal Privilege}, (London: Routledge, 1993) p. 56.
\item \textsuperscript{24} www.nhs.uk/NHSEngland/AboutNHSServices/doctors/Pages/patient-choice-GP-practices.aspx Patient Choice of GP Practice, 2014.
\end{itemize}
repeatedly and for now anyway being registered at more than one practice at any one time.25 Patient held records may be a thing of the future but for now these (electronic or otherwise) are held in the practice and only follow the patient in a manual form upon registration elsewhere. The result, along with an element of inertia perhaps, has until recently been a longstanding relationship between the patient and their GP. Now, this relationship has been ‘diluted’ with patients seeing GPs they may not know because the doctors have a specialist interest in a particular condition, or similarly practitioners working at sites distant to the GP practice and commissioned to provide elements of primary care.

The much vaunted patient choice agenda and the choice rhetoric that underpins the 2012 Health and Social Care Act have not altered the fact that the relationship between patient and GP is an unusual and unbalanced dynamic. Having your ‘own’ primary care physician is very much a product of the British NHS and not replicated worldwide to any significant degree. As patients, we expect to divulge personal, sensitive and often intimate information in this relationship based on trust, fiduciary if you will,26 to an unbiased, judgement neutral empathetic practitioner who holds much of the power in the interaction. In turn, the GP safeguards that information from external third part access and interference in the absence of the express permission of the patient to do otherwise. This seems fundamental in respecting individuals and their capacity as autonomous decision and choice makers, if at odds with the data downloading alluded to above, a practice unknown to most patients.27

This confidentiality is intrinsic to the doctor–patient relationship28 and arguably has been so since Hippocratic talk of secrecy.29 The 18th and 19th centuries saw the advent of a common law making reference to an obligation of confidence and to the restriction of information dissemination.30 That said it is only in the latter part of the 20th century that some form of codification of the principles of medical confidentiality has taken place and duly evolved. Prior to this, medical consultations were minimally documented, if at all, and any relevant paperwork remained in the possession of the

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25 Plans to enable dual registration at more than one GP practice have been shelved for the present, after professional protestations. 

26 Without reference to legal interpretations at this point in the article.

27 n. 16 above.


practitioner, often in the immediate locality. Confidentiality was more a function of the doctor holding an elevated and powerful status within a community and being party to the ‘secrets’ therein. With time, however, patients have been acknowledged as having both expectations and concerns about their medical records, and this gained further recognition in the legal system.

There are established common law principles of confidentiality in operation and tested in a (relatively) small number of cases associated with medical confidentiality and data anonymity. It is worth focusing on the latter issue a little more given the current proposals for extensive patient information databases and the howls of related malcontent; a topic that will be returned to later in this paper. At first glance it seems almost intuitive that if one’s information lacks identifying features, that is, anonymised, then confidentiality is preserved and the equitable duty of underpinning this is maintained. This simplistic view came under scrutiny in R v Department of Health, ex parte Source Informatics. Pharmacists and GPs were paid for supplying anonymised prescription information to a data management company who in turn sold the data on to the pharmaceutical industry.

At judicial review the applicants sought to overturn DoH ‘guidance’ that information from the patient delivered in confidence cannot be disseminated without patient consent by implication anonymised or otherwise. Their argument being that anonymised information loses its confidential quality. Latham J. considered the vagaries inherent in such a claim, such as unauthorised use of information even if anonymised and the potential for ‘subtle but not overt’ harm to the patient.

In response to submissions from counsel for the respondent, Latham J., touched upon the idea that

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31 Cambridge Institute of Health, n. 21 above.
32 Coco v A N Clark (Engineers) Ltd [1969] RPC 41, p.47.
34 X v Y [1988] 2 All ER 648.
35 W v Egdell [1990] 1 All ER 835.
37 R v Department of Health, ex parte Source Informatics n. 12 above.
38 Ibid.
40 See n. 33 above. In A-G v Guardian Newspapers (no 2) Lord Keith stated ‘...as a general rule, it is in the public interest that confidences should be respected, and the encouragement of such respect may in itself constitute a sufficient ground for recognising and enforcing the obligation of confidence even when he confider can point to no specific detriment to himself.’
41 See n. 32 above. In Coco v A N Clark (Engineers) Ltd, Megarry J stated ‘...three elements are normally required if, apart from contract, a case of breach of confidence is to succeed. First, then information itself...must ‘have the necessary quality of confidence about it.’ Second, that information must have been imparted in circumstances importing an obligation of confidence. Thirdly, there must be an unauthorised use of that information to the detriment of the party communicating it.
an individual might be ‘outraged’ if made aware of the use of their data in commercial transactions, even if anonymised. It seems on reflection that Latham J., was dipping a toe in the water of individual autonomy, in this case patient choice, if nothing else than by engaging them in any debate about utilising their information. In the event, and with a decision that may resonate well in the present day, Latham J. found that there was a potentially actionable breach of confidence. Kennedy and Grubb dissected Latham J.’s decision. Notwithstanding references to pertinent aspects of the Data Protection Act and the semantics around use and/or misuse of anonymised information, with or without patient knowledge and consent, their stance was that Latham J. had not argued effectively for ‘disclosure itself amounting to a breach of confidence’.  

Unsurprisingly perhaps Source Informatics went on to the Appeal Court. Simon Brown L.J. took almost the opposite stance to Latham J., challenging his reasoning thus:

The patient’s privacy will have been safeguarded, not invaded. The pharmacist’s [in this instance – my addition] duty of confidence will not have been breached.

And:

In my judgement…the concern of the law here is to protect the provider’s personal privacy….The patient has no proprietorial claim to the…form…or to the information which it contains….and [importantly – my addition], no right to control its use provided only and always his privacy is not put at risk…

This is an interesting statement. The patient is being told what information about themselves they cannot control or have any input to, by virtue of its anonymisation. The Court of Appeal has not been without significant critique. While agreeing with the decision overall, Kennedy and Grubb were concerned about a drift towards confidence becoming a facet of ‘privacy’ and as such:

Misunderstanding the essence of breach of confidence as going beyond unauthorised disclosure of the information so as to include other unauthorised or improper uses of the information.  

42 Kennedy, I., Grubb, A., *Medical Law*, [3rd edition] (London: Butterworths, 2000) p. 1069. In making their point Kennedy and Grubb drew an analogy ‘with an action in libel or slander.’ They equated disclosure with publication of information and as such the individual has to be identified or is identifiable to some others in the event of them having ‘particular knowledge’.

43 Ibid., p. 1072.
Conceptually this seems to mean that privacy is about information use or more likely misuse, and confidentiality hangs on disclosure or otherwise. So what in the real world? Without an NHS background the author would have been unaware of early anonymised commercial NHS IT data extractions and would have been un-nerved to discover this knowing the potential for re-identification. Sharing the facts and even the decisions over the data sale would have left one feeling valued. Yet, as a user of supermarket store cards that gather so called ‘rewards’ on itemised purchases linked to their name, the author is fully aware that analysts have the potential to access that data and make judgements accordingly. Are there any real differences? There is certainly a difference in the qualitative feel of the relationship of trust that the author feels with their GP; in comparison with the detached connections they have with the store and its analysts.  

As for Source Informatics, Miola, reviewing the case in the context of a reformulation of General Medical Council (GMC) guidelines on confidentiality, used a Human Rights Act (HRA) comparative and critical approach. Miola argued that the Source Informatics decision was ‘to be regretted’. The Court of Appeal’s decision was too simplistic in not considering the potential for wider consequences of the decision. Examples given included the patient who has ethical issues related to the pharmaceutical industry, insurance concerns related to anonymised ethnic data grouping and the ever present debate as to whether information about the self is, or ought to be, regarded as one’s own property. One could also ask now in this era of apparent patient choice if our information is not our property, then how can we have any power to choose in matters related to its access and use?

44 The author is grateful to the anonymous reviewer for suggesting this reflection on individual patient expectations in the differing scenarios.
Miola continues his critique of the judicial views in *Source Informatics* with reference decisions from the European Court of Human Rights (ECtHR). For justifiable information disclosure, the ECtHR required that HRA exceptions or necessities apply, *as well as* protections or ‘safeguards’ from data misuse to be in operation. Both have the potential to be matters of definition and interpretation by the individual and the State. The classic case involving the model Naomi Campbell, and her successful House of Lords attempt to balance (her) privacy under Article 8 of the HRA with freedom of expression as per Article 10, might have clarified matters of personal medical information and the law. As Baroness Hale stated:

> …information about a person’s health and treatment for ill health is both private and confidential. This stems not only from the confidentiality of the doctor-patient relationship but from the nature of the information itself.

This was after already saying, with reference to *Wainwright v Home Office* [2004] AC 406:

> That case indicates that our law cannot, even if it wanted to, develop a general tort of invasion of privacy.

I would contend that in reality the final decision in *Campbell* simply moved the boundaries for confidential *identifiable* information to include talk of interference and proportionality; the language of the ECtHR. After *Campbell* and despite subsequent leanings towards same, the fact remains that there is no Tort of Privacy in English law. The confidentiality arena may have been

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48 *Z v Finland* (1997) EHRR 371. At para 93 the court stated that ‘the protection of personal data, not least medical data, is of fundamental importance to a person’s enjoyment of his or her right to respect for private and family life as guaranteed by Article 8.’, and at para. 95 ‘Respecting the confidentiality of health data is a vital principle...It is crucial not only to respect the sense [bold – my addition] of privacy of a patient but also to preserve his or her confidence in the medical profession and in the health services in general.’

49 *MS v Sweden* (1997) 24 EHRR 313.

50 *Campbell v MGN Ltd* [2004] UKHL 22.

51 Ibid., at [145]

52 Ibid., at [133].

53 Ibid., With Lord Nicholls [21] talking of non-disclosure as a function of the related individual’s ‘reasonable expectation of privacy. Again, this appears to be a rather fluid concept.

54 *Douglas v Hello! Ltd* (No 3) [2006] QB 125. Lord Phillips MR at [53] indicating that in order to achieve Article 8(1) rights the Court had to ‘shoehorn’ into an action for breach of confidence a claim for misuse of private information. The ‘information’ concerned photographs of a social non-public occasion rather than medical matters.
expanded by case law to appreciate that privacy interests do exist but the laws themselves do not affirm this as a separate concept. Perhaps if such a tort did exist it would have more relevance in the use and misuse of information rather than the extraction of it in the first place. The precedents set by Source Informatics around the access to our information still stand. As for the GMC and their guidelines, in essence they defer to the laws of the land. Relatively recent attempts to widen access to an individual’s information were proposed for the Coroner’s and Justice Bill 2009 and were met with such opposition that they were dropped. The European Union (EU) too needs to be given due regard as new EU General Data Protection Regulations are imminent.

7.4.3 The Place of Statute

With English judges or Parliament yet, if ever, to develop a discrete tort of privacy relating to personal (medical) information, then it is an appealing notion to think that there is enough legislation in existence to afford the individual protection via the statutory route. For example, there is a general familiarity with there being a Data Protection Act (DPA) 1998. We often need or choose to share our personal details with banks, credit card companies, the insurance industry and, as illustrated above, commercial stores via their loyalty cards, expecting that those details are safeguarded by the recipient. Explanatory notes referring to the DPA appear reassuring; after all it is about data protection, safeguarding personal information. Few ordinary citizens really understand the complexities of the DPA. To use an old adage, the devil is in the detail (of the legislation). The DPA is complex in content and definition and well-detailed elsewhere; its essence appears protective. Medical details may be especially sensitive and not be bruited abroad. However, in Schedule 3 pertinent to our medical records as ‘sensitive, personal data,’ there is provision to access, process and hence release information without consent if:

55 GMC n. 28 above, pp. 10-11. General information is given to medical practitioners about disclosures required by statute such as those with ‘specific statutory requirements’ e.g., certain notifiable diseases, and to ‘various’ regulatory bodies including the GMC. In addition there is guidance over ‘disclosures to courts or in connection with litigation.’

56 Nathanson, V., ‘Amendments to the Coroners and Justice Bill’, BMJ 2009; 338:b895. Clause 152 would have permitted ministers ‘to remove or modify any legal barrier to data sharing.’ In the explanatory notes it reads “This could be by repealing or amending other primary legislation, changing any other rule of law (for example, the application of the common law of confidentiality to defined circumstances), or creating a new power to share information where that power is currently absent.”


…the use of the data is necessary for medical purposes (including the purposes of preventative medicine, medical diagnosis, medical research, the provision of care and **the management of health services** [bold type – my addition])…

The House of Lords (Constitution Committee) have stated that ‘the so-called ‘informational self-determinism’ inherent in the DPA is of ‘moral value’.  However this ‘self-determinism’, the person’s, the individual’s ‘choice’ remains relative and not absolute. Is the protection therefore about the ability to choose, ‘the act or power of choosing,’ rather than the ‘preferred or best part’ to opt for? Further, the ability to choose is much enhanced or restricted by the information given to the individual upon which to make that choice.

1998 also saw the enactment of the Human Rights Act (HRA) making the ECHR enforceable against public authorities and thus the NHS. This has relevance with Article 8 and protection for private life. Article 8(1) is subtly worded:

> Everyone has the right to respect for his private and family life, his home and his correspondence.

A right to respect for private life is not the same as a right to a private life; it is a rather weak right and it is not an inviolable right.

Unhappily for anyone who may feel this gives them autonomy as a self-determining choice over their medical information, privacy is (only) a relative right, not an absolute concept as the GMC also point out in their guidance on confidentiality.

Article 8(2) provides:

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There shall be no interference by a public authority with the exercise of this right except such as in accordance with the law and is necessary...in the interests of national security, public safety or the economic well-being of the country [bold type – my addition]....

Matters of confidentiality and national security\(^{63}\) and public safety\(^{64}\) have been debated in the English courts. Information and health economics has received less attention. It is hard to dispute that those who use the (tax-funded) NHS ought to contribute to its efficient and rational functioning. This means a willingness to devolve enough personal ‘private’ information in order to facilitate the economic governance of the NHS. In addition to research and outcomes data, controversially this would include enough information to make for efficient resource management. After all, the NHS is expected to make £20 billion of savings in the four-year period to 2015.\(^{65}\) ‘The economic well-being of the country’ must include the monolith that is the NHS. Might the European Court ruling in *Osman v United Kingdom*\(^{66}\) fill a gap in the context of data and medical law? With the Court declaring, (with reference to Article 2)\(^{67}\) that, positive obligations:

must be interpreted in a way that does not impose an impossible or disproportionate burden on the authorities.\(^{68}\)\(^{69}\)

The context of this in *Osman* was around ‘policing of modern societies’ and this could well be substituted with ‘the provision of state funded health care’. For patients, a polarity exists. There is a positive obligation on GPs to manage and protect the ‘wellbeing’ of the patient *including* the integrity of their data via the NHS. However there is no such obligation on the Government when acquiring and using patient information in a way that may or may not benefit the individual.

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\(^{64}\) See for example, *X v Y* [1988] 2 All ER 648.


\(^{67}\) Article 2 provides that ‘Everyone’s right to life shall be protected by law...’.

\(^{68}\) *Osman* at n. 66 above, para 116.

Maybe the patient could be reassured that the real protections lie not in the HRA but in specific (NHS) health related statute. This proves not to be so however. Take the NHS Act 2006,\(^70\) and specifically section 251(1) where:

The Secretary of State may by regulation….requiring or regulating the processing of prescribed patient information for medical purposes as he considers necessary or expedient –

a) in the **interests of improving patient care**, or

b) in the **public interest** [Bold type – my addition]

Despite any discussions about what constitutes the public interest, section 251 enables the common law duty of confidentiality to be over-ridden. Identifiable patient data can be accessed and utilised without individual consent.

The HSCA 2012 presented the ideal opportunity to clarify the legislation on data access, management and dissemination. That clarity could have extended to include the need for good data to equate with good governance as well as defining data protections. Unfortunately, it is a difficult statute to decipher in general. With respect to sections 254 to 259 involving systems and requirements for patient information management, Grace and Taylor call the Act ‘Byzantine’ in its complexity.\(^71\) They also provide as clear an analysis of the processes, procedures and new information management organisations as seems possible.\(^72\) So difficult was it for the (new) commissioning bodies like the Clinical Commissioning Groups (CCGs) and related organisations to access information for planning purposes in their early months, the Secretary of State for Health granted so called section 251 exemptions. This enabled commissioners to continue to obtain and use potentially identifiable patient data without consent out of a functional necessity. The prime data source being the Secondary Uses Service (SUS),\(^73\) a data warehouse that purports to aid ‘health care planning, commissioning, payment-by-results remunerations, improve public health and develop national policy.’

\(^70\) National Health Services Act 2006 c. 42 Patient information Section 251 Control of patient information.
\(^71\) Grace, J., Taylor, M. J., n. 10 above, 16.
\(^72\) Ibid., 15-18
Deep within sections 245 to 259 of the HSCA 2012, and despite the rafts of ‘protections’ in place that includes Government acceptance of the Caldicott II recommendations, the nub of it remains that identifiable information may be gathered when at section 254:

(2) (a)

The Secretary of State considers that the information obtained…is necessary or expedient for the Secretary of State to have…in connection with the provision of health services…..

And (2) (b)

The Secretary of State otherwise considers it to be in the interests of the health service in England. [Bold type – my addition]

It is possible that the requirements of the HSCA 2012 information management systems are complex enough to reduce any trivial demand for data. This is unlikely to apply however to those backed by organisations that see a market potential. That notwithstanding the new Care Act 2014 Section 115 sees significant amendments to the Health Service (Control of Patient Information) Regulations 2002.74 Already at Regulation 5 the Secretary of State can ‘approve’ the processing of confidential data (without consent).75 As those monitoring and commentating on the changes in information management have noted,76 amendments to both regulation 5 and regulation 6 appear to expand who can approve processing and hence devolution of confidential information to include the Health Research Authority. For confidentiality and privacy activist groups like ‘medConfidential’,77 the concerns do not stop at the semantics of dropping words like ‘patient’ and ‘confidential’ from some of the text, but raise the spectre of data ultimately being used for non-research purposes.78 The latter changes have received considerable critique from health policy academics and activists because of this potential for permitting data use/misuse at a

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74 Health Service (Control of Patient Information) Regulations 2002 (SI 2010/659).
75 See for example http://www.england.nhs.uk/wp-content/uploads/2014/ig-bull-10.pdf NHS England Who Pays? Information Governance Advice for Invoice Validation. Advises that under Regulation 5 CCGs and Commissioning Support Units (CSUs) are allowed to process Confidential Personal Data (CPD) for the purposes of invoice validation.
77 medConfidential describes itself as ‘an independent, non-partisan organisation working with patients and medics, service users and care professionals, drawing advice from a network of experts in the fields of health informatics, computer security, law/ethics and privacy.’ http://www.medconfidential.org/about/
78 See http://medconfidential.org/2014/section-251-to-be-amended/
commercial level. The same policy commentators put forward their own proposed amendments that address their concerns; the Government has yet to respond at the time of writing.79

So, it appears that neither case law nor legislation can be wholly relied upon to protect our patient information and identity. This leaves the relationship that exists between a patient and their doctor acting as perhaps the ultimate safeguard against unconsented and potentially identifiable information access, its disclosure and hence further management and manipulation. The ‘old’ form of confidentiality if you will. Bartlett described a number of core values for a fiduciary, which include:80

Fiduciaries must avoid conflicts of interest, or indeed possible conflicts of interest…

Fiduciaries must not profit from their position without prior disclosure to and authorisation from the vulnerable party.

The fiduciary owes a duty of undivided loyalty…[and – my addition] of confidentiality.

On the latter point this may well have been the case in near distant times; not so now however I would argue when it comes to information management. Therein remains the issue of trust; that of the patient in their GP. This would be consistent with the relationship being ethically fiduciary if not agreed as such in the English legal system.

7.4.4 Paternalistic ‘Friend’, Fiduciary but, now Technician?

Post inception of the NHS the model was of the GP being a (vulnerable?) individual’s ‘friend’, paternalistic and holding the balance of power over access to health information and treatment; confidentiality like medical practice was secured at a local level. This relationship has changed

over time as all relationships do. There was increasing interest in and debate about the ethics of medical practice.\(^{81}\) With continuing changes in GP training to improve communication skills,\(^{82}\) and despite legal debate,\(^{83}\) this evolved into something more fiduciary in nature; a relationship of trust and confidence that might maximise the autonomy of the patient while acknowledging that to the latter there were limits\(^{84}\) \(^{85}\) and I would add, the on-going power imbalance. Perhaps some would say this is still the nature of today’s GP-patient interaction.

However, with the rapid changes in health policy and subsequent practice demonstrated par exemplar via the HSCA and the rapid reforms that went before, many GPs are no longer able to practise in a way that develops individual relationships with patients and their families.\(^{86}\) Much of the work (and remuneration) is target driven and with the era of GP-led Clinical Commissioning and that remit to save in the order of £20 billion by 2015, other imperatives influence the interaction between doctor and patient. The GP has become adept at managing the detail of medical practice as illustrated by the pursuit of Quality and Outcomes Framework (QOF) targets,\(^{87}\) perhaps at the expense of time to engage with the patient as an individual. General practice has therefore become a technical speciality and the GP the technician. This is a change that had been foreseen, was not always welcomed and now it might take a brave GP to admit it. Those who find recent reforms too difficult will leave the profession early and there is evidence to suggest that this is the case.\(^{88}\) There is a massive tension to be had in serving the individual and the wider public (NHS), and earning a living.


\(^{82}\) Royal College of General Practitioners Curriculum 2010 revised August 2013 Statement 2.01 The GP Consultation in Practice.

\(^{83}\) Bartlett, P., n. 80 above, 193-224.


\(^{87}\) Gillam, S., Steel, N., ‘QOF points: valuable to whom?’, \textit{British Medical Journal} \textbf{346} 2013 21-23.

It has already been shown that a combination of case law and statute actually enable access to information and arguably it should if needed to facilitate the NHS. Whether or not GPs agree with enhanced data access, and as has been shown there has been much policy debate on the topic as well as individual commentary,\textsuperscript{89, 90} it has been happening and will be expanded at some future date. Paradoxically this acquisition of additional information may actually sit well with the ‘traditional’ gatekeeping role of the GP apropos access to and an efficiently run NHS. It sits less well with having a relationship of trust and confidence between patient and doctor. The GP retains the ultimate duty of confidence within the practice. That is acknowledged by staff as part of their employment terms and applies to accessing sensitive data (often about people with whom they may be familiar), and by the patient in their expectations of the relationship. This is very different from the distant and anonymised access of, for example, databases serving the pharmaceutical industry. It is unclear as yet as to whether patients regard this distant access of data and its potential for use/misuse with any real suspicion. Are we as patients aware or concerned that the level of data acquired might lead the unscrupulous to identify us? Will patients really choose non-disclosure of serious health concerns and issues, as the courts have already speculated?\textsuperscript{91}

From a technical viewpoint, all a GP has to do is undertake some way of making patients aware of the data extraction methods and advise them of any ‘opt-out’ procedures. This is rarely being done in person, rather, by posters in waiting areas, messages on prescription sheets and a national leaflet drop supposedly to all households.\textsuperscript{92} What is less clear is that GPs whilst they can opt-out of GPES, they will not be remunerated for QOF work as this is processed through GPES; an unlikely scenario therefore.

Some GPs have already expressed moral objections to being an instrument of personal information access; a conscientious objection (CO).\textsuperscript{93} Perhaps they might consider that the CO terms (Clause

\textsuperscript{89} Harris, S., ‘Data confusion’, personal correspondence \textit{BMA News} 9 November 2013.

\textsuperscript{90} Patel, K., ‘Whose data are they anyway?, \textit{BMJ} 2012;\textbf{344}e2135.

\textsuperscript{91} \textit{X v Y n. 34 above, Rose, J.}, at 653 ‘In the long run, preservation of confidentiality is the only way of securing public health; ...individual patients will not come forward if doctors are going squeal on them.’

\textsuperscript{92} NHS ‘Better information means better care’ (NHS, 2014). See also \texttt{www.nhs.uk/caredat} and \texttt{www.hscic.gov.uk/patientconf}

4) of the 1967 Abortion Act ought also to translate across to confidential information management?94

At present, trust in doctors remains high95 despite well profiled scandals such as that in Mid Staffordshire NHS Trust96 and less recently involving hospitals in Alder Hey, Liverpool and Bristol.97 However some within the profession are warning that this almost inherent trust ‘could sink as low as bankers’.98 Certainly, patients might feel that in devolving their information elsewhere doctors, in this instance GPs, are to be mistrusted and the old concerns about patients withholding critical information in fear of its distribution become pertinent once again. O’Neill gives fair warning:

Mistrust could mushroom within states that do not create well-constructed and toughly enforced data protection systems…prevent unconsented-to access and use…Even where regulation is good, mistrust may grow if systems are opaque…99

GPs cannot opt out of the care.data process and have no involvement with what happens to the information next. Patients can ‘choose’ to opt out of care.data but, as has been shown, demands for access to data can still be made under case law and statute; a fallacious choice. As for enabling patients to make that choice, it has already been established in case law that patients are entitled not only to information about medical procedures but also to have adequate time to consider their ‘options’ prior to consenting.100 Surely out of respect for maximising autonomy in a situation where this is and may well ought to be limited, the same principles might apply. The dissemination of the facts around modern NHS data sharing ought not to be left to notes and leaflets

94 Abortion Act 1967 Clause 4 (1)...no person shall be under any duty, whether by contract, or by statutory or other legal requirement, to participate in any treatment ...to which he has a conscientious objection: [...] As applied by the Courts currently the new data handling requirements are hardly likely to constitute treatment participation. See Regina v. Salford Area Health Authority (respondent) ex parte Janaway [1988] 2WLR 442; HA [1988] 3 All ER 1079 249. A moot point perhaps?
98 Smyth, C., ‘Doctors “could sink as low as bankers”’ The Times, 3 September 2013, quoting Professor Ben Bridgewater, Consultant cardio-thoracic surgeon.
which may not be received or read through choice or due to disability. As McCartney points out the national leaflet was ‘heavy on assumed benefits… but light on potential harms’.\textsuperscript{101} The technician, however, is unlikely to have the resources to enable detailed first hand explanations and as GPs they are unlikely to have the time. What is even less well explained is what will happen to (our) information once it comes into the possession of third parties via the NHS and linked by virtue of patient care, research or market partnership and risks therein.

7.5 Concluding Remarks

This paper seeks to identify the reality or otherwise of our choice as patients over the access to and use of our medical information given the rhetoric of choice in health policy and the drift towards privacy in law. Choices, if that is what they are, are increasingly limited. Rather than necessarily being a ‘bad’ development in the efficient provision of NHS care, what is lacking is transparency of activity in the management of our data.

As individuals, we seem of two minds. We are more than happy to share and share again personal, confidential, private you might consider, data with regard to finances along with commentary and information on what are sometimes our very personal activities; Facebook™, Twitter™, and Instagram™ are prime examples.

The ‘genie is out of the bottle’; our medical information has been on the move for some time. It is only now when the data sets are being expanded, it has become a requirement for the medical profession to co-operate and there is a more latterly developing public awareness that objections have arisen. It is the patient’s prerogative to expect judicious use of their data but more contentiously it is not their prerogative to opt out of its use completely if they are engaged with a tax-funded organisation such as the NHS.

What can be considered is that the ‘old’ relationship between doctor and patient under a relationship of confidence and trust probably sufficed at a local level to keep our medical conditions and disclosures protected. This is now the stuff that harks back to the era of old television.

\textsuperscript{101} McCartney, M., ‘Care.data doesn’t care enough about consent’, \textit{BMJ} 2014;\textbf{348}:g2831.
programmes and writings from the early days of general practice. It did, however, afford protections that are no longer available as a result of Article 8(2) of the HRA, the decision in [Source Informatics] and the inception of the HSCA in 2013. It is the [Source Informatics] position that still holds, despite any debate over anonymisation, pseudo-anonymisation and the risks therein. If it is ‘anonymised’ it is available. Why do some protest so much? Privacy is an overblown concept and confidentiality is already so diluted by our own actions let alone in law.

The issue of individual’s specific consent to the access, sharing and use of their data has had some discussion again rather late in the process. As reviewed elsewhere and in the context to treatment, it is a complex topic. Caldicott II emphasises ‘a data sharing model’ which engages the patient and gives them an awareness of what and how their information is used – so called dynamic model of patient consent.

McCartney says of the opt-out nature of care.data ‘...if people didn’t know they had an option, how could they exert the choice?’ The fact of the matter is that in reality there is no choice. Macfarlane and Pollock propose the concept of the patient opting in to care.data and related systems. At least this requires more actively engaging in the start of the process that utilises our information and has a much greater feel of respect for the person despite the fact that either can be over-ridden by case law and Statute. The patient does not really have a choice and it is disingenuous to say they have. At best they can express their preferences over their data. Trust requires transparency and shared decision making; and shared decision making makes for better information sharing. Without, there must be an enhanced possibility of a challenge to care.data, related information systems and the practitioners that use them in the European Courts under Article 8(1).

105 Caldicott II, n. 18 above, Section 5, para., 5.5 p. 57-58.
107 McCartney, M., n. 101 above.
7.6 Acknowledgements

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7.7 Author Biography

The author is a PhD student in the Centre for Social Ethics and Policy in the Department of Law at the University of Manchester, United Kingdom; formerly a general medical practitioner (GP) and medical educator in England, with a clinical career curtailed by the development of Multiple Sclerosis. A longstanding interest in the world of Bioethics and Medical Law led the author to undertake a Masters’ programme in 2003/04. The author has a particular interest in the uses and misuses of personal medical information, consent matters and shared decision making between practitioner and patient.

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8.0 Chapter 8 - Paper 3 - Medical Privacy: Health Professionals and Ministers

8.1 Abstract

While medical confidentiality is seen as important in modern health care there are clear and justifiable exceptions to this rule. Notably health care professionals are required to disclose health information about themselves that might endanger the welfare of others. Health care professionals privy to this information would be supported by the law in disclosing the information if this individual failed to do so. This paper considers the current approach to disclosure of medical information in the case of health care professionals and asks whether the public interest justifies a similar model of self-disclosure of health care information for others in public roles, for instance, senior government Ministers and politicians. There is abundant evidence that in this country and elsewhere details of serious illness affecting senior politicians’ ability to function has been ‘covered up’. If the rationale behind the mandatory self-disclosure of medical information is to protect others from harm then it would seem restricting this requirement to health care professionals, and doctors in particular, cannot be justified given the influence and potential disaster that could be caused by other professionals suffering from impaired performance. This paper argues that this is an issue that requires debate in order to consider a consistent approach that helps protect citizens from the possible harm caused by impairment not just from health care professionals. To this end it puts forward a template for an enhanced disclosure process applicable to politicians and senior civil servants that may be translated across other occupations. It argues that some people, by virtue of their position in society and the responsibilities that go with that, will have to accept that their choice over the protection of their information ought to be more limited than it is already is for the general public.

8.2 Keywords: Choice, Confidentiality, Disclosure, Doctors, Privacy, Politicians
8.3 Introduction

Early January 2015 found Pauline Cafferkey in a critical but stable condition in London’s Royal Free Hospital. As a nurse just returned from volunteering her skills with the Save the Children charity in an Ebola virus treatment facility in Sierra Leone, she was herself in a quarantine tent in receipt of both supportive and experimental treatments for Ebola. The detail of Ms Cafferkey’s early screening for the disease and her possible on-going ‘treatments’ became widely available in the media. It was reported that Ms Cafferkey had requested that Save the Children should not release her name. However the Royal Free did name their patient and it may be no coincidence that this was at the same time as Britain’s Prime Minister ‘sought to allay public concern…’

The disclosure of this information, apparently against the patient’s wishes, raises a number of questions. Is the public interest in such a case sufficiently compelling to trump Ms Cafferkey’s own interests? Is the fact that the patient is a health care worker relevant? Nurse William Pooley who contracted and survived Ebola and whose blood plasma has been used in the treatment of some later Ebola patients, has also been widely named, and details of his treatment placed in the public domain; it is a moot point whether his consent for disclosure was obtained. What if the patient was a diplomat serving at the British embassy in Sierra Leone or a government Minister responsible for overseas aid, and did not consent to the release of his/her name? Two related but different questions arise here. What infringements of privacy are justified by the risk that, in this instance, an Ebola patient whatever their role or occupation may pose to others? To what extent if any may certain patients’ privacy be infringed to satisfy the interest of the public and the media and to reassure the public that they are not at risk. Thus, ultimately this paper asks these questions: (1) In certain professions and occupations should the worker’s ‘right’ to confidentiality be reduced simply by virtue of the role the worker plays? (2) Should the model of mandatory self-disclosure applicable to health professionals be adopted more widely in relation to other professions and occupations?

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There is abundant literature on medical confidentiality and privacy in general.\(^4\) The particular context of confidentiality as it applies to health workers has been addressed in case law and literature.\(^5\) Much less has been written about whether the roles that some people undertake in society, for example government Ministers, pilots, senior military commanders and chief constables of the police,\(^6\) should mean that like doctors they have a much reduced entitlement to protect and control their own medical information, and an obligation to disclose information about their health if they have any reason to suspect health problems may impair their ability to do their job and puts others or society at risk? This paper addresses these questions of access to personal medical information in the light of the role and occupation of the patient, given that for the majority of us any guarantee of medical confidentiality is already limited.

NHS rhetoric around patient choice offers assurances around the access to, protection of, and use of our medical information\(^7\) regardless of who we are and what we do for a living. Medical privacy is in theory safeguarded by case law, Article 8 of the European Convention on Human Rights (ECHR) and many other statutes, and this protection is also now underpinned by the NHS Constitution.\(^8\) In reality, people will find that because of the job they do or who they are, medical privacy for them is much less well protected than for most; the legally qualified readers of this journal for example. For some people their claims of confidentiality and privacy are already diluted by virtue of existing case law, legislation and licensing requirements designed to be in the public interest and protect public safety.\(^9\) However recent (2015) tragic events involving non-disclosure by a pilot or his medical advisers and the concealment of a psychiatric condition may well have

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Mr Mike Todd was found dead in the October of 2008 having, an inquest found, ‘when his state of mind was affected by alcohol, sleeping drugs and confusion over turmoil in his private life.’ It was reported that an investigation was to take place ‘to see if it affected his ability to do his job or put national security at risk.’

\(^7\) See ‘Information: To Share or not to Share, Government Response to the Caldicott Review’ (Department of Health; London, 2013) p. 8 ‘...People will feel more in control of their personal medical information...People will know how to object if they don’t want their information to be shared...’

\(^8\) The NHS Constitution - the NHS belongs to us all, 2013. ‘You have the right to privacy and confidentiality and to expect the NHS to keep your confidential information safe and secure.’ (Department of Health, London: 2013) p. 8.

\(^9\) Note for example the requirements of the United Kingdom Civil Aviation Authority (UKCAA) with regards to obtaining a commercial pilot’s licence. See [http://www.caa.co.uk/default.aspx?catid=49&pageid=527](http://www.caa.co.uk/default.aspx?catid=49&pageid=527)
underpinned the pilot’s suicidal and calamitous actions.\textsuperscript{10} Human ‘rights’ to confidentiality and privacy are well recognised for their relative status rather than being absolute.\textsuperscript{11} In this article I look at whether the degree of dilution of confidentiality does and should depend on the public profile and role of an individual. I avoid obvious cases that might for example include the airline pilot after a debilitating stroke in favour of less manifest instances yet where de facto much medical privacy is potentially and, I argue, correctly to be sacrificed.

I will illustrate some of the issues at stake using two hypothetical yet plausible case scenarios. The first will look at the medical privacy or otherwise of health care workers, specifically doctors. This will consider the question as to whether the medical information of those in such a position of trust, authority and professional practice is and ‘ought’ to be more readily accessible to the public, some of whom will have direct involvement with that doctor. The onus may often be on others, perhaps the doctor’s doctor, to make or facilitate disclosure as the primary duty is, however, for the doctor herself to self-disclose. The second scenario involves those more detached from us as individuals yet with the ability and authority to make highly influential decisions on behalf of the people of the United Kingdom, the senior Cabinet Minister and arguably their respective shadow opposition Minister. It looks at the issue from the perspective of whether it should be incumbent on such a person to disclose their own medical information in to the public domain. In the United States of America, Presidential candidates detail their health status to a greater or lesser extent, as part of their election campaign, and on a regular basis once in office, with obvious risks of non-disclosure; it is a process not without critique.\textsuperscript{12} What also for the individual who is the personal medical


\textsuperscript{11} See for example, \textit{W v Egdell} [1990] Ch 359, [1990] 1 All ER 835 and note Article 8 (2) of the HRA ‘there shall be no interference by a public authority with the exercise of this right [to confidentiality – my addition] except such as in accordance with the law and is necessary in democratic society.’

practitioner, either to another doctor or to a politician, and has a real dilemma when in possession of medical information about an ailment that may affect their patient's performance to the detriment of a few or the many? This is an invidious position to be in and in the ethos of the guidance established for doctors in England via the General Medical Council (GMC), and the Care Quality Commission (CQC) requirements on health information disclosure and access to medical records, I put forward a potential model for the scrutiny and monitoring of the physical and mental health and wellbeing of our politicians that also lends itself to other professions and occupations with the potential for causing harms consequent on ill health. I analyse proposals put forward by former medical doctor and Cabinet Minister (amongst other things) Lord Owen in his recent work about the health or otherwise of heads of state in the last one hundred years.

Focusing on doctors and politicians by no means ignores wider issues. Your taxi driver may have an illness that compromises their ability to drive you around safely. Your electrician may have an ailment that affects dexterity and judgment. It becomes increasingly clear that the relativity of medical confidentiality is (and should be) becoming increasingly role specific and opens up an argument that changes the way we look at medical confidentiality altogether.

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13 This paper is not concerned with the so-called dual obligation doctors who function within an organisational occupational health service. Their dilemmas are well addressed elsewhere. See Tamin, J., 'Models of occupational medicine practice: an approach to understanding moral conflict in “dual obligation” doctors', *Medicine, Health care and Philosophy* 16 [3] August 2013, 499-506.

14 General Medical Council (GMC) *Good Medical Practice* (London, 2013) p. 11, ‘If you have concerns that a colleague may not be fit to practice and maybe putting patients at risk, you must ask for advice from a colleague, your defence body or us. If you are still concerned you must report this, in line with our guidance and your workplace policy, and make a record of the steps you have taken.’ [my italics] and p. 12 ‘If you know or suspect that you have a serious condition that you could pass on to patients or performance could be affected by a condition or its treatment, you must consult a suitably qualified colleague. You must follow their advice...You must not rely on your own assessment of risk...’

15 For an individual doctor to practise as a provider, for example, as a General Practitioner, they have to apply to the Care Quality Commission (CQC) and complete an application form that includes a section where the applicant must release details of their own GP as the CQC state ‘We may need to contact your doctor about your application,’ and require the applicant to give permission for the CQC to contact that GP [situation regardless – my addition], see CQC, *Application for registration as a new provider of regulated activities*, sections 2.6 and 2.7, [www.cqc.org.uk/content/apply-new-provider](http://www.cqc.org.uk/content/apply-new-provider) Further see the CQC associated guidance that states at 3.10 ‘If a partner has any physical or mental health conditions that are relevant to their ability to carry out regulated activities ...they must check or tick yes...’ and at 3.11 ‘...we do ask you give permission to contact your GP about this application....If you do not do so we may contact you about this.’ [http://www.cqc.org.uk/content/apply-new-provider-guidance #14](http://www.cqc.org.uk/content/apply-new-provider-guidance #14) These are requirements underpinned by the UK Statutory Instrument The Health and Social Care Act 2008 (Regulated Activities) Regulations 2014 No. 2936 Schedule 3 Information Required in Respect of Persons Employed or Appointed for the Purposes of a Regulated Activity, para 8. [http://www.legislation.gov.uk.ukdsi/2014/9780111117613/schedule/3](http://www.legislation.gov.uk.ukdsi/2014/9780111117613/schedule/3)

16 See [http://www.lorddavidowen.co.uk/category/biography](http://www.lorddavidowen.co.uk/category/biography)

8.4 For Some More (Choice) is Less

8.4.1 Setting the Scene

I use the following scenarios to assist my argument that the nature of the job you do and your role in society may diminish your claim to medical privacy. In the first, involving a medical practitioner, I work on the premise that doctors already have less choice and control over their own medical information than members of the general population and consider if this is reasonable.

Consider two fictitious patients. (1) Ms J, a 44 year old neurosurgeon who has multiple sclerosis (MS). Her employers are aware of the diagnosis as part of the occupational health process. Her dextrous surgical skills are currently unimpaired. Ms J’s concentration and memory do fluctuate very occasionally and this is known only to her General Practitioner (GP) and hospital neurologist. (2) Mr J is a 54 year old Member of Parliament (MP) who has MS and also a stable, inert, benign19 cyst on the brain. He has just been appointed Secretary of State for Defence in the UK Government. No-one knows Mr J’s diagnosis other than his GP and hospital based neurologist. He too appears unaffected to everyone else but is also aware that his memory and concentration fluctuate very occasionally when he is overtired. Although as an MP, he does have local constituency duties and meets individuals from time to time, his primary role is at the whole population level in the procurement and delivery of defence policy. Arguably then he is much more detached than the neurosurgeon from the life of the individual and less likely to cause direct harm if his concentration is impaired. But Mr J has the potential for adverse influence on the international front as well as the national stage given the necessary interactions with other world leaders, in an extreme case that threatens national security.

The neurosurgeon is bound by a duty of care to her patients set not just by historical oaths20 but by professional codes21 and the law.22 It is established that if Ms J injures a patient, due to a lapse in judgment (disease related in this instance), then she is in clear breach of her duty of care. With Ms

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18 For detailed information about MS, a progressive and incurable neurological condition, see www.mssociety.org.uk and www.mstrust.org.uk.
19 In this instance benign means non-cancerous. It is acknowledged that benign brain lesions can still be problematic depending upon size and location issues.
20 More specifically, the Hippocratic Oath which in both ancient classical and modern versions essentially binds the doctor to the keeping of the patient’s secrets.
J, should she leave a swab in a patient’s cranial cavity, as a result in this instance of a lapse in judgement due to her condition, this is a classic breach of the surgeon’s duty of care resulting in liability for clinical negligence.\(^{23}\) Not only is Ms J expected to acknowledge and act when her own health compromises her performance but so are her colleagues if they have concerns about her.\(^{24}\) As for Ms J’s own medical advisers, should they have concerns about her that Ms J is unhappy to disclose and act upon, by virtue of her profession the GMC sets out guidance requiring external information disclosure.\(^{25}\) This guidance is directed towards serious communicable disease yet the intention and spirit of the requirements translate across disease boundaries and practice domains as will be shown later in this paper. Turning to the politician, Mr J, in his role as a Minister there is no duty of care to individuals in the classic negligence sense but he is accountable for what he does to both Parliament and the nation. Mr J’s own health and its impact on others in his role as a Cabinet Minister has the potential for affecting whole populations and the national interest and this ought to carry with it a non-partisan political duty of disclosure.

### 8.4.2 The Politic Body - Past and Present

There is as noted above a wealth of literature\(^{26}\) and guidance\(^{27}\) on doctors whose ‘ill health’ may pose a risk to patients. There is little on the question of senior politicians. Yet there are analogies. Both professions place individuals in a position of trust and responsibility. There is an intrinsic power imbalance in the relationship between doctor and patient, and politician and the public. In England the majority of politicians will be registered with a general medical practitioner (GP), NHS or private, with whom they may well share ‘secrets’ on health and other matters. In the case of senior politicians at least this has the potential for a reversal of the usual doctor-patient relationship with the politician carrying the power balance within the relationship given their status and possible spheres of influence. It has become clear in recent years that senior politicians have

\(^{23}\) Ibid., 101-164.
\(^{24}\) GMC, n. 14 above.
\(^{25}\) See General Medical Council *Serious communicable diseases*, (London: GMC, 1997) p. 12 Treating colleagues with serious communicable disease p. 35 ‘If you know, or have good reason to believe, that a medical practitioner ....has, or may have, a serious communicable disease, is practising, or has practised, in a way which places patients at risk, you must inform an appropriate person,,, or.... the relevant regulatory body.
\(^{27}\) See [http://www.gmc-uk.org/concerns/doctors_health_concerns.asp](http://www.gmc-uk.org/concerns/doctors_health_concerns.asp) ‘Your health matters’ and [www.php.nhs.uk](http://www.php.nhs.uk) ‘...a service for doctors who have a mental health, addiction or physical health problem affecting their work.’
in the past managed to keep confidential serious health problems that must have influenced their ability to undertake the role. David Owen has undertaken a review of some high profile and influential figures and their health. 28 One notable example is that of Winston Churchill 29 who had a number of health issues in his long political career including a severe cerebrovascular event or ‘stroke’ whilst Prime Minister in 1953. For a time he was left with speech and mobility difficulties as well as the fatigue so typical of such a brain insult. What is very telling is that his own physician, Dr Charles Wilson (later Lord Moran), details in his diary 30 episodes of transient brain ischaemia that pre-dated the stroke and the changes in Churchill’s mood and mental performance that occurred as a result.

Dr Wilson’s medical bulletin read:

For a long time the Prime Minister has had no respite from his arduous duties and a disturbance of the cerebral circulation has developed, resulting in attacks of giddiness. We have advised him to abandon his journey to Bermuda and to take at least a month’s rest. 31

The Chancellor of the Exchequer (Rab Butler) and the Foreign Secretary (Lord Salisbury) however altered the bulletin and the version that was finally distributed read:

The Prime Minister has had no respite for a long time from his very arduous duties and is in need of a complete rest. We have therefore advised him to abandon his journey to Bermuda and to lighten his duties for at least a month. 32

It was the politicians not the doctor that made the decision to conceal the Prime Minister’s true illness and Churchill himself was in agreement. 33 Dr Wilson himself commented ‘…if he recovers

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28 Owen, D., n. 17 above.
29 Winston Churchill was not blessed with good health. His battles with mental ill health including severe depressive episodes that he referred to himself as his ‘black dog’, along with his apparent capacity for enormous amounts of alcohol are widely reported. Owen questions as to whether the modern day diagnosis would be one of bi-polar disorder, n. 17 above, pp. 40-42.
31 Ibid., p. 411.
32 Ibid.
33 Ibid.
and wants to carry on as Prime Minister, the less we say about the stroke, the better for him.'\textsuperscript{34} July 1953 had Churchill stating ‘I can understand death or illness but not this. I had a busy, scheming brain once, and now’ [pointing to his head] – ‘it’s empty.’\textsuperscript{35}

Tellingly the diaries of Lord Moran have an entry dated August 26 1953:

> It is my job to try and persuade the P.M. to be sensible about his health. I do not look forward to the task. He is a poor listener unless you agree with him…\textsuperscript{36}

It would seem then (as now) doctoring a politician, particularly one of senior status, places the practitioner in an unenviable position if the said politician is unfit to fulfil his duties but hiding serious illness. What were the consequences of the 6 month delay in convening the tripartite Summit in Bermuda\textsuperscript{37} and, perhaps more pertinently, what would have happened had Churchill been in attendance having just had a stroke? Furthermore his slow and incomplete recovery must have had consequences on and for his professional performance. Despite the rhetoric of rest and respite, the British press seemed unconvinced, having gained information about Churchill’s stroke via \textit{The New York Herald Tribune}. \textit{The Daily Mirror} wrote in August of 1953:

> Is there any reason why the British people should not be told the facts about the health of their Prime Minister…information at second hand from tittle-tattle abroad…The public is baffled and worried. Let us know if Sir Winston Churchill is fit enough to lead us.\textsuperscript{38}

More recently, in 2003, Britain’s then Prime Minister Tony Blair had several admissions to hospital, the initial details of which Owen states were ‘leaked’ to the media.\textsuperscript{39} It would seem that denials of any medical problems at all were happening at the same time as incorrect details of cardiac (heart) problems were being released. Downing Street officials then advised the press that Mr Blair had problems with an intermittent rapid pulse, secondary to an electrical conduction problem in the heart. Subsequently it was advised that this was inaccurate and Mr Blair was suffering with a heart rhythm problem called atrial flutter requiring hospitalisation and an invasive cardiac procedure. The messages from Downing Street and Mr Blair himself were mixed and ranged from playing down the accuracy of the diagnosis to misrepresenting the number of cardiac episodes the PM had

\textsuperscript{34} Ibid.
\textsuperscript{35} Ibid., p. 424.
\textsuperscript{36} Ibid., p. 462.
\textsuperscript{37} Ibid., p. 406.’Intended three-power conference between Britain, France and the United States at Summit level, to discuss the upkeep of military forces in Western Europe.
\textsuperscript{38} Ibid., p. 455.
\textsuperscript{39} Owen, D., n. 17 above, p. 316.
suffered. It would appear that had hospitalisation not been necessary little if any information about Mr Blair’s health might have reached the public domain. Yet this was a man in a position of enormous power. Who was running the country?

The Scotsman newspaper, amongst others, felt that the timing of the hospitalisation announcement and what might be called the clarification of the facts was a politically savvy move given a by-election on the same day, the result of which might have led to questions about the Labour leader’s position. Regardless of the breach in Mr Blair’s confidentiality, and the possible adverse effects of the cardiac condition on Mr Blair’s performance as a leader in home and world affairs, was his health information actually used to ‘trump’ any potential negative press? It was confidential information until it was not confidential, that is, useful and the same information had a public and press interest many months previously when first announced, yet under a more minor mis-diagnosis label. Was it however deceitful and where does that leave the public with those they hold and (and elect) to positions of trust?

Manoeuvres around the medical information of senior politicians have not been confined to the United Kingdom. Across the Channel in France, and six months after being elected as President in 1981, François Mitterrand found himself with metastatic cancer of the prostate: he already had bony secondary tumours. As part of his election bid he had promised six monthly health updates and following diagnosis these continued with one notable omission, his cancer diagnosis. His own personal doctor Claude Gubler retained the trust of the President, his patient, by continually lying to the public in these updates and consistently abusing the public’s trust in the truthfulness of a medical practitioner’s word. Something of a dilemma for a doctor as detailed by Lord Owen, who cites Gubler thus, ‘I was caught in a trap…The lie covered everything…’

The New York Times rather sardonically reported Mitterrand as having said ‘that his frequent dealings with the medical profession brought him into contact every day with Molière, the 17th Century French playwright, who frequently satirised doctors as being pompous, ineffective and

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41 Owen, D., n. 17 above, p. 224.
money grabbing. The Elysée Palace was not a comfortable place for Dr Gubler it would appear; the dilemmas must have been frequent.

To sum up, whilst empathising with the person-politician who becomes ill some of these individuals hold positions of enormous power and responsibility. Intrinsic to that is the trust that the electorate have placed in that individual. If the ill health of the politician has the potential to affect their performance to the detriment of, and possible danger to, the public ought that public to know? As for the clinicians, treating the patient-politician whose health may threaten the public, they find what might be considered their usual position of power, responsibility and trust over and with that patient significantly eroded. Where does their ultimate responsibility lie; with the patient-politician or to the wider community that their patient serves? There is, of course, a different question beyond the scope of this paper but worth acknowledging. What if a senior politician becomes ill in the middle of a political crisis, for example with their forces engaged in armed combat? Is it in the interests of the public to know at the time, or would that knowledge have a detrimental effect on public morale with the crisis on-going?

**8.4.3 The Assorted Shades of Confidentiality - Do Doctors Have Less Choice?**

If politicians have been able to hide their health problems from the public even when they raise the question of the capacity to govern, what of doctors? If there is one episode in recent medico-legal history that still holds notoriety and has continuing ramifications for medical practice, it is the case involving Dr Harold Shipman, a General Practitioner who also happened to be a mass murderer and used his position to satisfy his criminal intents. The inquiry that followed his conviction, The Shipman Inquiry, was lengthy and detailed. Dr Alan Banks the Medical Adviser for the West Pennine Health Authority that contracted with Dr Shipman in its locality, found the following statement about himself in the public domain during the course of the Inquiry:

> Arrangements for hearing evidence of Dr Alan Banks Fri 14 June 2002.

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44 Harold Shipman was a General Practitioner in Hyde, a town in the Tameside area of Greater Manchester. He was found guilty of 15 murders in January 2000 – all had been patients registered at his single handed practice. In all likelihood he killed in the order of 250 patients.
46 Ibid., See witness statement of Dr Alan Banks, WB 14 00057-50 for a summary of the role of Medical Adviser.
Dr Alan Banks was scheduled to give evidence to the Inquiry on 17, 18 and 20 June 2002.

He submitted a medical report written by Dr Philip Lewis, a consultant cardiologist, who expressed the opinion that, as Dr Banks had a heart attack in November 2001 and still suffers from angina, it would be too stressful and unsafe for him to give evidence in public in the Hearing Chamber at Manchester Town Hall.

The inquiry proposed that he should give his evidence by video link, but this proposal was rejected on the ground that the experience would also be too stressful for Dr Banks.

On Monday, 10 June, on the instructions of the Inquiry, Dr Banks was examined by Professor Crossman, a consultant cardiologist from Sheffield University.

Professor Crossman advised that Dr Banks would be able to give evidence in private…Dame Janet Smith, Chairman of the Inquiry will hear the evidence, which will be recorded. Transcripts will be posted on the website as soon as possible.

What is notable is that Dr Banks did not give his permission for this level of detail about his medical problems to be placed in the public domain and had made an incorrect assumption that consent would be sought. The named consultant Dr Lewis did not consent to the public release of his medical opinion, having engaged in correspondence with Dr Banks’ own GP about the patient’s condition; a relationship normally bound by the accepted rules of medical confidentiality. This Inquiry needed to afford the public a degree of reassurance and establish trust, certainly in its own workings and quite possibly back in the medical profession, general practice in particular. Public anxiety on the transparency of the Inquiry needed to be assured; there appeared to be no other reason for this level of medical information disclosure.

Contrast this with a more recent yet arguably equally notorious investigation, The Mid Staffordshire NHS Foundation Public Inquiry, 2013, (to be called the Mid Staffs Inquiry here on in). The Chief Executive of the Mid Staffordshire NHS Foundation Trust, Mr Martin Yeates, was given permission

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48 Dr Banks’ transcript at WB 14 00086, 17 June 2002, reads ‘...I have been absent from my post at the health authority, due to ill health. I suffered a heart attack on 28 November 2001 and I continue to suffer ill health in the form of disabling angina.’

49 Tribunals of Inquiry (Evidence) Act 1921 s1 (1)(b). Judges are able as in this instance to subpoena medical records in such tribunals with no legal privilege (of confidentiality) applicable. That said what is released to the media may well be at the judges’ discretion.

on health grounds to provide a witness statement (only)\textsuperscript{51} and not appear in person at the Mid Staffs Inquiry, even by video link. In that statement he wrote:

I understand that there are a number of people who would wish me to give my evidence personally…For medical reasons, this is not possible. I hope that following receipt of my statement, I will be allowed to move forward with my life. The personal costs to me and my family of being hounded by the press and certain campaign group is irretrievable [sic]; I have lost my family, my career and my health.\textsuperscript{52}

For whatever reason Mr Yeates was able to ‘avoid’ appearing in public or by video and this was not lost on the press and criticism was forthcoming. Max Pemberton, columnist (and medical doctor) wrote:

That Mr Yeates was not made to stand up and explain what happened – even by video link – seems unbelievable. It is deaths, not a drop in share prices, being investigated.\textsuperscript{53}

As with proceedings in court, in Judge-led inquiries there are substantive powers to compel the giving of evidence. Existing case law (and GMC guidance) is very clear where the balance of public and private interest falls in favour of disclosure of medical information; that is, where there are identifiable harms. In addition, the application of broader social values, such as in the administration of justice, also warrants complete disclosure in court or at an Inquiry. Courts do endeavour to minimise breaches of medical privilege however, so why were these two Inquiry cases considered differently? \textsuperscript{54} There seems to have been no particular reason for handling the medical information of Dr Banks and Mr Yeates in a different manner respectively, and given the serious nature of the investigations undertaken it is hard to think of one.

\textsuperscript{52} Ibid., p. 2.
\textsuperscript{53} Pemberton, M., “‘Fat cat’ chief should have to answer for hospital deaths”, \textit{Daily Telegraph}, 7 October 2011.
\textsuperscript{54} For a fuller discussion on the concept of medical privilege see McHale, J. V. Medical Confidentiality and Legal Privilege, (Routledge: London, 1993) pp. 99-142.
8.5 Duty to Disclose – The Public have an Interest

8.5.1 The Law Applied: Doctors and Ministers

Few would contest that a general duty of confidence exists between patient and practitioner, even when the patient is also a medical practitioner or works in any other occupation where ill health may endanger others. The question then arises as to the circumstances in which the public interest in not allowing information disclosure is overridden by the public interest in the revelation of medical information. Extreme examples are perhaps easy to solve. One such example is the pilot with suicidal thoughts where his mental condition becomes as damaging to passengers as any significant physical condition might. In English case law such an ‘easy’ question was addressed in 1990, in *W v Egdell*. Dr Egdell was sued for breach of confidence for enabling a psychiatric hospital medical director and consequentially the Home Secretary to be made aware of an ‘unfavourable’ medical report about patient W. W had multiple manslaughter and wounding convictions and was on indefinite detention in a secure hospital on the grounds of diminished responsibility. Following an unsuccessful application for a transfer to a regional secure unit W went on to appeal at a mental health tribunal seeking a conditional discharge. Dr Egdell was commissioned to undertake an independent psychiatric report. His opinion was that W was a dangerous psychopath who lacked insight and held a ‘morbid’ interest in explosive materials. In withdrawing W’s application his solicitors also declined to forward the doctor’s report to the secure hospital claiming both a breach of legal privilege and a breach of confidence. Dr Egdell then sent his report without delay to the Director of the secure hospital agreeing that a copy was sent on to the Home Secretary. W sued for breach of confidence.

The Court of Appeal agreed that Dr Egdell did have a duty of confidence to his patient but found however two competing public interests were at play and required balancing. There was (and is) a public interest in protecting confidences yet there may well be another over-riding public interest, in this instance it was public safety. *W v Egdell*, if anything, had the potential for adding further dilemmas for clinicians and their decision making over the disclosure of concerns about their patients, rather than simplifying matters as might initially be thought. Equally, it can be argued that the case facilitates the disclosure of information to an appropriate authority when a patient is a risk to others. Had the pilot involved in the recent GermanWings air tragedy been British and a patient in the NHS (or private health care sector) with *W v Egdell*, the doctor would have been able to disclose.

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55 *W v Egdell* [1990] 1 All ER 835.
In 1987 in *X v Y*, the plaintiff, a health authority, had been giving treatment to two HIV positive general practitioners. Via an authority employee a British tabloid newspaper obtained information about the identity of the GPs, both of whom were still practising as doctors. The authority sought an injunction preventing the doctors’ names being published. The tabloid was of the view that there was public interest in knowing that some doctors were positive for HIV; more specifically the patients of said doctors. Rose J. had made it clear first that even if the harm to a patient posed by the GP was negligible and reduced by seeking help and counselling, permitting breach of confidence such that doctors might not seek medical help if their information was not kept confidential posed a potentially far higher risk. Rose J stated:

Confidentiality is of paramount importance to such patients, including doctors.

There are two elements to this comment. One is that doctors, like everyone else have an interest and hold a value in the preservation of their confidentiality. Equally the fact that the status of these plaintiffs was as medical practitioners and flagged up as such gives the air of doctors being in some way a special case. The comment might easily read as:

Confidentiality is of paramount importance to such patients, even doctors.

*X v Y* came at a time when the public understanding around a diagnosis of being HIV positive was limited and the popular press were whipping up a degree of hysteria. Rose J. was conscious of press freedoms in saying:

I keep in the forefront of my mind the very important public interest in freedom of the press. And I accept that there is some public interest knowing that which the defendants seek to publish…But [my emphasis] in my judgment those public interests are substantially outweighed when measured against the public interests in relation to confidentiality…

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57 Using information obtained via a pre-existing breach of confidence by a health authority employee.
58 *X v Y* n. 56 above.
59 In the 1980s and early 90s there was little public or press understanding of an HIV positive status and the disease process itself, Acquired Immunity Deficiency Syndrome (AIDS) and the status and the disease were often conflated.
60 The author recalls that at this time some hospital phlebotomists were refusing to take blood tests from HIV positive patients and the phlebotomy role being ‘delegated’ to junior hospital doctors.
For Rose J. the public do have an interest in having access to medical information about persons, in this case medical practitioners, but not to the level that overrides an individual's own confidentiality interests (unless there is a real and significant risk) and the public interest in doctors seeking treatment (and not hiding or self-treating their ill-health\textsuperscript{61}).

In *McKennitt v Ash*\textsuperscript{62} in 2007 a Canadian folk singer (McKennitt) had gained an injunction that prevented the publication of a book that contained information about her health. At the Court of Appeal, Buxton LJ was not impressed by any argument that as a folk musician and in the public eye, there was a public interest in knowing her affairs. As Aplin notes:\textsuperscript{63}

\begin{quote}
...Ms McKennitt did not hold a position where higher standards of conduct can be rightly expected by the public: this was the 'preserve of headmasters and clergymen, who according to taste may be joined politicians, senior civil servants, surgeons [sic] and journalists.'\textsuperscript{64}
\end{quote}

*McKennitt v Ash* is indicative of a growing interest by the public via the media into the health information of people in the public eye. Whose information needs to be known, and whose does not; why were senior civil servants and journalists selected by Buxton LJ as role models who might be held to higher standards and enjoy less control of private information including medical information? Why were surgeons singled out and not general physicians or GPs; or was the use of the term surgeons intended to cover all medical practitioners at a time when the surgeon carried a loftier status? Whatever the answer, Buxton LJ’s list of professionals seems to identify professions in whom the public ought to be able to place a significant level of trust, and who in return may lose some degree of privacy.

Medical confidentiality took on added dimension with the advent of the Human Rights Act in 1998 (HRA, 1998).\textsuperscript{65} Article 8(1) was used to extend protection for private life enabling privacy claims where no classic relationship of confidentiality existed in common law. However, now a balancing exercise had to take place between Article 8 and its protection of a private life, and Article 10 and

\textsuperscript{61} GMC, n. 25 and Howe, A., n. 26 above.
\textsuperscript{64} *McKennitt* n. 62 above, 139.
\textsuperscript{65} More specifically with reference to Articles 8 and 10.
press freedom. In the 2002 case of *H (a healthcare worker) v Associated Newspapers Limited and N (a health authority)*, the HIV positive health care worker had to deal with his health authority undertaking a ‘look back’ exercise and offering all his/her patients the opportunity to be screened for the virus. H would not enable access to the contact details of his private patients and gave only limited access to some NHS patient identities. H’s core argument was that the likelihood of HIV was very low and thus it did not warrant breach of his confidentiality. H sought an injunction to prevent the health authority notifying his patients. At the same time the national newspaper *The Mail on Sunday* heard about the case and H went on to gain an injunction to prevent release of his identity, speciality or the name of the employing health authority as the latter would effectively result in his identification. In the court of first instance Gross J was willing to reveal the specific health authority and H’s speciality. H appealed and in the Court of Appeal initial arguments suggested that the result of *X v Y* would prevail. The Court decided that H’s identity and name of the health authority should remain confidential. However, as a result of considering the balance to be had between Articles 8 and 10 the Court went on to allow disclosure of the speciality involved, on the basis the issues warranted public debate and that any other restriction was ‘draconian fetter on the freedom of expression…’

A much ignored element in this case is that the clinician had initially, and reluctantly, felt able to release details of NHS patients to the health authority, but had given a flat refusal in the case of his private patients. Yet confidentiality, related duties and regulations apply as much to the private sector as much as it does to the NHS. While subsequent to H there are very specific regulations that apply to information generated in the NHS the fundamental principles relating to the balance of confidentiality and privacy apply as much in private medicine as in publicly funded medicine.

The balancing of Articles 8 and 10 by the courts gives judges the ability to determine what information is of public interest and thus what can remain ‘private’, rather than one Article appearing to trump the other. English law has seen forays into the world of informational privacy involving that attempt in some way to trump the existing principles on confidentiality. This is despite there still being no tort of privacy in English law. In her judgment in *Campbell v MGN* (2004) Baroness Hale almost suggested that there is gradation in the nature of medical information imparted; some things are of more interest than others perhaps:

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68 See *Campbell v MGN Ltd* [2004] UKHL and *Douglas v Hello! Ltd* (No 3) [2006] QB 125.
Not every statement about a person’s health will carry the badge of confidentiality...the privacy interest in the fact that a public figure has a cold or a broken leg is unlikely to be strong enough for the press to report it. What harm could it possibly do?69

A cold or a broken leg, however, are usually fairly obvious and do not require access with or without consent to the medical record for onward publication. But what if these were no more than symptoms of a much more serious underlying disorder? Dr Banks’ ailments were not obvious nor were Mr Yeates’ and yet differing policies applied. What then for our sample case histories? There would seem to be a need for a staged process. In the first instance, knowledge about Ms J’s MS and Mr J’s MS and benign brain cyst would only be known about by their own medical practitioners and, in Ms J’s case, by her occupational health service. Making these ailments known to a wider public would seem a misuse of Ms J’s and Mr J’s confidential patient information, and would only come to any wider attention if performance were to be affected. The added dimension, however, is that Mr J has significant public responsibilities. Do his medical conditions pose any risk to his performance? The brain cyst is benign and non-progressive and the answer is no. Mr J’s MS might be considered a different matter given the nature and range of his duties. What if he was required to be in extensive negotiations involving night as well as day; MS is a disease that requires managing and that includes adequate rest and sleep; as part of the disease process cognitive abilities may be affected. Does the public have an interest, therefore, in the material effects of the Minister’s MS? They probably do, given that we have elected him to our Parliament and entrusted him to undertake major obligations and decisions.

There is a dynamic about the relationship between a patient and their practitioner that does not seem to operate in, for example, a person and their financial adviser; though trust features in both.70 The giving of potentially sensitive personal information to a doctor appears to have a more intrinsic value that extends to keeping that information a secret. On this basis a prior knowledge of any ailment that our neurosurgeon may suffer from, it could be argued, needs to be known for any patient to make a decision about consulting with that practitioner. On the other hand we share little if anything with our politicians at an individual level; many of us hardly know them or what they do and they do not know us. On that basis how much of our example politician’s medical record is it of interest for the public to be aware? To date there has been little press appetite for exploring the

69 Ibid., Campbell at [157].
medical information of those who have the power to make decisions that can affect millions of us and not necessarily for the better. What seems to happen is that politicians will release medical information about themselves when opportune to do so.\textsuperscript{71} Trust generally has been eroded and is particularly low when the public are asked about their politicians.\textsuperscript{72} Does this lend support to a wider claim that expands the need to know (more) about those in whom we place our confidence and trust?

For Ms J the classic doctrine of confidentiality applies. As in $X v Y$ there is some risk to patients but it is marginal at this time; and contentiously her current skill level might well equate to that of the older neurosurgeon colleague without an active health problem. Both Ms J and the older neurosurgeon cannot be absolved from monitoring however, given the possibility of a progression in Ms J’s MS and an age related loss of dexterity in the latter’s surgical skills. In the event of Ms J recognising and disclosing her deterioration to her employers and suitable work adjustments are made, or Ms J retires before any harms ensue, a wider announcement is not appropriate. What, however, if Ms J opts not to make her employers aware, or perhaps worse still if employers opt to take no action once informed? Following $H$\textsuperscript{73} does Ms J become an example of where the press are entitled to put information in the public domain where risk overrides individual choice in the public interest?\textsuperscript{74}

\begin{quote}
\textsuperscript{71} Cates, S., Pitel, L., "Ukip candidate resigns after calling gay party members ‘poofers’", \textit{The Times} 15 December 2014. Kerry Smith, UKIP candidate for South Basildon and East Thurrock, citing a back injury for which he was taking ‘strong morphine-based prescription medication.’ See also BBC News Politics, \textit{Home Secretary Theresa May diagnosed with Type 1 Diabetes}, 28 July, 2013. \texttt{http://www.bbc.co.uk/news/uk-politics-23413273} There had been ‘speculation’ that Mrs May’s rapid weight loss was part of a strategy to bid for the conservative leadership. It was due to her diagnosis of diabetes.

\textsuperscript{72} Ipsos MORI Trust in Professions Trust and Influence 1993-2014 5 January 2015. \texttt{https://www.ipsosmori.com/researchpublications/researcharchive/} Interestingly over this time doctors have consistently remained the most trusted profession and considered the most likely to tell the truth; politicians however are ranked alongside journalists as the least trusted and least likely to tell the truth.

\textsuperscript{73} $H$ (a Healthcare Worker) n. 66 above.

\textsuperscript{74} Without wishing to deviate towards an in depth discussion on data management in Statute, it might be argued that one’s medical confidentiality is more than amply protected by this route. Closer examination suggests that this is not really the case. Article 8(1) of the HRA is apparently protective of a ‘private’ life and the Data protection Act (DPA), although complex, sounds like it ought to fulfil the role of guarding our information. However, Article 8(2) of the HRA enables medical records to be accessed without consent ‘...in the interest of...public safety...’ ‘...for the protection of health’. See also $MS v Sweden$ [1997] 45 BMLR 133 (ECHR) and $Z v Finland$ (1998) 25 EHRR 371. As for the DPA Schedule 3 unconsented medical information release can happen if ‘...processing of the data is necessary for medical purposes (includes...the provision of care and the management of health services)...’ See n. 22 above, Jackson, E., pp. 370-373. See also Section 254 of the Health and Social Care Act 2012, suitably vague, with identifiable information able to be gathered without consent ‘...in connection with the provision of health services...’ and ‘...in the interests of the health services in England.’
\end{quote}
8.6 Duty to Disclose – in the Public Interest – The Facts of the Matter

Whether as a result of the press and public ‘interest’ in the health or otherwise of the medical profession and/or because of assorted medical scandals, the doctors’ regulatory body, the General Medical Council (GMC) has codified its health requirements on the basis of protecting patients and colleagues in the document ‘Good medical practice’.75

If you know or suspect that you have a serious condition that you could pass to patients, or if your judgement or performance could be affected by a condition or its treatment, you must consult a suitably qualified medical colleague. You must follow their advice about any changes to your practice they consider necessary.76

Tellingly, it also states that ‘You must not rely on your own assessment of the [your – my addition] risk to patients.’ Ms J is obligated to consult a medical practitioner about her MS and also obligated to do as she is advised apropos continuing medical practice. Furthermore her own doctor, be that a specialist, GP or occupational health physician, must comply with the GMC thus:

If you have concerns that a colleague may not be fit to practise and may be putting patients at risk, you must ask for advice from a colleague, your defence body or us. If you are still concerned you must report this, in line with our guidance and your workplace policy, and make a record of the steps you have taken.77

When the GMC states ‘you must’ it defines this as ‘…an overriding duty or principle.’

What of Mr J, Secretary of State for Defence? Would it be fair to say therefore that a neurosurgeon’s MS carries less of a public interest than that of a high profile individual like Mr J, our politician? It would be beneficial if there were clear guidance about the obligations of politicians in such matters just as there already is for doctors. Yet Mr J does not currently have any obligations in matters of his own (or a colleague’s) health to, for example, the Parliamentary Standards

76 Ibid., p. 12.
77 Ibid., p. 11.
Authority, (PSA) unlike Ms J and her relationship with the GMC. Mr J at present is not forced to disclose any health problems or allow others to assess their effects on his ability to do his job.

It is commonplace for self-disclosure of health status and medical data to occur in the United States of America (as in France) apropos Presidential and Federal candidates, with the obvious potential risk of physician and candidate colluding to hide negative information either freely or under coercion. Lord Owen makes a number of suggestions with regard to informing and reassuring the United Kingdom public about the health of their politicians. These include allying the Electoral Commission with independent doctors who would undertake medical checks on Prime Ministerial candidates; a panel of doctors from which prospective PMs could choose. The doctors would then ‘be guided by the Electoral Commission on how to release information to the public.’

Arguably, and hopefully this is the start of a debate, it is possible to look at Lord Owen’s recommendation and evolve it much further. Firstly, the Electoral Commission may not be the best organisation to undertake this work. Independent in nature, it nevertheless has close relationships with political parties when it comes to scrutinising their finances, briefing them on matters relating to electoral law and any changes proposed, as well as supporting (independent) election officers on voting matters. Furthermore the Electoral Commission’s role is largely confined to matters around general elections, now routinely held every five years. What would happen if the existing Prime Minister or indeed other senior politicians’ health deteriorated significantly with their five year tenure?

The GMC, although a regulator of doctors, was radically reorganised post-Shipman amid accusations that the organisation was too supportive of the medical profession, perhaps at the expense of putting patient welfare first. This is an accusation from which it is yet to completely recover. However doctors now undergo a revalidation procedure every five years as well as regular appraisal; health questions are intrinsic to this process. In the event of health adversely affecting a doctor’s performance, the GMC has a number of procedures and protocols in place to

78 In fact the PSA remit thus far is primarily concerned with overseeing and regulating the expenses, pay and allowances of Members of Parliament. http://parliamentarystandards.org.uk/aboutus/Pages
79 For information on the Electoral Commission see www.electoralcommission.org.uk.
80 Owen, D., n. 17 above, p. 341.
81 Ibid., p. 341.
manage these situations. Given the emphasis on ‘overriding duties’ in the event of Ms J not reporting any clinical deterioration, in theory a colleague would and must report. There would appear to be no such code or regulation in place for Mr J, our elected politicians, or indeed for health service managers such as Mr Yeates in his role as Chief executive of the Mid Staffordshire NHS Foundation Trust.

If we accept that there is a need for increased limitations on what politicians (as per doctors) can choose with regard to the access to and use of their medical information, in a spirit of trust and transparency, there is a need for some form of monitoring and possibly regulatory body. In a staged process involving first an obligation to report physical and psychological problems to the Cabinet Secretary\(^{83}\) (perhaps in the manner of the CQC formulation and declarations\(^{84}\)), who is aided by a group of independently appointed specialist medical advisers; this could become the remit of the pre-existing PSA.\(^{85}\) Starting at the national level for the sake of argument and with cross party agreement (utilising a model not dis-similar to that used by the GMC and the CQC, noting the criticisms thereof\(^{86}\)). The requirement needs to apply to all politicians at a national level in this first instance. After all, suppose a sudden cabinet re-shuffle; someone in a relatively ‘tame’ post in Environment and Rural affairs may suddenly be elevated to a position of considerable power, say Defence and their potential for harms will alter overnight. What if that politician’s doctor had grave concerns; does it require secret ‘whistle-blowing’ calls to the press? Unlike the scenario suggested by Lord Owen those doctors undertaking the screening and assessments would be independently appointed and allocated to the politician rather than chosen by the politician themselves, thus going some way to obviating any power imbalance or coercion within the relationship. There should be close liaison with the individual’s own NHS doctors and an obligation on the politician to comply with any medical directives.\(^{87}\)

\(^{83}\) Beesley, I., ‘Men of Secrets The Cabinet Secretaries’, A series of interviews with Cabinet Secretaries from 1979 to the present day. The Mile End Group, Queen Mary University of London, 2014. See also Jones, G., Blick, A, ‘The Cabinet Secretary – A Tale of Three Roles’, No 10 Guest historian series, co-ordinated by History & Policy, (1 April 2012).

\(^{84}\) CQC, n. 15 above.

\(^{85}\) PSA, n. 78 above.


\(^{87}\) Further speculative detail is likely to provoke as much negative argument as constructive critique. However there would need to be a line of communication from the Cabinet Secretary to the Parliamentary Standards Authority. This would enable release of medical information into the public domain, consented or otherwise.
Role specific disclosure is not just about quantifiable harms such as the doctor who maims a patient or acts in a way that leads to a death. In the context of the politician putting the public at risk this must fall within the remit of the administration of justice; the PSA would have to undertake the same sort of balancing exercise that a Judge might do in court or that the GMC undertakes, when in this instance a claim of medical privilege might be advanced. A system does need to be in place to ensure that when the health of those who govern us, be they politicians or civil servants, is problematic for the public ensuring that the clinicians acting for them have access to advice and support. Further if there was any suspicion that the patient in question was putting out false information that obviated a problem or implied it was well managed, the PSA would have the power to gather evidence. Contrast this with the USA where non-independent health statements can be seen as advantageous to the politician and ‘reassuring’ to the public but the lack of independent scrutiny can lead to disingenuousness.

8.7 Conclusions

It is hardly contentious to state that choice in general, and over our medical information in particular, is relative and limited. In this paper I have argued that the nature of the job that a person does will in some cases mean that a person’s choice about access to medical information may be significantly limited. I acknowledge that if the ability to make decisions over the access to and use of particular individuals’ medical information is reduced or removed, there are risks to them and to others in that they will not seek advice and treatment, may resort to self-treatment and, more generally, lead to difficulty in recruitment to and premature departure from the relevant professions. The latter two elements have potential consequences for the wider public. Conversely, failure of disclosure can be detrimental to public trust.

Medical practitioners have attracted an interest in their health matters in a way we have yet to see in our politicians; other than via the route of self-disclosure exemplified by Theresa May. The essence of my argument is that increasingly there are people in a variety of roles whose very role limits their claim to confidentiality. This seen expressly in terms of the medical profession where

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88 British Medical Association, ‘GP recruitment crisis threatens patient care’, BMA News 30 October 2014. http://www.bma.org.uk/news-views.../gp-recruitment-crisis-threatens-patient-care Accessed 8 June 2015. General Practice is once again facing a recruitment crisis as are certain high pressure specialisms e.g. Accident and Emergency. It has already been shown above that fear of a loss of confidentiality inhibits doctors from disclosing ill health, seeking treatment, or turning to self-treatment; it is not unreasonable to suggest that threats to their confidentiality might inhibit both recruitment and retention. See Telford, N., ‘GP partners’ state of health’, BMA News, 4 July, 2015 , ‘I found that I am supposed to give the CQC carte blanche to access my GP to find out whether I am healthy enough to be a GP partner. It is yet another door closed for GP support - I can no longer feel confident that I have any doctor-patient confidentiality with my own excellent GP.’

89 n. 71 above.
there is guidance centring on the duty to self-disclose. I have sought in this paper to extend the same principles to politicians but that principle could appropriately be applied to other occupations and professions where there is potential for harms and risk to others.

This paper has focused on ‘hard’ cases well recognised in society, the doctor and the politician. A suggestion has been made in order to fill the gap in process and procedure in dealing with the ‘health’ of our politicians, based on a degree of modelling on that that is already in existence for doctors. However my arguments and concerns have a much wider reach. It is important that professions and occupations reflect on health, responsibility and risk issues way beyond that dealt with by occupational health services. This changes the nature of self-disclosure and management of behaviours and illnesses as well as the responses of the advising clinicians as a result, I suggest:

I will self-disclose to the extent that is necessary to protect those for whom I am responsible. My clinician will disclose if I am not in a position to do so.

Self-disclosure and appropriately administered actions as a result should promote the development of firm and publicly available guidelines and codes. The doctor no longer is in the position of having to drive the proverbial ‘coach and horses’ through their patients’ confidentiality; the duty is on the patient to share in the first instance, with the clinician acting as the safety net.

Management of our medical information and the confidentiality of the same should and can be increasingly role specific. Crucially, the need for disclosure itself should become a transparent part of any occupational role and job description. This requires a new way of thinking about our medical confidentiality.

8.8 Acknowledgments

I am grateful to Professor Margot Brazier, Professor Rebecca Bennett and Professor Suzanne Ost for their comments and thoughts on drafts of this paper. All errors remain my responsibility.

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90 See Tamin, J., n. 13 above.
Chapter 9 – Choice: Conclusions

9.1 Introduction

This thesis demonstrates the difference between recognising certain rights to choose, correlating these with the ‘choices’ on offer and conceptualising these as consumer choices. It shows that choice in health care can be a misleading word. What is on offer is not free, unfettered choice, and limitations on choice, when openly expressed, are acceptable and justifiable and in the spirit of respecting the autonomy of the individual. It suggests that presenting people with options in a transparent manner and acknowledging and discussing preferences (with no guarantees), in a spirit of engagement, is an approach that could promote and enhance trust in the patient-practitioner relationship and in the health care system.

The question of who makes decisions about treatment and how such decisions are made has been central to debates about health care ethics and law for many years. In a sense, choice has been an integral part of such debates ever since lawyers, ethicists and patients began to challenge medical paternalism. Until more recently, however, the language used in these discussions tended to centre on patient autonomy, liberty, bodily integrity and privacy. All these elements involved ‘choices’ but were not stated as such. The language of choice came to the fore in a series of political agendas. How far ‘choice’ within the NHS or health care as a whole has any consistent meaning and whether it is fact or fallacy has been addressed in this thesis. What is clear is that ‘choice’ has permeated legal and ethical debates and may well become more prominent. If so serious consideration has to be given as to what ‘choice’ means given the complex factors involved. Lady Hale in Montgomery\(^1\) puts it succinctly:

There are choices to be made, arguments for and against each of the options to be considered, and sufficient information so that this can be done…\(^2\)

The thesis incorporates a review of underlying health policies as well as looking at a number of pertinent historical and ethical developments around this rather nebulous concept of choice. What emerges is that there is a distinct lack of clarity in the use of the term patient choice and lack of consistency in its application; as it is presented in health care law in association with autonomy as

\(^1\) Montgomery v Lanarkshire Health Board [2015] UKSC 11.
\(^2\) Ibid., at 109.
well as in recent health policy. Patient choice risks being no more than a rhetorical idea with no little substantive agreement of what it could and should mean for the individual patient. The thesis has gone on to identify that some restriction on choice is by no means a negative thing, nor does it necessarily undermine respect for autonomy, as might happen in the event of too much choice or so called choices that are ill explained or have the potential for negative future consequences; for example, as reduction in care services as a direct result of patients’ prior selections. More likely, autonomy is threatened when there is a lack of transparency and discussion over what choices are, and are not, available and/or accessible and why. People value being valued as choice makers and for being treated as adults that recognise that no resource limited system can have free unfettered choice.

9.1.1 The Growth of the Choice Agenda

As stated earlier in this thesis, in Chapter 1, patient choice was not part of general NHS policy prior to the 1990s, although informally a certain degree of choice was available in practice. All the governments of whatever political persuasion since the 1990s embraced patient choice language in association with competition and linking of English health care with the market. The first schemes such as GP Fundholding and that of Health Authorities making providers compete for contracts did little if anything for patient choice. Patients were restricted to the ‘choices’ that their GPs and Health Authorities had made and these were often quite restricted. New Labour developed the policy of patient choice much further, in theory allowing each patient to pick where they would have treatment, supposedly enhancing their autonomy as well as making the providers more efficient and responsive. The Coalition Government that followed New Labour developed a huge expansion in patient choice policy and rhetoric culminating in the still controversial Health and Social Care Act 2012. This was geared towards enabling the patient to choose treatments from beyond the NHS including the private and volunteer providers. The reality has proved rather different, given that locality based health care priorities and resourcing issues are the paramount drivers for health care commissioners, with patient choice a secondary issue.

Choice talk has effectively ignored facilitating the ability of a person to exert a choice, in favour of presenting them with a series of, at times, complex actions to complete and so called ‘choices’ to consider, in order to make health related decisions and to obtain appropriate treatment. For many plausible reasons little discussion takes place, other than perhaps at GP level, as to what is the best or preferred option for the patient. This opportunity is also becoming constrained. In all three research papers common themes have emerged. The use of the term choice can be misleading and contrary to what some of the rhetoric suggests is available to and accessible by the patient.
The policy does nothing to highlight when and why choice is not on offer or indeed that it is right for ‘choices’ to be restricted. Perhaps it was unsurprising that the same issue is applicable when considering issues around the control of, access to, and use of an individual’s medical information. In this thesis my argument remains that this limited form of ‘choice’ is justifiable. The reality of ‘choice’ in matters of treatment, agreement or refusal for example, only has context if there is information disclosure, engagement and shared decision making. What has the potential to undermine a respect for the individual’s autonomy is a lack of these features that enable the person to consider what is actually on offer or not on offer and why this may be so.

9.1.2 Ethics and Choice

From history it is fair to say that those who had money in the days before an NHS did have an ability to choose from what care was available, if they had the resources to fund it. The same people will have found their choices constrained as the NHS took over as the main health care provider, whereas for those without finances the NHS opened up a world of limited choices; quite a paradox in discussion around autonomy. As shown in Chapter 4, the depth and expertise of the many analyses around health care and its ethics indicate that choice is intrinsically linked with the ethical concept of respect for self-determination, that is, autonomy. Further, nothing in ethics appears to support free unfettered choice whether, for example, on a utilitarian spectrum with its consideration of the greater good, or neo-Kantian with its principled autonomy that respects the individual but reins in freedom of individual choice. For respect for individual autonomy to flourish there has to be trust in the relevant relationships, be that between patient and practitioner, patient and state and, out of the scope of this thesis, the practitioner and the state. Choice policy appears to be an attempt to value the autonomous individual; this is superficial. Choice can be a tool for self-determination or the self-responsibility for implementing policy and change, ‘placing a number of demands or responsibilities upon the patient.’ As a result of the policies in place in health care it can be hard for the patient to choose not to choose; a point not lost on Sunstein when he talks of ‘choice requiring paternalism.’ Overemphasis on choice in health policy is fraught with problems, potentially platitudinous, and risks undermining autonomy not respecting it; partly by not telling the truth and partly by manipulating the system under the guise of choice.

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9.1.3 Choice Talk

Early in this thesis the definitions that relate to choice were given due consideration. As the research progressed it has become apparent that a lack of consistency in definition and application of the term is in itself problematic. From an ethical perspective choice is about respect for autonomy and it is about agency⁶ and as such allies itself with ‘the act or power of choosing’. This latter point is fraught with difficulties because of the intrinsic and extrinsic difficulties that people have when it comes to making a choice, a point not lost on a behaviourist and psychologist like Schwartz.⁷ From the Government point of view the messages become much more complex and even confounding. Policy language such as ‘free choice’ is very suggestive of wider opportunities for unfettered choice. Schlesinger noted that choice is ‘redolent with positive associations’.⁸ State policy also talks of choice in terms of the alternatives available to the patient, features that nuance better with the definition ‘the preferred or best part.’ Yet these ‘choices’ are pre-set, and can even be the result of choices made previously by other patients. Thus the individual changes from being an agent acting in their own interests to being a state agent and the responsibility holder for the choices made or indeed not made.⁹ A lack of clarity in definition, purpose and use of a term like patient choice has the potential to undermine trust.

9.1.4 Choice Law

For the purposes of this thesis the legal analysis has concentrated principally on two elements; the law as related to treatment consent and information disclosure, and the law on patient information management and confidentiality and privacy. In the English legal framework choice has only entered the judicial language in the past thirty years and has been primarily associated with issues around autonomy, liberty and freedom from interference.¹⁰ Correspondingly, with the advent of the consumer society as a whole and a consumerist approach to medicine enhanced by choice in health care policy, the language in the Montgomery¹¹ case might appeal to the consumer in us and suggest that choice as demand is becoming more acceptable. I argue however that in this context the law remains as established, by way of example, in Pearce,¹² with no right of demand. Certain

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⁹ Veitch, K., n. 4 above, 317-322.


¹¹ Montgomery n. 1 above, at 75.

sorts of choice are recognised and respected by the law, for example, the need for adequate information, time and engagement in matters regarding consent and information disclosure. It falls short however of recognising the notion of consumer choice.

In my first research paper I endeavoured to establish the place of choice in cases related to the medical law and moving on from a position supportive of medical paternalism with Lord Denning in Hatcher v Black, as previously cited:

…he [the doctor – my addition] knew there was some risk, but he did for her own good…In short he told a lie. 13

Despite the increasing presence of choice language in matters of consent and risk disclosure in claims framed in negligence the patient’s choice was not paramount despite the rhetoric. Even with Sidaway, where the decision went against the patient, with Lord Scarman only dissenting on the reasoning, it was held that it was acceptable to withhold information from the patient. Paternalism prevailed as the judgement favoured the ‘reasonable doctors and reasonable bodies of medical opinion’ viewpoint. What followed I see as a maturing in the medico-legal decision making process. There was an acknowledgement that patients do require information, and that this includes risk disclosure and the understanding of risk. This major development in ‘protections of one’s own bodily integrity’ and ‘respect for self-determination’ came in Birch.14 With regard to acknowledging the patient’s choice to decline a treatment, whether or not it might be the right treatment for them, was addressed in Re T15 and Re W16 with all their choice talk; recall this from Lord Donaldson in Re T:

This appeal is about the right to choose how to live…the patient right of choice exists whether the reasons for making that choice are rational, irrational, unknown or even non-existent.17

I would extend this further with the patient’s right in choosing not to choose. Furthermore my concern is that the offering of choice becomes (just) a procedural matter rather than one of genuine

14 Birch v University College London Hospital NHS Trust [2008] EWHC 2237 (QB).
17 Re T n. 15 above.
engagement. Without shared decision making choice serves as a medical defence not a patient centred policy.

9.1.5 Choice and the ‘Consumer’

9.1.5.1 Choice: Consents and Demands

Given the language of choice, and the association between the consumer market and medicine, what then for the consumer patient who demands treatment? In 2004 Mr Burke had demanded treatment; the continuation of hydration and nutrition until he died naturally. Here the advance of consumer oriented medicine came to a halt. As Munby J. stated:

Autonomy and the right to self-determination do not entitle the patient to insist on receiving a particular medical treatment…

An initial review of the consumer oriented language within Montgomery might suggest a further judicial shift in considering the right of the patient to make a demand or positive choice. Montgomery marked the formal and final demise of Sidaway. In practice, as was noted in Chapter 3, the Supreme Court endorsed Lord Woolf in Pearce setting the standard for information and risk disclosure based on the ‘reasonable patient’, enabling patient choices but not, in general, endorsing choice as treatment on demand. Nothing in law supports unfettered and unlimited choice, more it engages in and accepts respect for the individual and calls it choice. What Montgomery has done is highlight that this respect relies upon a trust based relationship between patient and practitioner, with sharing not with-holding of information and time (where clinically appropriate) to consider the options and express an opinion.

9.1.5.2 Choice: Managing Confidentiality Matters

There is little in medical practice more sacrosanct than the idea and ideal of confidentiality and privacy for the information discussed by the patient with the practitioner; without it there can be no relationship based on trust. My second research paper looks at the realities of choice, confidentiality and privacy as determined by the law in modern English health care. The health

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18 R (on the application of Burke) v General Medical Council [2004] EWHC 1879 (admin) and R v (on the application of Oliver Leslie Burke) v The General Medical Council [2005] EWCA Civ 1003.
care rhetoric is highly indicative of an individual’s right to privacy and confidentiality with regard to their medical information. There is little to be found that advises the patient of the need to extract and analyse their data in order to promote efficiency and best use of resources as well as gain information on health and ill health for planning purposes. Sometimes that information becomes identifiable, again a feature that is not well known. Statute and case law are increasingly framed towards the language of privacy and confidentiality, yet are constructed in such a (complex) way as to enable data access and use without patient knowledge and/or consent. A ‘traditional legal analysis’ acknowledged that the decision in the case of Campbell was about interference and proportionality in matters of identifiable confidential information, not about developing a tort of privacy. The 1999 decision from the Source Informatics case prevails by virtue of the policy of anonymisation. The technology to unravel anonymised data however is well in advance of the law on this point, which perhaps ought to develop more in managing data misuse.

Further there is a strong argument for enhancing data access and use if it contributes to a functioning health care system even if at times, and out of necessity, a degree of identification is required. What the research did highlight was that yet again, as with consent, there is a lack of transparency in data management matters; patients do not know what is happening to their information and perhaps more critically, why. Efforts to remedy this are likely to increase patient understanding but also their engagement in the process. Without it trust is compromised, a point well developed by O’Neill.

9.1.5.3 Choice and the Chosen Few

In reviewing the NHS and elements of the private health care sector (where in both the restrictions on individual choice are, in reality, at odds with the language in information policy), it became apparent that whilst for the general population medical confidentiality ‘choices’ should, out of necessity have some limitations, there are a number of individuals in society who by virtue of their role responsibility ought to have a more reduced ‘choice’ over the disclosure of their medical information. No one, whatever their professional status, is immune from ill health, physical or psychological. This was reinforced by analysing a combination of recent tragic events and from a more historical perspective involving doctors and politicians. What was found lacking was an

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22 *Campbell v MGN Ltd* [2004] UKHL 22.
23 *R v Department of Health, ex parte Source Informatics* [199] 52 BMLR 65, CA.
acknowledgment that some peoples’ information has to be more available and accessible and that few structures exist to facilitate this in a controlled and acceptable way, and associated with advice and treatment programmes. If anything, policy and guidelines utilised by the GMC are the nearest to a functioning model that could be applied across the professions and trades. The paper also endeavoured to put forward a perhaps audacious model framework for use by politicians and might lend itself to be translated across professional boundaries. Paper 3 has reinforced that confidentiality and privacy over medical information access and use is rightly constrained and that for some people also there needs to be further limitations on their privacy and confidentiality ‘rights’ above and beyond the general population.

9.2 Choice: Fact or Fallacy

At the outset of my research and by its completion there has been little conclusive evidence that patient choice in terms of the competitive health care system or market has had any significant impact on increasing either efficiency in or quality of health care. Further, in terms of respect for self-determination, there is no significant evidence that patient choice improves equity in health care access and may even enhance inequity when the sociological impacts of pre-existing inequalities such as age, class and income are taken into account. There is an intrinsic value in choice at the level of being valued as a self-determining individual. This is imperative when used in association with ‘no decision about me without me’.

9.2.1 Processes Needed

Patient choice and its associated rhetoric would be better placed if the emphasis was on the process and outcomes of patient engagement and shared decision making between the patient and the practitioner. This is well acknowledged in the literature and by the health care professions. This is not without its problems, in particular the possibility that health care professionals have

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‘insufficient…communication skills.’ However, there is a move towards more nurse practitioners, physician associates, so called third party navigators, decision aid tools as well as enhanced ‘help’ services such as the Patient Advice and Liaison Service. All have the potential to both share the workload and facilitate communication. The concern might be that to suggest such a process change would further add-on costs to an already strained system. However this level of support would go a long way to enhance the patient’s sense of value at an intrinsic individual level and of trust in the health care system as a whole.

9.2.2 Outcomes

Is choice in health care a fact or a fallacy? The nebulous answer may be that ‘it depends.’ If the options available to the patient are clearly expressed, discussed and preferences acknowledged then it might be considered a limited form of choice, with the limits to this being made clear. If these elements are not embraced then there can be no real respectful individual choice. Further, if these elements are lacking, any ‘choice’ that attempts to associate patient choice with consumer choice is a fallacious endeavour.

9.3 What Next for Choice?

In order to establish and practise real respect for the autonomous individual there is a need for change in the language of choice. What I argue for is a shift in emphasis from loose ‘choice’ talk that results from variations in interpretation and use of the term, resulting in an opaque concept in health care. The argument is for a semantic shift based on honesty and transparency. It is reasonable and respectful to advise people of the options available to them and acknowledge their preferences. This requires information dissemination and shared discussion and decision making; it requires time and a clear recognition that preferences cannot always be met. Choice is not and should not be unlimited or unfettered. These points have been acknowledged in recent case law and in particular in Montgomery. Here the Supreme Court was right in commentating on the importance of information sharing, but was wrong in engaging (even if briefly) in the language of consumer choices without giving full consideration to its consequences. This is not something a system like the NHS, or health care in the wider perspective, can or should accommodate; it is impossible to isolate the individual from society as a whole. Nor is this an argument for a return to

31 Schlesinger, M., n. 8 above, 377-378.
the days of the doctor simply telling a patient what to do, unless of course that patient has chosen to delegate decision making to the doctor. Doctors have little choice themselves in what they can offer a patient but what they and the policy makers or a ‘third party’\textsuperscript{32} can do is clearly engage with the patient on the presentation of options and the rationale for the latter’s limitations.

### 9.3.1 A New Agenda for Choice, by Research

A core aim for a mantra like ‘no decision about me’ should be to engage the patient in (preferably) shared decision making. It does not mean a supermarket, ‘pick and mix’ approach to medicine. In all categories addressed in this thesis - choice and consents, choice as demands, choice and individual medical confidentiality, limiting the choice of health information and its management for some society members in a role specific way, as well as choice in health care policy, it is noted there has been little genuine effort made such that the patient is part of a trust based, transparent, unambiguous dialogue and engagement. Further, much choice talk is related to having a resource limited NHS, yet the whole issue of health care resources has, in the academic literature, been hived off into a rather separate and specialist field.\textsuperscript{33} However, the patient and their ‘choices’ cannot be divorced from funding matters, possibly requiring a deeper level of engagement still as part of that informed discussion.

Since the advent of patient charters and the patient choice agenda, individuals have been encouraged and solicited into a build-up of expectations of what is on offer from the health service. It would be interesting and opportune to research how patient trust can be retained and enhanced whilst breaking down these expectations to ones that are viable, realistic and affordable in a modern NHS and do not necessarily involve choice. This lends itself to empirical research within the patient and practitioner communities and, perhaps more of a challenge, within the ranks of the politicians. There also appears to be a gap in the research base in terms of empirical research around beyond what patients want and value but looking at where their priorities are over the options available to them and how those options were presented and reasoned. This would necessarily include those patients who choose not to choose, preferring to delegate their decision making. Similarly it would be worthwhile researching within the same communities the understanding of and attitudes to the necessary limitations on access to medical information along

\textsuperscript{32} Schlesinger, M., n. 8 above, 377.

with really establishing the knowledge and opinions about (their) information use and possible misuse.

It would be naïve not to acknowledge that there are inherent difficulties in getting agreement about the real facts around patient choice and the potential for it being no more than fallacious talk. This includes resistance in terms of the political agenda; to clarify patient choice at this deeper and more complex level does not assist the ‘sound-bite’ culture of policy promotion. In terms of the law making, taking forward an honesty and transparency policy is rather limited because in English law this is not codified; decision making depends on the happenstance of what cases come before the courts. Perhaps then it would have been better for the courts to resist ‘choice’ talk and retain autonomy, liberty and freedom from intrusion as the preferred language. One place for my recommendations based around honesty, transparency, engagement and trust to be considered would be the GMC guidelines (under review as of September 2015) on both consent and on confidentiality. This would raise the profile and legitimacy of shared decision making and clarify what is really meant and should be meant by patient ‘choice.’

9.4 Errors of Commission

In any piece of research there are areas with the potential for investigation that remain unaddressed. There is much talk of rights when engaging in discussions around patient choice, yet I have opted not to place any emphasis of competing rights theories. Rights theories are well addressed elsewhere, and are complex and potentially conflicting. I felt the addition of a rights analysis would acknowledge the disparities that I have already identified in the use of choice rhetoric but potentially detract from my main findings and recommendations by becoming a rights not rhetoric analysis. Having endeavoured to substitute choice with preference I acknowledge that I have not delved further in dividing preferences into first and second order hierarchies as per Dworkin and others. I recognise that not all will agree, yet such a discourse would detract from the practical and realistic application of my central thesis.

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9.5 Concluding Remarks

Choice rhetoric quietly slipped away towards the end of the 2010-2015 Government, not featuring in any major party manifesto for the election of 2015, or in the NHS review by Simon Stevens so promoted by the returning Conservative Party. The implication is that whatever the government had set out to accomplish via a patient choice agenda had either been achieved and it was time for a change, or that whatever the original aims of patient ‘choice talk’ had not proved the tool of utility or satisfaction as had originally been intended. My research is indicative of the latter. By the May 2015 General Election in Britain Chris Ham had already observed that:

Competition and choice have gone on the back burner to be replaced by regulation and transparent reporting of information…to improve performance.36

Choice policies remain in place however and continue to be a guise or cloak under which individuals can find their health care being steered towards something that would not feature as their preferred or best part, their choice. The cloak that is patient choice remains non-transparent.

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APPENDIX

The Published Papers
The Fallacy of Choice in the Common Law and NHS Policy

Ingrid Whiteman

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Abstract Neither the English courts nor the National Health Service (NHS) have been immune to the modern mantra of patient choice. This article examines whether beneath the rhetoric any form of real choice is endorsed either in law or in NHS policy. I explore the case law on ‘consent’, look at choice within the NHS and highlight the dilemmas that a mismatch of language and practice poses for clinicians. Given the variance in interpretation and lack of consistency for the individual patient I argue for a semantic change that obviates the use of ‘choice’, focussing instead on the options for treatment that are available and accessible, with due acknowledgement of individual patient preferences, without raising unfettered and false expectations.

Keywords Choice · Demand · English medical law · English National Health Service · Fallacy · Options · Preferences

Introduction

Until recent times both the law relating to patient care in England and National Health Service (NHS) policy was heavily paternalistic, in contrast to the position in the USA. Today patient choice is often invoked both in the judgments of English courts in cases relating to consent to, refusal of and even demands for treatment and in the provision of health care within the ‘modern NHS’. The rhetoric is impressive. Lord Hope in Chester v. Afshar [17]† opined that: “The choice between [these]

† This case hinged on matters of clinical information disclosure and resulted in a modification of causation principles in order to protect autonomy.

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alternatives was for her to take, and for her alone. The function of the law is to protect the patient's right to choose.” The Department of Health has also been clear: “Choice matters because it is at the heart of the Government’s public service reform agenda to empower patients, reduce inequalities in access to healthcare and improve health outcomes for patients” [30, p. 4].

In this paper I analyse some of the medico-legal dimensions of judicial decisions apropos choice and the patient and explore the vogue for proffering ‘choice’ in the English NHS. I shall show that in neither arena is any form of real choice fully endorsed. I hope to demonstrate that choice, an apparently simple notion that appeals to the individual, becomes a complex concept with the potential for flawed understanding. Choices, as we commonly understand them, are neither available to nor accessible by all in a publicly funded health system like the NHS. There is no presumption of choice being inherently good in this paper. Rather, in common law there are boundaries to patient choice that are less apparent in policy and practice making the term neither accurate nor useful. The analysis is Anglo centric, as the devolved administrations of Scotland and Wales have not engaged in choice policy.

This paper is organised into six sections. Following this introduction the next section looks at definitions and interpretation of choice, indicating room for confusion at even this basic level. Choice can be associated with other concepts that are also open to interpretation; ‘autonomy’, ‘consent’ and ‘equity’ for example. The third section concerns itself with the interpretation of choice by the English courts; the developing rhetoric is illuminating. I will argue that, at least until Re T [77], patient choice was rarely taken into account in the face of judicial deference to medical practitioners’ decision making. For 3–4 decades choice was not on the agenda of either the NHS, or the common law as it touched on issues of consent [95, pp. 1–16]. The fourth section addresses and reviews choice as an NHS policy, its recent evolution and practical application, with reference to relevant external policy analyses. In the penultimate section I look at the place and influence of the General Medical Council (GMC), given its relationship with the health care professional, in this instance the doctor tasked with advising the patient. I conclude with a recommendation for a semantic change that more fully represents what the patient can expect from law to health policy in England at this time. Instead of the language of choice we should focus on respect for preferences. There is a hint of this in the NHS Constitution with an association between needs and preferences [25, p. 3].

Why should replacing the word choice with preference make a difference? While the law and policy are weighted towards ensuring that patient preferences are usually met in the area of consent, there is little if any enforcement of patient demand. Thus an abandonment of the term choice, in favour of presenting the options for treatment that are available and accessible requires a transparent engagement and enablement process that allows the patient to express preferences or preferred options, recognising that there are no treatment access assurances in the public sector. It is important to note that preferences may also include the refusal of, as well as the request for, treatment. Both the law and the NHS present a concept of

[2] Notwithstanding that certain preferences may be seen as so bizarre as to trigger a manipulation of the capacity test.

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choice that is neither determinative nor unfettered for the individual; yet the impression given to, and potentially expected by, the patient can be the reverse.

Choice: Definitions and Associations

‘Choice’ is a word that has, arguably, become near-ubiquitous in UK political discourse. It has an air of simplicity in meaning, ingrained in casual use and yet the word is value-ridden. The term ‘choice’ in the context of health care and beyond has become an extension of expressing (or choosing) preferences. To have choice implies that there is the opportunity for an individual to have what they want, when they want it; demand if you will. The most basic dictionary definitions highlight the complexities in using the term with meanings that include, “choice: the act or power of choosing ... the preferable or best part” [15, p. 302] as well as “the opportunity or power of choosing ...” [19, p. 286]. It is this notion of ‘power’, as well as opportunity, which implies a control of outcomes by the individual rather than being merely an expression of preference.

That the individual should be enabled to select his preferred health care treatment would appear to be more than implied by the language of choice. This suggests that choice, in whatever context, is an exercise in self determination and to be applauded. However, such a conclusion is too simplistic. The definition of choice given above is not indicative of choice equating with demand, though current interpretations of choice in health care suggest otherwise. Choice has become a ‘soft’ term, open to interpretation. Health care is promoted to the patient-as-consumer, as in the NHS Constitution, Lord Darzi’s NHS Next Stage Review Final Report and via the Coalition Government’s White Paper Equity and excellence; liberating the NHS. It is unsurprising that patients interpret choice as meaning that their requests and demands can be met. Fotaki [40] have noted that “Choice is a many-sided, diffuse and value laden concept ... the term choice invokes assumptions ...” [40, p. 26]. The problem can be seen in the way the law, health care policy and related commentaries each take a different slant on the process and outcome of patient choice. The same word bears different meanings.

Consider what an English trial judge said in up-holding one Mr Burke’s claim for the continuation of artificial nutrition and hydration:

the personal autonomy which is protected by art 8 embraces such matters as how one chooses to pass the closing days and moments of one’s life, and how one manages one’s own death [81, at 62].

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3. ‘Choice is fundamental to the delivery of a truly patient-centred NHS as it empowers people to get the health and social care services they want and need.’ [My emphasis]. DH Implementation of the right to choice and information set out in the NHS Constitution (London: DH Publications, 2009).

4. Known informally as ‘The Darzi report’, after Lord Darzi of Denham who was commissioned to undertake this review by the Government of the day.

5. Note that this document is applicable to the NHS in England only.


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The Court of Appeal did not agree but the judge’s language illustrates a growing legal association between the idea of choice and the concept of personal autonomy or self-determination. But the appeal court decision set clear limits on personal choice, limits that conflict with the rhetoric used by policy makers and sometimes judges today.

In terms of NHS policy, choice is, or has been, associated closely with equity as much as self-determination. Choice is said to be a tool that enhances equitable health service use, as indicated by Milburn [64] stating when Secretary of State for Health that “greater choice can mean greater equity … making choice more widely available on the NHS so that it is extended to the many not just the few” [64]. He went on to counter this with what may well prove to be a key comment in the future of the NHS: “There are of course limits to choice in the health service … no health care system … can provide unlimited choice” [64].

On the issue of choice and equity however there are powerful arguments to counter any positive association and as indicated by Fotaki et al. [40], “how at the very least, choice policies have the potential to increase inequity” [40, p. 118]. Further, NHS policy documents stop short of advising people what might be unavailable to them or perhaps less popular still, inaccessible.

In a separate work Fotaki [39] notes:

The role that individual patient choice occupies in government designs … shifts the balance of power from professionals to the NHS itself, in favour of the user-consumer while self-appointing itself as a guardian of patients/users’ rights to healthcare … redefined in terms of a consumerist commodity [39].

Efforts to enable individual or consumer choice are perhaps further confounded when at times “A paradox may arise: the patient chooses not to choose” [40, p. 26], a subject worthy of further, separate discussion.

Information dissemination and the time to consider that information in order to make meaningful choices are now accepted in English law. At this time it appears that the law is at least in parallel with the thinking of the health care analysts:

For policy makers, the main message is that giving information needs to be a specific priority if patients are to exercise meaningful choice. Providing information in a way that is useful to patients is not straightforward … a key issue if the provision of choice is not to increase inequity [40, p. 121].

Maclan [60] and Veitch [92, 93] have both recently addressed many of the complex legal issues that arise from the association between choice, health care law and policy and by default, it could be argued, the resulting clinical practice. Maclan raises a counter-argument to that of expanding information disclosure to include options not open to the patient. For example, if a treatment is not “available” to the patient then knowing about its existence becomes ‘irrelevant’ to consent [60, p. 125]. Extending this further raises the question as to whether imparting knowledge about a treatment that is available but inaccessible to a patient ought also to be restricted; the choice that may be available to some becomes no choice for another. The obligation to provide information in such a case becomes a matter of professional ethics and duty of care. Veitch [93, p. 44], in presenting the consumer
choice health policies of the 2005 Labour Government, envisaged increasing litigation based less on clinical negligence claims and hinging more on a lack of choices available or, in the case of resource limited treatments, accessible. Choices that may be available and accessible to some, but inaccessible for others are hardly conducive to equity and may bring the law into conflict with health care policy and practice.

The consequences of the latest proposals in Equity and excellence and its supporting documents have yet to be determined. Commissioning responsibilities involving eighty per cent of the NHS budget in England are to be devolved largely to general medical practitioners in association with secondary care colleagues and a lay membership forming clinical commissioning consortia. Doctors will have to learn to say ‘no’ to patients on purely on fiscal grounds. Some patients will have access to information and be educated about their treatment options, many will not. Will the virtuous professional disseminate information about treatments that the same professional will have to refuse or be unable to commission, or will utility prevail and the patient no longer be told about treatments they cannot ‘choose’?

Choice: The Law in England

Choice (in English law) has developed in an incremental manner that can be classified into three phases. What may be called ‘old’ law made no real reference to choice at all. This led to a phase where the rhetoric of choice could be heard although rarely did decisions favour the patient. Most recently there are judgments that give some (but not necessarily full credence) to the choice of the individual. Paradoxically some recognition of the significance of choice and consent in medical law decision making pre-dates the founding of the NHS, by almost 200 years [87].

Yet within 6 years of the NHS’s inception, in Hatcher v Black [49, 70], Denning L. J. determined that:

it was for the jury to say whether he [the doctor] told the plaintiff that there was no risk or merely proravitiated to stop her worrying ... he knew there was some risk, but he did it for her own good ... In short he told a lie.

This judgment in 1954, supportive as it was of medical paternalism, intimated that doctors might utilise their privileged position over information and its dissemination in the consent process. Perhaps this is because the NHS and its doctors could be seen as benevolent and something for which the patient should be grateful. Subsequently there were infrequent legal challenges [53] to what can be considered paternalistic medical decision-making and its lack of involvement of patients in their own care. Skegg [84] highlighted the emphasis on so called informed consent, rather than choice, with regard to treatment alternatives. He noted

... it was improper to desist the culptus without consent ... it is reasonable that a patient should be told what is about to be done to him, that he may ... put himself in such a situation as to enable him to undergo the operation'.

See also Re W (A Minor) (Medical Treatment: Court’s Jurisdiction) [1993] Fam 64CA where Donaldson, LJ likened consent to a ‘flak jacket’ for doctors.

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both the complexity inherent in the term 'choice' when used in parallel with consent, and intimated that choice in the guise of consent may be less about the patient and more about (protecting) the health care practitioner:

It is the overwhelmingly great emphasis on consent (even 'informed' consent), rather than on choice. Consent does, of course, involve choice. However the choice is usually a matter of whether or not to consent to a particular proposal. The role of consent is often seen to be that of protecting a practitioner from a risk of legal proceedings: information is disclosed to ensure that consent is legally effective [84, pp. 135–165 and p. 149].

In Re W [78, at 635] Lord Donaldson saw consent as analogous to a "legal flak-jacket", protecting doctors from litigation to thus not necessarily favourable in the handing over of power from the patient to the professional via consent. Yet in Re T, as I will amplify later, Lord Donaldson advocated strongly for consent; consent as choice, firmly associating the patient's interests in the language of rights [93, p. 79]. At the present time following a series of recent cases recognising damages for violation of autonomy, judges have moved towards giving some significance to the negative patient choice compared with earlier years. This is not, and may never be, full and unfettered, as positive choices are by no means allowed to be demands.

My Choice is to Accept the Treatment on Offer

In 1981 the first of a series of claims in England relating to what came to be called 'informed consent' was heard. English law seemed to be concerned less about individual patient choice as such and more about claims relating to adverse consequences of treatment. Such injury, accompanied by an apparent lack of information disclosure, might be litigated either in battery or in negligence. If considered in negligence, as most such claims are, the central question is more concerned about the appropriate standard of care for doctors advising patients rather than choice. This was articulated by Bristow J., in Chatterton v. Gerson, "once the patient is informed in broad terms of the nature of the procedure ... the cause of action on which to base a claim for failure to go into risks and implications is negligence, not trespass" [16, 57]. Negligence requires proof of harm in physical terms and until recently English law has largely held that lack of choice per se is not a legally recognised harm. Although it may occasionally have been open to a patient who feels denied of the opportunity to make an informed choice to pursue a claim in battery instead; an inherent presumption of harm arising from violation of bodily integrity might have been a more favourable way of both acknowledging and protecting choice [37].

Recognition that the patient had a substantive role in treatment decision making can be traced to the United States and Canterbury v. Spence [13, 60] in 1972, a

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9 See also General Medical Council (GMC), Seeking Patients' Consent: the Ethical Considerations (1999) Note the statement ‘... take appropriate steps to find out what patients want to know and ought [my emphasis] to know about their condition and its treatment.’

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claim framed in negligence. The judicial language used was firmly oriented towards the patient having choice:

True consent to what happens to one's self is the informed exercise of a choice ... to evaluate knowledgeably the options available and the risks ...

Academic comment in UK went on to advocate a 'transatlantic' approach to the disclosure of risk within the context of negligence [5, pp. 110–111, 116]. Brazier [6] made the point that trespass as a means to endorsing patient autonomy, 'a right to choice', had been in retreat anyway [6]. Further, Brazier's commentary noted that there was "an absence in general of a consumerist approach to medicine ..." That can no longer be considered the case.

In Sidaway v Governors of Bethlem Royal Hospital [85] Lord Bridge talked more specifically in terms of risk disclosure enabling a rational and informed choice:

although a decision on what risks should be disclosed for the ... patient to be able to make a rational choice ... the disclosure of a particular risk ... might be so obviously necessary for the patient to make an informed choice.

Sidaway, a case involving neurosurgery to the cervical spine, has resulted in much academic discussion summarised by Maclean [60, pp. 162–169]. Despite disagreements between the judges regarding standards of care there was a degree of consensus that the patient has a right of (information) disclosure, and thus a doctor the duty to disclose [85, at 905]. In order to make a choice the patient has that entitlement or rather, the enquiring patient. Their Lordships considered that this did not apply to the un-enquiring individual for whom unsought information had (apparently) the potential to be detrimental. Lord Bridge tempered a full shift in favour of the patient, finding that disclosure enabling 'rational' choice was "primarily a matter of clinical judgement" [85, at 505; 55, pp. 273–286]. The argument became rather circular back in favour of acceding to medical opinion; the necessity of informed choice by the patient essentially allowed the medical professional to define the boundaries of the choice(s) available.

Mrs Sidaway's claim that a lack of complete11 risk disclosure constituted negligence was rejected, in spite of Lord Scarman's adoption of a prudent patient standard that appeared more oriented towards the individual patient's choice [85, at 654]. Thus Mrs Sidaway had no choice as, perhaps unsurprisingly at this time, for the majority of their Lordships the 'reasonable doctor' standard from Bolam [10]12 (albeit modified) still prevailed despite the dissent of Lord Scarman [72, pp. 109–110]. It is noteworthy that Lord Scarman himself, whilst utilising a pro-patient choice of language, found against Mrs Sidaway and did not endorse a

10 Lord Templeman. See also Lord Diplock at 895 and 898.

11 Mrs Sidaway alleged that the neurosurgeon (Mr Falconer—deceased) whilst having warned her of possible damage to the cervical nerve roots, had failed to warn her of possible damage to the cervical cord itself.

12 See also [56, p. 123]. '... this judicial deference to medical opinion is partly due to the complexity of the medical evidence, but might also be explained by a sense of professional solidarity, and by the high regard in which the medical profession has conventionally been held.'
situation of unfettered choice, protecting the concept of (medical) professional 'therapeutic privilege' on the basis that:

a reasonable medical assessment of the patient would have indicated to the doctor that disclosure would have posed a serious threat of psychological detriment to the patient.

For many years Sidaway prevailed and there continued to be uncritical judicial acceptance of the views of a responsible body of medical opinion, per the so-called Bolam test. That the level of information disclosure was a matter for the medical professional to determine came with strong judicial endorsements in 1987 in Blyth v Bloomsbury Health Authority [9] (not reported until 1993) and Gold v Haringey Health Authority [46] in 1988. In both cases even the enquiring patient was subject to the Bolam standard and medical paternalism was preserved. Not until 1994 however when a 28 year old man developed impotence after rectal surgery did a claim that a patient had not been warned of such a risk prove to be successful. The judge in Smith v Tunbridge Wells Health Authority [86] found that the common practice of not warning patients, as noted by the expert witnesses, should not be considered 'reasonable or responsible', implementing Lord Bridge's 1985 recognition of choice.

Subsequently in Bolitho v City and Hackney HA [11] the judiciary reasserted the power of the court to question expert medical opinion. The expectation of logical medical decision making derived from the Bolitho case was applied in Pearce v United Bristol Healthcare NHS Trust [73]. The claimant was pregnant with child number 6 and 14 days past her expected delivery date. Her request for Caesarean section was refused on safety grounds. A fetal death in utero occurred 5 or 6 days later with a stillborn baby being induced after a further 24 h. Mrs Pearce claimed that the obstetrician had not disclosed the risk of still birth, a risk of 0.1–0.2%, by waiting for natural labour to begin. Lord Woolf recognised the paternalism inherent thus far in information disclosure and that a patient needs information in order to choose:

that if there is a significant risk which would affect the judgment of the reasonable patient … it is the responsibility of the doctor to inform the patient of that significant risk … so that the patient can determine for him or herself as to what course he or she should adopt.

Read literally Lord Woolf seemed to suggest that the doctor now owed a duty to the patient to disclose risk; risk that any ‘reasonable’ patient would require in order to consider their decision, and so make a choice [63]. And yet still the decision did not fall in Mrs Pearce’s favour, hinging more on significance of risk as determined by the medical profession, than an entitlement to information in order to make or support a choice. So while Lord Woolf associates risk significance with information

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13 It is notable that Morland J found that a failure to give a risk warning (impotence in this case) could be considered 'neither reasonable nor responsible.' Judicial views were shifting.

14 In Bolitho their Lordships defined the requirement for any professional opinion, including a body of opinion, to 'withstand logical analysis'. That analysis is judicial analysis.
disclosure, he appeared to trust the doctor’s view as to what actually constituted a significant risk:

the doctors called on behalf of the defendants did not regard that risk as significant ...

In practical terms, as Jackson [56, p. 277] points out, Mrs Pearce’s own judgment as to whether a risk was sufficiently material for her to have her choice endorsed, was over-ridden by virtue of a reliance on the doctors’ assessment.

Pearce also raises another question not fully explored previously. Mrs Pearce was not just in a position to consent to or refuse treatment; she was placing a demand on the health service, a demand for Caesarean section, the treatment of her choice. This aspect of the case has not been addressed and yet to place a demand on the system opens up a new aspect on patient choice considered later in this paper.

Lack of Choice Equals Harm?

So far the courts had been ascribing relatively little value to choice but a series of decisions relating to failed sterilisations brought about some change. By 1999 the courts were giving consideration to infringements of claimants’ autonomy, which by default had influenced their choices or rather a lack of the same. In two wrongful pregnancy cases, McFarlane v Tayside HB [61] in 1999, and developed further in 2003 in Rees v Darlington [76] modest damages were awarded in acknowledgement of the harms resulting from such a breach of an individual’s autonomy, even though the substantive harm was found irredeemable. Do these judgments reflect a robust endorsement of patient autonomy and choice at last? Coggon [18], in an insightful reflection on the position of English law, opines that judges do not treat autonomy with a ‘full intellectual rigour’ and equate it with self determination and bodily integrity despite it being ‘a concept of unspecific scope or meaning’ [18, 236–237; 93, pp. 77–104]. Perhaps the same is true when endeavouring to equate choice with autonomy. However, from 1999 the jurisprudence relating to consent gives credence to patient choice in two ways. The first is via the violation of autonomy route and secondly, as I will show, by a ‘mauling’ of the law on causation.

Chester v Afshar [17], emanating from the private healthcare sector in 2004, has the potential to alter both choice seeking and affording behaviours inherent in the consent process. In addition it resulted in a judgment that introduces a significant cognitive element to consent and hence choice. Miss Chester underwent spinal surgery that resulted in a paralysis known to occur in 1–2% of such cases, with the facts of the case bearing similarities to Sidaway. The statistical risks were not disclosed to Miss Chester pre-operatively and on this occasion the defence acknowledged the materiality of that risk. Lord Steyn [17, at 18] makes an association between choice and autonomy citing Dworkin’s [34] Life’s Dominion:

The most plausible account emphasizes the integrity rather than the welfare of the choosing agent ... the value of autonomy. Recognizing an individual right of autonomy makes self-creation possible [34, p. 224].

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It was found that Miss Chester would have been subjected to the same risks if she had consented to the operation at a later date by a different surgeon. The majority in the House of Lords agreed to a modification of the principles of causation. In moving the reference points for conventional causation, Lord Hope seemed clear, that:

For some [patients] the choice may be easy—simply to agree or to decline the operation. But for many the choice will be a difficult one, requiring time to think, to take advice and weigh up the alternatives. The duty is owed as much to the patient who, if warned, would find the decision difficult, as to the patient who would find it simple and could give a clear answer to the doctor one way or the other immediately [17, at 86].

The decision has not been without subsequent academic legal comment [47, pp. 1–21; 38]. Maclean puts this apparent shift in causation succinctly:

Following Chester ... claimants will succeed if they can show that disclosure of risk would simply have altered their decision. Claimants no longer need to show that they would have refused consent to the proffered treatment [60, p. 188].

The structure and resourcing of the NHS rarely enables repeated visits from patients whilst they consider issues around a particular treatment. Can the courts ever really differentiate between decisions made in the NHS and the private health system? [94]. That notwithstanding, it is noteworthy that causation has now been expanded. The concept no longer includes (just) the disclosure of treatment information and risk, but rather there is a recognition that some people, sometimes, need more time to reflect and consider all the options (choices) open to them. In his analysis of the 2006 case Al Hamwi v Johnston and another [1] Miola [66] further enhances this cognitive and temporal element:

the notion that what is important about risk disclosure is that the facts are imparted rather than communicated effectively [my emphasis] should be resisted [66, 113, and 33].

Jackson [55, 56] acknowledges that whilst the competent adult (usually) has a right to decline a treatment that they do not want, the decision has to be made having considered the appropriate risks and benefits of any ‘available’ treatment. In turn this requires the dissemination of information: “... whether or not patients will get this information still generally lies within the doctor’s discretion” [55, p. 285]. These are valuable points given recent developments in health care policy and practice, as this paper will show.

Chester may have resulted in a shift in judicial thinking. The individual once in possession of information and given the time to consider that information, may refuse or defer medical treatment even when their advisers consider proceeding to

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15 Lord Hoffman acknowledges the ‘political and economic’ consequences of litigation on the NHS perhaps implying that there is the potential shift in causation rules dependent upon whether the cases emanate from the public or private health care sectors.
be in the patient’s best interests. Furthermore, the enablement of a choice over one’s treatment enhances both the protection of one’s own bodily integrity [75, p. 11] [16] and respect for self-determination, as illustrated in Birch v University College London Hospital NHS Foundation Trust; [8] where the claimant had suffered a stroke following cerebral angiography. It was found that had the patient been ‘properly informed’ about alternative procedures and the comparative risks, she would have declined the procedure that ultimately resulted in that stroke; her choice was impaired.

My Choice is to Decline the Treatment on Offer

The patient’s preference may be to refuse a recommended treatment. Any discussion of treatment refusal does risk focussing on patient capacity rather than patient choice. However, it is illustrative how a patient’s choice in such cases becomes a malleable entity depending on the prevailing norms and mores. The influence of medical opinion and the judicial interpretation or manipulation of mental capacity thresholds still have a bearing on the individuals’ opportunities to decide for themselves, to have their preferences given force. Choice is not just about accepting or agreeing to treatment.

In Re T [77] there was a complete rejection of the patient’s choice. The pregnant Ms T, having agreed to a Caesarean section following a road traffic accident went on to decline any blood transfusion on faith grounds. Following a stillbirth Ms T haemorrhaged and became comatose. Ms T’s father, supported by her partner, applied to the court seeking a declaration that it would not be unlawful for a transfusion to be given. An interim order was made and the transfusion given before a full hearing took place. Subsequently, in the Court of Appeal Lord Donaldson utilised choice language and argument. He commenced his judgment thus:

This appeal is about the right to choose how to live ... even if the choice, when made, may make an early death more likely.

Further stating that:

... the patient’s right of choice exists whether the reasons for making that choice are rational, irrational, unknown or even non-existent.

Lord Donaldson addressed ‘the conflict of principle’, that is, the conflict that exists between the individual and their society:

Society’s interest is in upholding the concept that all human life is sacred and that it should be preserved ... [77].

This highlighted the difficult equation of meeting the choice of the individual when the choices made can be hard for others to accept and leading to what Maclean calls, “a sliding scale risk related standard of competence” [60, p. 156; 38, as cited

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[16] Priaulx recognises that bodily integrity can be considered a basic physiological need, and the ‘critical importance of bodily integrity to one’s sense of self.'
in 56, p. 229] derived from Lord Donaldson belief in Re T that “... capacity ... was commensurate with the gravity of the decision.” Recall Lord Donaldson’s ‘flak-jacket’ analogy in Re W [78]; where consent was seen as a mechanism for protecting the practitioner from the patient. Correspondingly, it could be argued that an emphasis on having offered the patient a choice, acknowledging same but not exploring or enabling it, would a priori suggest that choice talk serves much the same function. The affording of an apparent choice may serve to protect the health care professional from lapses in engagement with the patient and any critique or potential litigation that might ensue.

A person’s capacity appears to feature more in situations that involve the consequences of choosing to decline treatment rather than the risks of agreeing or consenting to interventions, where capacity will rarely be questioned [80]. Brazier and Cave summarise the three areas that led the Court of Appeal to determine that T’s choice was not autonomous [5, p. 102]18 and whilst due acknowledgement was given in this case to the notion of individual autonomy as a function of choice, the sanctity of life argument was the final determinant.

In case of doubt, that doubt falls to be resolved in favour of the preservation of life for if the individual is to override the public interest, he must so do in clear terms [77].

In 2002 there was a further development in Re B [67]. Again the consequences of accepting the choice of this competent adult patient would result in her dying, but to allow her choice required that doctors act to switch off the ventilator. Ms B’s wish, her choice, after years of severe disability and artificial ventilation, was that treatment cease. Those health care professionals whose own choice was not to participate in the cessation of Ms B’s ventilatory support were able to decline, and a unit was then found that accommodated her needs and wants. One can only speculate on the consequences for clinical conscience, medical duties and patient responsibilities if no such unit had been available, or there was no vacant bed. The patient may not be the only arbiter of choice. Ms B had to go through some 18 months of psychiatric assessment in order to convince doctors and the courts of her capacity, and achieve her wishes; it took time to prove the validity of her choice [7, 291–301].

The issue of capacity and the choice to decline treatment is challenging despite the decision in Ms B. The difficulty remains, once an assessment of capacity is deemed necessary, and to paraphrase Glover-Thomas [45], in how to tease out what is a rational mental state from mental illness, personality disorder or incapacity [45, p. 104]. If refusal of treatment is seen as demonstrative of a compromised capacity then treatment can take place despite the choice of that individual. This was demonstrated both in R v Collins ex parte Brady [83], where Brady challenged being force-fed, and in NHS Trust v T (Adult Patient: Refusal of Medical Treatment)

17 Note the somewhat paradoxical decision where during the time C was refusing consent to a caesarean section she was challenged as lacking capacity, yet once the courts became aware that C had changed her mind in favour of consent, her competency to consent was no longer in doubt.

18 A multi-factorial situation that included the effects of injury and medication, a lack of credible information apropos the consequences of treatment alternatives and extrinsic family (maternal) pressures making Ms T’s decision ‘less than independent and voluntary.’
[69], with T's advance refusal of blood transfusion. There is a blurring between competencies and enabling irrational and bizarre decisions, versus incapacity and preventing irrational decisions being carried through.

What then for that individual whose choice is a positive one: a request or demand for treatment? The above apparent respect for autonomy and hence choice would suggest that these people too should be afforded the same opportunities to access treatment as those who decline. Is this the case? It would appear not to be so however, with a further and controversial development apropos choice and consent.

My Choice is to Demand Treatment that is Available but Not on Offer

Mr Burke [81] also argued that his preferred treatment choice should be met. He suffered with an incurable degenerative neurological disease that in all likelihood would leave him sentient but totally immobilised and dependent on others. He would be unable to feed himself or take fluids naturally. Mr Burke sought to choose artificial nutrition and hydration (ANH) until his own vital organs failed. Just as Ms B chose to die and the law endorsed her preference, he chose to live as long as he could. Mr Burke's preference was based on a claim that he could demand treatment. The Court of Appeal however was clear that Mr Burke should receive the treatment that he sought but on clinical grounds and not through his own demand preference.

Mr Burke challenged the 2002 GMC guidelines for doctors on withholding and withdrawing treatments that may prolong life:

it is your responsibility to make the decision about whether to withhold or withdraw a life-prolonging treatment, taking account of the views of the patient or those close to the patient [44, Part 2 para. 322, p. 17].

Further:

Adult patients who have the capacity to make their own decision can express their wishes about future treatment in an advance statement [44, Part 1, para. 13, p. 9] ... However, where a patient wishes to have a treatment that—in the doctor's considered view—is not clinically indicated, there is no ethical or legal obligation on the doctor to provide it [44, Part 1, para. 16, p. 10].

Mr Burke endeavoured to utilise Articles 2, 3, 8 and 14 of the European Convention on Human Rights (ECHR), to assert there was incompatibility between this guidance and his human right to remain alive with the aid of ANH, having already made an advance directive detailing his choice.

Munby J, performed a critical and comprehensive analysis of the ethics, common law and Convention law [36; 5, pp. 27–39] that underpinned the case as well as engaging with the medical professional issues raised [81, at 213 and 214]. The issue of health care resourcing was notably absent [81, at 26 and 27]. The judgment might have been seen as moving from a situation where the patient could expect to be able to refuse medical treatment once in possession of enough information and given the

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19 It should be noted that as of July 2010 this document is replaced by 'Treatment and care towards the end of life: good practice in decision making' (London: GMC, 2010), p. 88.
time to consider the consequences, to the position where a patient could demand an established medical treatment, ANH. It is noteworthy that Munby J. rarely mentioned choice himself, being content to cite preceding cases that utilised choice language [81, at 42, 55, 56, and 62]. There is one exception when he refers to:

... the personal autonomy which is protected by article 8 embraces such matters as how one chooses to pass the closing days and moments of one’s life, and how one manages one’s own death [81, at 62].

Munby J. considered that Mr Burke had reflected on his situation and his judgment indicated a cogent analysis of what could be considered universal principles, underpinned by the European Convention. This could have been another pivotal moment for patients, practitioners and medical law alike. The Court of Appeal did not agree [82] and ensured that the boundaries, as far as patient choice in their own treatment is concerned, remained where they had been pre-Burke. Choice does not include a claim to demand a treatment.

Where a doctor offered a patient more than one possible treatment but with a particular recommendation for one of them, the patient’s right to refuse that one appeared to give the patient the positive option to choose an alternative treatment. However that choice was nothing more than a reflection of the doctor’s duty to provide a treatment considered to be in the best interests of the patient ... [82]²¹

Furthermore:

Autonomy and the right to self-determination do not entitle the patient to insist on receiving a particular medical treatment ... Insofar as a doctor has a legal obligation to provide treatment this cannot be founded simply upon the fact that the patient demands it [82, at 31].

The patient does not have the power to choose certain options, just the power to refuse treatments and express certain preferences. Mr Burke’s ‘demand’ for his choice to be met was a step too far and firm limits on apparently autonomous choice now appear set. Gurnham comments similarly:

... it makes good practical sense to allow doctors some legal leeway when a patient demands resources that cannot justifiably be provided to the detriment of other’s needs [48].

It might be argued that any such ‘leeway’ ought to be part of an overt and transparent process that involves the patient in understanding NHS limitations.

Veitch [93] analyses both the reasoning of Munby J. and the Court of Appeal highlighting the tension that has emerged in health care law as a result of human rights talk. There is a tension between the stance taken by Munby J., and that which involves an “avoidance of judicial engagement” in ethical dialectic issues in favour of a ‘case-by-case’ approach based on a standard legal rationale [93, pp. 123–127].

²⁰ There is a semantic argument to be had that treatment is at variance with management and that ANH is no more than management.

²¹ See headnote.
Were there extrinsic influences upon the Court of Appeal decision-making given the involvement of the Secretary of State for Health because of the wide ranging implications for policy and practice had the decision of the court of first instance prevailed? For the GMC after Burke, perhaps it is unsurprising that their guidelines for doctors on seeking patient’s consent were revised in the light of recent case law, into a document that aims to address both consent to treatment and demand for it [43]. Note the following statement apropos Burke: 

... for the purposes of this guidance, the key point is the court of appeal’s opinion that doctors are under no legal or ethical obligation to agree to a patient’s request for treatment if they consider the treatment is not in the patient’s best interests [43, p. 39].

Now questions can be raised with regard to Pearce which classically is considered in terms of informed consent and thus choice. Mrs Pearce like Mr Burke was actively choosing a specific treatment rather than refusing an intervention. Perhaps like Mr Burke, it could be argued that she had no right to demand treatment of her choice, but what she was denied was the information needed to enable her to express her preferences or seek a second opinion. More controversially perhaps, had Mrs Pearce demanded Caesarean section based on personal choice rather than concerns about risk, would the GMC and/or the Secretary of State for Health be involved as interested parties, and would those interests be based on medical concerns or financial and resource limitations?

In English law what choice the patient can have is currently based on what may be called intrinsic and cognitive factors; the receiving of information and being given the time to assimilate that information. This has led to a right to say no, and even then constraints may be in place on a choice that could be perceived to be a flawed preference. A tension has emerged as demonstrated in Burke that centres on the acceptance of negative patient choices that may favour the patient. Allowing the individual patient to state what treatment they want and receive it as a (self) determinative option remains unavailable and potentially unacceptable.

As English law has developed incrementally in favour of acknowledging that the patient has a form of choice, albeit limited, does English NHS policy and practice have a similar accord?

**Choice and the English NHS**

Patient choice, the where and when you can be treated, not what treatment you may want or can have, has been core government strategy [90]. It has developed a high profile in English NHS policy [32, p. 89; 29; 30, p. 4; 27, p. 3], focussing on the individual and their health care choices [79]. Lord Darzi, in his 2008 report, ‘High Quality Care For All’ [28], talked specifically of patient empowerment allied with

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[32] Known informally as ‘The Darzi report’, after Lord Darzi of Denham who was commissioned to undertake this review by the Government of the day.

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choice: “empower patients with greater choice, better information, and more control and influence” [28, Section 3 para. 25, p. 38].

The change of Government in the UK has reinforced this philosophy [51, pp. 24–26]. The July 2010 White Paper “Equity and excellence: Liberating the NHS” [24], which remains to be implemented in the controversial Health and Social Care Bill, states that “Patients will have choice of any provider,” and for the first time in writing, “... and choice of treatment” [24, p. 3]. A subsequent consultative document “Liberating the NHS: greater choice and control” [23] translates the White Paper rhetoric further by attempting to illustrate what is meant by phrases such as “choice of any willing provider” [23, pp. 6–7] and “we will introduce choice of named consultant-led team” [23, pp. 9–10].

Such statements need to be placed in the context of the major changes in NHS care commissioning. In the order of 80% of the NHS budget is to be transferred to locality based clinically-led commissioning consortia. These will have the power to negotiate service provision with any ‘qualified’ (formerly ‘willing’) provider and only a limited number of services and care conditions will be centrally managed [24, p. 28]. Contracts may be made with providers from the existing NHS and from the private sector. Some of the latter are likely to be large and experienced overseas-based health management organisations (HMOs); others are already established as alternative providers in the UK [35]. It is plausible that in time HMOs and experienced clinical commissioners may find the proposed national tariffs designed to expand patient choice unprofitable to work with and in time may develop the economic market force to amend the list of choices on offer. Clinical commissioners will be expected to run lean and efficient services at consortia level at the same time as offering this choice mantra to the individual patient. The consultative document talks in terms of:

people should be offered choice of treatments as a matter of course. This is not just about whether to have treatment, but also which treatment to have.

From a consumer point of view this would seem a significant step in the new market economy of the NHS, yet the same statement also talks in terms of choice not being offered ‘where clinically inappropriate or unfeasible’. There is an inherent tension within the statement because it becomes a case of who decides. Is the choice ultimately still one made by doctors? If a lack of feasibility is determined to be a consequence of commissioning and contracting decisions, there is a risk that choice as such is a function of availability not patient preference or need. This seems at odds with the earlier ‘free choice’ rhetoric.

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24 An NHS Commissioning Board will be responsible for commissioning dentistry, community pharmacy and ophthalmic services, as well as national specialised services such as transplantation.
Choice, per se, was never part of the original NHS vision. A patient choice programme sounds like a complication in the fine balance between the individual and general utility, in favour of the individual (autonomy) [3]. This would suggest that the best any public service can and should offer is the acknowledgement of individual preferences from a limited list of services on offer. Yet the NHS Constitution might suggest otherwise:

You have the right to make choices about your NHS care. The options available to you will develop over time and depend on your individual needs [25, p. 7; 26, p. 23].

The NHS Constitution of 2009 appears to place patient choice firmly in the language of rights and is barely countered by the statement that:

You have the right to drugs and treatments recommended by NICE ... if your doctor says they are clinically appropriate for you.

This statement did have the potential to become redundant with Coalition government plans to remove the role of the National Institute for Health and Clinical Excellence (NICE) on mandatory matters of medicines approval and cost; in favour of centrally organised value based drug pricing, with clinical commissioners then making the decision as to whether their locality can afford the chosen treatment [58]. This raised fears of internal health tourism between consortia boundaries. A recent policy U-turn that allows value based drug pricing but retains NICE in its drug approval role has not however removed the present ‘postcode lottery’. Consortia will still have to balance their books and as with the current PCT system they may decline to fund some treatments at a locality level. Patients of one commissioning group may be able to access or choose a treatment, yet a patient in a neighbouring area under a different clinically-led commissioning consortium potentially may not [12, 91].

Does the NHS Constitution give patients like Mrs Pearce or Mr Burke the right to demand treatment as their individual needs develop over time? Could the Constitution underpin legal challenges on the basis of patients’ positive choice-as-demands, such as those argued for in Burke and given the legality that the Constitution has acquired by the Health Act of 2009 [50]? Alternatively will the health White Paper and any resulting primary legislation underpinned by the NHS Constitution lead to an increase in judicial review cases? These are likely to be challenging the decision making of clinically-led commissioners engaged in the difficult equation of managing locality demands with those of the patient and their individual choices and preferences.

There exists a wide spectrum of opinion about the rationale for a choice agenda within NHS policy, ranging from cost containment [52] through to promoting enhanced quality initiatives, and concerns about equality [2] and quantity rather than quality [68, p. 92]. Consumer organisations have raised concerns about the new

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health market economy having the potential to restrict patient access rather than enhancing such access for all patients [62]. Veitch [92] makes a case for this, asserting that affording choice to the patient makes them an unwitting tool in the political manoeuvres of cost containment and resource management. If someone needs hospital treatment and the local hospital downsizes or closes as a result of efficiency measures then the only ‘choice’ available to them is to travel. Thus if patient choice results in a service closure, the patients have themselves to blame. The responsibility for a particular policy becomes that of the patient and patients have already been told that with rights come responsibilities. This may be restrictive to those who are most in need: the immobile and the vulnerable. It remains unclear whether choice is always what the patient actually wants, preferring clean, local and accessible health care facilities instead [14]. Currently, all patients when referred for non-urgent treatment under the free choice policy can choose to have that treatment at any hospital listed in a service directory; a list that includes NHS and independent (private) sector service providers.

Results from the Kings Fund collaborative on how patients choose a provider and how their providers respond are unsurprising if complex to interpret. Almost half the patients did not recall that they had been offered a choice. For those who did so, the majority of patients chose their local provider. The reasons cited again included (as perhaps could be expected) care quality, hospital cleanliness and the standard of facilities, along with a lack of transport to more distant providers. Previous poor quality care in the locality seemed to be the rationale for selecting a non-local provider.

But the recent research by the Kings Fund [89], as summarised by Coulter [20] notes that an “offer of choice has an intrinsic value to patients”, regardless if their intention or action involves changing from one health care provider to another. This has a resonance with the present English law on treatment consent and refusal. There is an emphasis on the intrinsic or cognitive nature of choice rather than on an extrinsic policy structure purporting to deliver choice.

Pollack, in 2005, raised concerns about the introduction of competition between health care providers:

The new financial system creates conflicts between the interests of patients and the interest of hospitals ... the new incentive system has nothing to do with need and everything to do with the supermarket model of care [74, p. 231].

The recent health reform proposals enhanced the place of competition in commissioning. Subsequent protests have resulted in amendments that at first glance dilute the role of the market; time will tell.

The King’s Fund endeavoured to establish if the competitive element between providers aimed at creating efficiencies and enhancing quality had been achieved. The results indicated a variety of purchaser models primarily working to retain and enhance their reputations rather than being in significant competition for new patients. Providers complained about GPs ‘giving little attention to quality’ and GPs complained about the actual structures and processes in place such as the electronic appointment booking facility ‘Choose and Book’ [31]. The study identified that GPs
were enabling the patient to choose a provider should a referral be deemed routine, yet were 'more directive' in the event of feeling that more specialist services were needed. How this might now change will be interesting.

In England for both the patient and the doctor there are two parallel streams of activity utilising choice language. There is a need to navigate a legal system that more or less endorses negative patient choice and a policy and practice that says a lot about where and when a person can be treated. Yet despite recent and enhanced choice rhetoric it does not in reality permit the patient to demand treatment or necessarily improve accessibility to care. It is not clear from the Health Bill or its proposed revisions how, if at all, equitable access will be seriously considered. Is 'choice of treatment' an extrinsic economic tool that perhaps fortuitously (for health policy) appeals to the intrinsic values of the patient.

**Choice: Practitioner Perspectives and the GMC**

If Mr Burke or any other patient with a positive treatment choice feels let down by the legal system, health policy or both, it leaves the doctor facing that patient demand and acting as a linchpin when the two streams converge. From the perspective of the medical practitioner in the front line for the delivery of NHS care and its choice policies, and mindful of the English legal expectations, they may look to their regulatory body, the GMC, for guidance on managing this era of patient choice, the mismatch of patient expectations and the reality of law and policy [43, p. 8 and 39]. Linking back to the doctor's duty to impart information, Miola [65] indicates that the recent GMC guidance expects the doctor 'to communicate with the patient rather than just list the risks inherent in the treatment' [65]. In this context communication does not just mean listing the choices on offer and risks attached, but engaging in a much more holistic manner in the patient's ideas, concerns and expectations as well as the practicalities of clinical management. This must include dealing with patient demand for treatment, now potentially perceived as not just a choice but their right.

The decision in *Burke*, encapsulated in best interests, was not restricted to just Mr Burke himself, but the wider concept of the doctor-patient relationship where patients are deemed unable to demand treatment that doctors feel is not in (any) patients' interests. Patients need to be made aware that there may be treatments that the doctor does not believe will be effective despite the patients' own desires. And patients will need to be aware of treatments that the doctor thinks will be effective but are not or no longer available via the NHS [71].

The GMC guidance following Burke is very specific about managing a patient's positive choice or demand: [43, p. 39]

Doctors are under no legal or ethical obligation to agree to a patient's request for treatment if they consider the treatment is not in the patient's best interests.

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26 Given the release in July 2010 of *Equity and excellence: Liberating the NHS* [23], it remains to be seen how devolving 'power and responsibility ... to GPs and their practice teams working in consortia' in a primary care commissioning format will influence the concept of patient choice.

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It is less clear whether the doctor has to be open about the reasons for turning a request down when the argument remains in the realms of ‘best interests’. GMC guidelines also remain less than specific on advising patients about the treatment options that may be in their interests but are not accessible to them, including those not obtainable via the NHS [59, p. 14]. Furthermore they may need to be reviewed and changed in the light of current health reforms. For example, in the context of the White Paper proposals patient A should be able to choose between treatments offered by any consultant led team (or similar) that their doctor believes will be effective. These may be provided via the NHS (e.g., a Foundation Hospital Trust) or by private health care companies with whom the patient’s consortium has an NHS contract. That sounds equitable. However, what if the patient’s commissioning body has decided against a contract with the organisation that offers the chosen service for whatever reason? Further, there may be situations as already demonstrated in contracts with the private sector in recent years, where provider companies have been able to ‘cherry pick’ the patients to whom they are prepared to offer treatment [21]. Patient A chooses the treatment; his GP endorses his choice but the chosen provider turns him down. A fit patient may be seen for a routine hip replacement but is it possible that another individual who happens to be elderly and immobile and diabetic may be excluded from the contract terms, not just for reasons of clinical risk management but also to contain the risks of costly follow up?

Does GMC guidance assist the doctor in knowing how far he must inform individuals of what treatments they cannot choose, or in considering how to manage the case of an individual for whom a listed choice is not accessible, for reasons of health, distance, personal finance or public resourcing perhaps? If not this would support the potential scenario described by Maclean earlier, that is, the possibility of withholding information from patients when options are not available, or accessible.

GMC guidance does develop a model of patient centred care that seems to overtake anything that English case law has developed. Miola [65] alludes the GMC guidance more to an antipodean model such as the New Zealand Code of Health and Disability Consumers’ Rights (1996) in that patient-doctor discussion needs to include ‘unsolicited’ information [65, p. 106]. In practical terms there is a question about how applicable such guidance can ever be, in a resource limited service such as the NHS, although the same GMC document is specific about giving patients time to reflect on treatment information [43, p. 13] and obliges practitioners to raise concerns with their own employers/contractors should that time be restricted [43, p. 25]. This raises a further question for the practitioner-patient relationship. Are there genuinely the resources available to facilitate a patient-doctor alliance in the way recommended, such that the individual can genuinely state and make their choice? Concurrently and not yet codified, as part of the guidance on ‘a relationship based on openness, trust and good communication’ [43, p. 7], the doctor should, I argue, be able to advise or refer on for advice about the potential methods by which a patient can challenge decisions that decline their ‘choice’ of treatment. This would

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See also GMC, Treatment and care towards the end of life (2010). Detailed professional guidance on the complex issues that arise at the end of life/near end of life (including resource constraints) that also emphasises involvement of the patient, their partners/family/careers and the health care team in decision-making.
need to include challenging decisions at local consortia level through to the more complex challenges of process as in judicial review.

The White Paper supporting document Liberating the NHS: An Information Revolution [22] is concerned with the structure of health care information strategies and the outcomes from the use and dissemination of the resulting data. It is sketchy on the process element that includes engaging the patient with the practitioner and vice versa. The following statement does hint towards a shift in the language away from ‘choice’:

A genuine dialogue in which each brings an important perspective to bear: the health care professional brings knowledge about conditions and treatment options; the patient or service user brings individual needs, protected rights and values, preferences and personal circumstances. (My emphases) [22, p. 22].

In context it is expected that many of these interactions will be via remote internet based methods as well as with face-to-face conversations. The implications for patients, not all of whom will be comfortable or able with newer technologies, and for the GMC with its self stated role of ‘Regulating doctors are ensuring good medical practice’, have yet to be determined. The GMC response to the White Paper proposals has so far been limited [42]. This is largely because the GMC reports that its existing guidelines are able to cover the challenges posed by the reforms and are ‘strongly aligned over matters of the doctor-patient relationship.’ The consequences intended or otherwise for patients of GP-led consortia and for commissioning itself will become clear if the White Paper proposals are implemented and given time to operate. It seems likely that given the so called information revolution, the meshing of the private and public health care sectors, and complex contracting arrangements that still have to afford choice, the GMC may need to develop and expand its guidance further to encompass the specifics of availability and access.

Using a word like ‘choice’ in health care law and health policy/practice might imply that there is a gold-standard (a best part) to be achieved. Just as there are now (many) models of the optimal patient-doctor consultation [41, pp. 184–188] so too are there models of consent to medical treatment [60, pp. 143–145; 4, pp. 171–173 and 319–325]. The reality may be different. The ability of professionals to communicate with the patients in an extensive enough manner to permit an informed choice may well be restricted by the administrative constraints of the choice agenda, the choices may not be available or accessible; that is, not choices at all. This leaves the good practitioner frustrated and the under-performing practitioner potentially shielded behind a method that allows them to state that they have followed the role expected of them by policy. In which case is it ever a choice or merely an expression of preference?

From the policy and practice perspective choice as a term might be abandoned as it becomes a construct fraught with confusing messages. Instead, illustrating what treatment options is really available and, importantly, accessible (by whom and by

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28 GMC publications carry this phrase as a tagline.
what method) is more genuine. Further, there needs to be a detailing of why particular options are on offer or otherwise. The result would be that the patient is in more of a position to express realistic treatment preferences. This is a semantic argument perhaps, but these are important semantics if transparency is to be recognised as part of the engagement process that should take place between patient, provider and practitioner.

Choice: Conclusions

Two systems, of health care law, and policy with practice in health care, can be seen to operate in parallel at the present time. The law has established a boundary at which negative patient choice is usually safeguarded, if open to interpretation in the context of contested capacity, and has resisted an opportunity to enhance decision making that would encompass positive choice or demand. Further disputes on this facet of the law may yet arise but for now a limited and limiting form of choice prevails in law.

The NHS in England is delivering a limited and limiting form of health care, under the guise of patient choice, focusing on where and when care is delivered. The choices offered can impact on the lives of almost all by being part of a modernisation and rationalisation policy in the NHS. The problem centres not on the need to promote the shape and function of the health service, but rather to ensure that the boundaries to any treatment on offer that are necessarily in place are clear and transparent to the user. Without such transparency and despite the clarity at law that now exists, further legal challenges to health services and care seem inevitable.

There must be a tension in any system where the choice that you can have is only the choice that that system or your particular GP can offer, and is not necessarily that which is available. It is a concept that is neither unfettered nor determinative and how those preferences are enabled, or otherwise, remains a function of the health care professional and/or the courts, risking being the rhetorical. Further, if the choice on offer is available but not accessible, is it choice at all? I believe that it is this element that is unclear to the modern patient who is encouraged even by the NHS Constitution to behave as a consumer [28, Section 2, para. 8, p. 26].

Engagement is a popular term in health care, [54] engagement between patients, practitioners and policy-makers; a therapeutic alliance [88]. Any engagement process must stretch beyond just materiality of risk. To facilitate this, ambiguities in language need to be reduced and choice as a term should be abandoned. Terms such as ‘treatment options available’ and the acknowledgement of patient preferences set a clear line on the interactions that take place in health care, without encouraging any perceived guarantees that an individual’s choice can be met. This is more than mere semantics. A greater transparency in both policy and practice is required within a process that ensures accessibility to both information and available treatments. This would go a long way to dispel any illusion of unlimited and unfettered choice in favour of reasonable options.
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46. Gold v Haringey Health Authority [1987] 2 All ER 888, CA.
50. Health Act 2009, Chap. 21, Part 1, Chap. 1. See para. 2. Duty to have regard to the NHS Constitution.


76. *Rees v Darlington Memorial Hospital NHS Trust* [2003] UKHL 52, HL.


78. *Re W* [1992] 4 All ER 627, at 635.


82. *R (on the application of Oliver Leslie Burke) v The General Medical Council* [2005] EWCA Civ 1002.


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The decline of medical confidentiality
medical information management:
The illusion of patient choice

Ingrid Ann Whiteman

Abstract
It is reasonable to consider and trust that information taken from us about our medical health and history will be protected by rules on confidentiality and consent. Apart from very rare cases, perhaps of major public interest or for public health reasons, this information will not be shared with others without our consent. However, both a number of reforms in National Health Service patient data management policy (now enshrined in legislation) and developments in the general law on privacy challenge this traditional view of our control and choice over our medical information, as this article will show. In doing so, it analyses the question as to whether in spite of the rhetoric do any of us now really have choice over the access to and use of our medical data? In reality, our choices are limited and in any relationship of trust and shared decision making this ought to be transparent.

Keywords
Choice, confidentiality, privacy, trust, health care law, human rights, fiduciary, shared decision making

You have the right to privacy and to confidentiality and to expect the NHS to keep your confidential information safe and secure¹ (NHS Constitution, 2013).

Introduction
Recent National Health Service (NHS) operational reforms in England and the data management systems that underpin them continue the patient choice theme so promoted in the White Paper Liberating the NHS,² summarised by the mantra ‘no decision about me without me’³ and subsequently incorporated into legislation in the NHS Constitution above and the Health and Social Care Act, 2012 (HSCA, 2012).⁴ Most people have a sense of what is meant by medical confidentiality. In line with this, at first glance, many patients might be of the belief that no information about them would be shared with others save with their own consent or individually justified by a major public interest concern, for example, that a patient posed a risk of harm to others. Some readers might then be surprised and unhappy to learn that data about them and sometimes data identifying them may now be subject to data extraction. That is to say NHS organisations and private companies are able to access his medical information. What can be called a ‘traditional’ idea of medical confidentiality has been altered and now confidentiality and patient choices associated with it are limited.

Rather late in the day, a furor⁵ has emerged over two related data extraction systems that are being based in general medical practice.⁶ They are intended to take a combination of health care activity information and personal confidential medical information with the intention of ‘support[ing] – my addition] a diverse range of services and initiatives that aim to improve the diagnosis, treatment and prevention of illness’,⁷ as well as facilitating payments to practitioners and service commissioning organisations.

The General Practice Extraction System (GPES) is already in operation and its more controversial element, ‘care.data [sic] has been piloted by general medical practice; the service highlighted in this paper.⁸ At the Centre for Social Ethics and Policy Institute for Science, Ethics and Innovation, Department of Law, University of Manchester, UK

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time of writing, there has been a six-month delay imposed on the implementation of the latter; a so-called public awareness period. Concerns have arisen over the potential for identification of individuals as well as the potential for the selling of personal information to third (non-NHS) parties. In addition, the manner in which patients are being advised about these systems and their options concerning opting out have provoked further debate as will be shown. The policy and practice rhetoric, however, is to afford the patient a choice over their own data.

This controversial episode hides the reality of existing case law and statute relating to individual patient confidentiality and privacy, and the reality inherent in running a communitarian NHS. I argue that case law and legislation as well as health care policy provide gateways to data access often gauged by talk of a right to patient choice and the right to privacy. The relationship of trust and confidence between patient and doctor, in this instance General Practitioners (GPs), has facilitated the discussion and protection of sensitive and personal issues within a ‘safe’ place. Case law appears at first glance to protect this, but as a result of the 2001 decision in *R v Department of Health ex p. Source Informatics Ltd.*, that ‘safe place’ began to be undermined. At the same time and perhaps controversially, I would contend that the fiduciary nature of the patient–GP interaction relating to confidentiality has become eroded as changes in health care policy and practice have been implemented; becoming less fiduciary and more technical in nature. It is tempting to assume that confidentiality is complementary to privacy and as such rights to privacy prevail. Certainly of late, judges have talked more of privacy, albeit where there is no classic relationship of confidence. However, the defences provided for by Articles 8(2) and 10 of the European Convention on Human Rights (ECHR) enable further statutory intrusions to take place beyond those already enacted via Schedule 3 of the Data Protection Act (DPA) 1998, Section 251 of the 2006 NHS Act, Section 9 of the HSCA, 2012 and now the ‘deficient amendments’ to the HSCA via the 2014 Care Act.

The core funding of the NHS is rarely discussed in the same forum as individual patient data management. The key, however, is that this tax-funded service is available for individual members of the public to use. Is it reasonable therefore to expect (our) patient data to be accessed and utilised to the benefit of that NHS; be that as a way of optimising efficiency or improving patient management? Data sharing (our) individual patient information throughout the NHS and beyond to its supply sectors such as the pharmaceutical industry might well be seen as a reasonable trade off in terms of utility and also a necessary reality in resource limited environment despite the veiled rhetoric of patient choice. The key is less about the access use of such data but its potential for misuse. Current and proposed regulations do not easily address the risks inherent in what are already large and will become enormous publicly held databases.

The first part of this article undertakes an analysis of the concept of individual medical confidentiality that is apparently well underpinned by existing case law and statute. In reality, however, is far removed from this. Then, having looked at how confidentiality is branded within primary care in particular, the second part of the article considers whether the traditional fiduciary (patient–GP) relationship in this regard is anachronistic. I consider that efficient and rational data access and management of individual health data are an imperative when utilising a resource limited NHS. Further as established case law and statute over-rides traditional concepts of the doctor keeping our secrets safe from others, what is required is an open discussion about the rationale for data sharing and management; not a faux strategy of offering patients choice, when beyond a certain practical level there is none. The relationship should now be one of trust but not guaranteed confidence. Patient benefiting from the NHS should accept responsible information sharing; a more technical yet truth based relationship.

Perceptions and protections in information management

Problems of interpretation

Information management health policy literature is liberal with its use of terms like confidentiality, privacy and choice. The NHS Constitution is a prime example as is the forward in the Government’s response to Dame Fiona Caldicott’s information governance review (to be called Caldicott II throughout) that contains statements such as:

> …it is vital that we respect people’s privacy and put them more in control of how their information is used.

As well as:

> …health and care organisations should do more to increase people’s understanding of how their personal confidential data is used and the choices they can make…

What is less clear is the interpretation of such terms and as such their consequences.
McHale drew a distinction between confidentiality and privacy as far back as 1993:

An obligation of confidence arises in a situation in which one person gives information to another expecting that person to keep that information ‘confidential’ by not disclosing it to third parties. The person who imparts the information binds the recipient by an obligation of confidentiality. Issues of privacy however may arise whether or not we regard the information as ‘confidential’. The right to privacy relates to the right of the individual to control access to his or her personal information and this does not simply cover information which he or she has passed to others expressly or implicitly expecting them to keep it in confidence. It applies to all personal information.21

On reflection, this statement is prescient. Much of a patient’s medical information is no longer just shared with one other person, a health care practitioner. Computerisation and data distribution means that data can be shared with other IT systems and distant third parties. Arguably therefore, the existing law on matters relating to an individual’s medical confidentiality will no longer be enough as the obligation of confidence is subsumed into matters of privacy, and medical privacy becomes ever more qualified by common law and statutory exceptions.

Confidentiality – Traditional legal analysis

In the early years of the NHS, care was largely carried out in the individual’s locality, letters between practitioners written like personal conversations. Doctors had no need to provide data about the activities they were undertaking in order to be remunerated. Change came in the late 1980s and more rapidly with the 1989/1990 GP contract that saw a rapid expansion in the computerisation of patient notes and the beginnings of the downloading of computerised information to more distant sites, for payment and audit purposes. It was not just the NHS that could access such information. Interrogative systems were developed that could batch download, often overnight, apparently anonymised patient data for use by commercial (usually pharmaceutical) companies. With some systems, the practitioners were remunerated for those downloads.22

Nonetheless, there remained something familiar, comfortable and unique about the relationship between patient and ‘his’ NHS GP. Despite recent changes involving ‘choice’ of GP surgery,23 the process of patient registration prevents the individual from moving from practice to practice repeatedly and for now anyway being registered at more than one practice at any one time.24 Patient held records may be a thing of the future but for now these (electronic or otherwise) are held in the practice and only follow the patient in a manual form upon registration elsewhere. The result, along with an element of inertia perhaps, has until recently been a longstanding relationship between the patient and their GP. Now, this relationship has been diluted with patients seeing GPs they may not know because the doctors have a specialist interest in a particular condition, or similarly practitioners working at sites distant to the GP practice and commissioned to provide elements of primary care.

The much vaunted patient choice agenda and the choice rhetoric that underpins the 2013 HSCA have not altered the fact that the relationship between patient and GP is an unusual and unbalanced dynamic. Having your ‘own’ primary care physician is very much product of the British NHS and not replicated world-wide to any significant degree. As patients, we expect to divulge personal, sensitive and often intimate information in this relationship based on trust, fiduciary if you will,25 to an unbiased, judgement neutral empathetic practitioner who holds much of the power in the interaction. In turn, the GP safeguards that information from external third part access and interference in the absence of the express permission of the patient to do otherwise. This seems fundamental in respecting individuals and their capacity as autonomous decision and choice makers, if at odds with the data downloading alluded to above, a practice unknown to most patients.26

This confidentiality is intrinsic to doctor-patient relationship27 and arguably has been so since Hippocratic talk of secrecy.28 The 18th and 19th centuries saw the advent of a common law making reference to an obligation of confidence and to the restriction of information dissemination.29 That said it is only in the latter part of the 20th century that some form of codification of the principles of medical confidentiality has taken place and duly evolved. Prior to this, medical consultations were minimally documented, if at all, and any relevant paperwork remained in the possession of the practitioner often in the immediate locality. Confidentiality was more a function of the doctor holding an elevated and powerful status within a community and being party to the ‘secrets’ therein. With time, however, patients have been acknowledged as having both expectations and concerns about their medical records,30 and this gained further recognition in the legal system.

There are established common law principles of confidentiality in operations31,32 and tested in a (relatively) small number of cases associated with medical confidentiality33-35 and data anonymity.36 It is worth focussing on the latter issue a little more given the current proposals for extensive patient information databases and the host of related malcontent; a topic that will be
returned to later in this paper. At first glance, it seems almost intuitive that if one's information lacks identifying features, that is, anonymised, then confidentiality is preserved and the equitable duty of underpinning this is maintained. This simplistic view came under scrutiny in *R v Department of Health, ex parte Source Informatics.* Pharmacists and GPs were paid for supplying anonymised prescription information to a data management company who in turn sold the data on to the pharmaceutical industry.

At judicial review, the applicants sought to overturn DoH ‘guidance’ that information from the patient delivered in confidence cannot be disseminated without patient consent, by implication anonymised or otherwise. Their argument being that anonymised information loses its confidential quality. Latham J considered the vagaries inherent in such a claim, such as unauthorised use of information even if anonymised and the potential for ‘subtle but not overt’ harm to the patient. In response to submissions from counsel for the respondent, Latham J touched upon the idea that an individual might be ‘outraged’ if made aware of the use of their data in commercial transactions, even if anonymised. It seems on reflection that Latham J was dipping a toe in the water of individual autonomy, in this case patient choice if nothing else than by engaging them in any debate about utilising their information. In the event and with a decision that may resonate well in the present day Latham J found that there was a potentially actionable breach of confidence. Kennedy and Grubb dissected Latham J’s decision. Notwithstanding references to pertinent aspects of the DPA and the semantics around use and/or misuse of anonymised information with or without patient knowledge and consent, their stance was that Latham J had not argued effectively for ‘disclosure itself’ amounting to a breach of confidence.

Unsurprisingly perhaps *Source Informatics* went on to the Appeal Court. Simon Brown LJ took almost the opposite stance to Latham J, challenging his reasoning thus:

The patient’s privacy will have been safeguarded, not invaded. The Pharmacists’ [in this instance - *my addition*] duty of confidence will not have been breached.

And:

In my judgement… the concern of the law here is to protect the provider’s personal privacy. The patient has no proprietary claim to the…form… or to the information which it contains…. and [importantly – *my addition*], no right to control its use provided only and always his privacy is not put at risk…

This is an interesting statement. The patient is being told what information about themselves they cannot control or have any input to, by virtue of its anonymisation. The Court of Appeal has not been without significant critique. While agreeing with the decision overall, Kennedy and Grubb were concerned about a drift towards confidence becoming a facet of ‘privacy’ and as such:

Misunderstanding the essence of breach of confidence as going beyond unauthorised disclosure of the information so as include other unauthorised or improper uses of the information.

Conceptually, this seems to mean that privacy is about information use or more likely misuse, and confidentiality hangs on disclosure or otherwise. So what in the real world? Without an NHS background, the author would have been unaware of early anonymised commercial NHS IT data extractions and would have been un-nerved to discover this knowing the potential for re-identification. Sharing the facts and even the decisions over the data sale would have left one feeling valued. Yet, as a user of supermarket store cards that gather so-called rewards on itemised purchases linked to their name, the author is fully aware that analysts have the potential to access that data and make judgements accordingly. Are there any real differences? There is certainly a difference in the qualitative feel of the relationship of trust that the author feels with their GP, in comparison with the detached connections they have with the store and its analysts.

As for *Source Informatics*, Miola, reviewing the case in the context of a reformulation of General Medical Council (GMC) guidelines on confidentiality, used a Human Rights Act (HRA) comparative and critical approach. Miola argued that the *Source Informatics* decision was ‘to be regretted’. The Court of Appeal’s decision was too simplistic in not considering the potential for wider consequences of the decision. Examples give included the patient who has ethical issues related to the pharmaceutical industry, insurance concerns related to anonymised ethnic data grouping and the ever present debate as to whether information about the self is or ought to be regarded as one’s own property. One could also ask now in this era of apparent patient choice if our information is not our property, then how can we have any power to choose in matters related to its access and use?

Miola continues his critique of the judicial views in *Source Informatics* with reference decisions from the European Court of Human Rights (ECtHR). For justifiable information disclosure, the ECtHR required that HRA exceptions or necessities apply, as well as protections or ‘safeguards’ from data misuse to be in
operation. Both have the potential to be matters of definition and interpretation by the individual and the State. The classic case involving the model Naomi Campbell, and her successful House of Lords attempt to balance (her) privacy under Article 8 of the HRA with freedom of expression as per Article 10, might have clarified matters of personal medical information and the law.49 As Baroness Hale stated:

…information about a person’s health and treatment for ill health is both private and confidential. This stems not only from the confidentiality of the doctor-patient relationship but from the nature of the information itself.50

This was already saying, with reference to Waterfront v Home Office [2004] AC 406.

That case indicates that our law cannot, even if it wanted to, develop a general tort of invasion of privacy.51

I would contend that in reality the final decision in Campbell simply moved the boundaries for confidential identifiable information to include talk of interference and proportionality; the language of the ECHR. After Campbell and despite subsequent leanings towards same,52,53 the fact remains that there is no Tort of Privacy in English law. The confidentiality arena may have been expanded by case law to appreciate that privacy interests do exist but the laws themselves do not affirm this as a separate concept. Perhaps if such a tort did exist, it would have more relevance in the use and misuse of information rather than the extraction of it in the first place. The precedents set by Source Informatics around the access to our information still stand. As for the GMC and their guidelines, in essence, they defer to the laws of the land.54 Relatively, recent attempts to widen access to an individual’s information were proposed for the Coroner’s and Justice Bill 2009 and were met with such opposition that they were dropped.55 The European Union (EU) too needs to be given due regard as new EU General Data Protection Regulations are imminent.56

The place of statute

With English judges or Parliament yet, if ever, to develop a discrete tort of privacy relating to personal (medical information), then it is an appealing notion to think that there is enough legislation in existence to afford the individual protection via the statutory route. For example, there is a general familiarity with there being a DPA 1998. We often need or choose to share our personal details with banks, credit card companies, the insurance industry and as illustrated above commercial stores via their loyalty cards, expecting that those details are safeguarded by the recipient. Explanatory notes referring to the DPA appear reassuring: after all, it is about data protection, safeguarding personal information. Few ordinary citizens really understand the complexities of the DPA.57 To use an old adage, the devil is in the detail (of the legislation). The DPA is complex in content and definition and well detailed elsewhere; its essence appears protective.58 Medical details may be especially sensitive and not be bracketed abroad. However, in Schedule 3 pertinent to our medical records as ‘sensitive, personal data’, there is provision to access, process and hence release information without consent if:

...the use of the data is necessary for medical purposes (including the purposes of preventative medicine, medical diagnosis, medical research, the provision of care and the management of health services [bold type – my addition]).

The House of Lords have stated that the so-called informational self-determination inherent in the DPA is of ‘moral value’.59 However, this ‘self-determination’, the person’s the individual’s ‘choice’ remains relative and not absolute. Is the protection therefore about the ability to choose, ‘the act or power of choosing’, rather than the ‘preferred or best part’ to opt for? Further, the ability to choose is much enhanced or restricted by the information given to the individual upon which to make that choice.

1998 also saw the enactment of the HRA making the ECHR enforceable against public authorities and thus the NHS. This has relevance with Article 8 and protection for private life.60 Article 8(1) is subtly worded:

 Everyone has the right to respect for his private and family life, his home and his correspondence.

A right to respect for private life is not the same as a right to a private life; it is a rather weak right and it is not an inviolable right.

Unhappily for anyone who may feel this gives them autonomy as a self-determining choice over their medical information, privacy is (only) a relative right; not an absolute concept as the GMC also point out in their guidance on confidentiality.61 Article 8(2) provides:

There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary... in the interests of national security, public safety or the economic well-being of the country...
Matters of confidentiality and national security\textsuperscript{62} and public safety\textsuperscript{63} have been debated in the English Courts. Information and health economics has received less attention. It is hard to dispute that those who use the (tax-funded) NHS ought to contribute to its efficient and rational functioning. This means a willingness to divulge enough personal 'private' information in order to facilitate the economic governance of the NHS. In addition to research and outcomes data, controversially this would include enough information to make for efficient resource management. After all, the NHS expected to make £20 billion of savings by in the four-year period to 2015.\textsuperscript{64} The economic well-being of the country' must include the monolith that is the NHS. Might the European Court ruling in Osman v United Kingdom\textsuperscript{65} fill a gap in the context of data and medical law? With the Court declaring, (with reference to Article 2\textsuperscript{3} that, positive obligations:

must be interpreted in a way that does not impose an impossible or disproportionate burden on the authorities.\textsuperscript{63,66}

The context of this in Osman was around 'policing of modern societies' and this could well be substituted with 'the provision of state funded health care'. For patients, a polarity exists. There is a positive obligation on GPs to manage and protect the 'wellbeing' of the patient including the integrity of their data via the NHS. However, there is no such obligation on the Government when acquiring and using patient information in a way that may or may not benefit the individual.

Maybe the patient could be reassured that the real protections lie not in the HRA but in specific (NHS) health-related statute. This proves not to be so however. Take the NHS Act 2006\textsuperscript{67} and specifically section 251(1) where:

The Secretary of State may by regulation … requiring or regulating the processing of prescribed patient information for medical purposes as he considers necessary or expedient –

a) in the interests of improving patient care, or
b) in the public interest [Bold type -- my addition]

Despite any discussions about what constitutes the public interest, section 251 enables the common law duty of confidentiality be disregarded. Identifiable patient data can be accessed and utilised without individual consent.

The HSCA 2012 presented the ideal opportunity to clarify the legislation on data access, management and dissemination. That clarity could have extended to include the need for good data to equate with good governance as well as defining data protections. Unfortunately, it is a difficult statute to decipher generally. With respect to sections 254 to 259 involving systems and requirements for patient information management, Grace and Taylor call the Act 'Byzantine' in its complexity.\textsuperscript{70} They also provide as clear an analysis of the processes, procedures and new information management organisations as seems possible.\textsuperscript{71} So difficult was it for the (new) commissioning bodies like the Clinical Commissioning Groups (CCGs) and related organisations to access information for planning purposes in their early months, the Secretary of State for Health granted so-called section 251 exemptions. This enabled commissioners to continue to obtain and use potentially identifiable patient data without consent out of a functional necessity. The prime data source being the Secondary Uses Service (SUS),\textsuperscript{72} a data warehouse that purports to aid 'health care planning, commissioning, payment-by-results remunerations, improve public health and develop national policy'.

Deep within sections 245 to 259 of the HSCA 2012 and despite the raft of 'protections' in place that includes Government acceptance of the Caldicott II recommendations, the sub of it remains that identifiable information may be gathered when at section 254:

(2) (a) The Secretary of State considers that the information obtained… is necessary or expedient for the Secretary of State to have… in connection with the provision of health services …

And (2) (b)

The Secretary of State otherwise considers it to be in the interests of the health service in England. [Bold type – my addition]

It is possible that the requirements of the HSCA 2012 information management systems are complex enough to reduce any trivial demand for data. This is unlikely to apply however to those backed by organisations that see a market potential. That notwithstanding in the new Care Act 2014 Section 115 sees significant amendments to the Health Service (Control of Patient Information) Regulations 2002.\textsuperscript{73} Already at Regulation 5 the Secretary of State can 'approve' the processing of confidential data (without consent).\textsuperscript{74} As those monitoring and commenting on the changes in information management have noted,\textsuperscript{75} amendments to both regulation 5 and regulation 6 appear to expand who can approve processing and hence evolution of confidential information to include the Health Research Authority. For confidentiality and privacy
activist groups like ‘needConfidential’, the concerns do not stop at the semantics of dropping words like ‘patient’ and ‘confidential’ from some of the text but raise the spectre of data ultimately being used for non-research purposes. The latter changes have received considerable critique from health policy academics and activists because of this potential for permitting data use/misuse at a commercial level. The same policy commentators put forward their own proposals that address their concerns; the Government has yet to respond at the time of writing.

So, it appears that neither case law nor legislation can be wholly relied upon to protect our patient information and identity. This leaves the relationship that exists between a patient and their doctor acting as perhaps the ultimate safeguard against unconsented and potentially identifiable information access, its disclosure and hence further management and manipulation. The ‘old’ form of confidentiality if you will. Bartlett described a number of core values for a fiduciary, which include:

Fiduciaries must avoid conflicts of interest, or indeed possible conflicts of interest.
Fiduciaries must not profit from their position without prior disclosure to and authorisation from the vulnerable party.
The fiduciary owes a duty of undivided loyalty...[and—my addition] of confidentiality.

On the latter point, this may well have been the case in near distant times; not so now however I would argue when it comes to information management. Therein remains the issue of trust; that of the patient in their GP. This would be consistent with the relationship being ethically fiduciary if not agreed as such in the English legal system.

Paternalistic ‘friend’, fiduciary but, now technician?

Post inception of the NHS the model was of the GP being a (vulnerable?) individual’s ‘friend’, paternalistic and holding the balance of power over access to health information and treatment; confidentiality like medical practice was secured at a local level. This relationship has changed over time as all relationships do. There was increasing interest in and debate about the ethics of medical practice. With continuing changes in GP training to improve communication skills, and despite legal debate, this evolved into something more fiduciary in nature; a relationship of trust and confidence that might maximise the autonomy of the patient while acknowledging that to the latter there were limits and I would add, the ongoing power imbalance. Perhaps some would say this is still the nature of today’s GP-patient interaction.

However, with the rapid changes in health policy and subsequent practice demonstrated par exemplar via the HSCA and the rapid reforms that went before, many GPs are no longer able to practise in a way that develops individual relationships with patients and their families. Much of the work (and remuneration) is target driven and with the era of GP-led Clinical Commissioning and that remit to save in the order of £20 billion by 2015, other imperatives influence the interaction between doctor and patient. The GP has become adept at managing the detail of medical practice as illustrated by the pursuit of Quality and Outcomes Framework (QOF) targets, perhaps at the expense of time to engage with the patient as an individual. General practice has therefore become a technical speciality and the GP the technician. This is a change that had been foreseen, was not always welcomed and now it might take a brave GP to admit it.

Those who find recent reforms too difficult will leave the profession early, and there is evidence to suggest that this is the case. There is a massive tension to be had in serving the individual and the wider public (NHS), and earning a living.

It has already been shown that a combination of case law and statute actually enable access to information and arguably it should if needed to facilitate the NHS. Whether or not GPs agree with enhanced data access, and as has been shown there has been much policy debate on the topic as well as individual commentary, it has been happening and will be expanded at some future date. Paradoxically, this acquisition of additional information may actually sit well with the ‘traditional’ gatekeeping role of the GP apropos access to and an efficiently run NHS. It sits less well with having a relationship of trust and confidence between patient and doctor. The GP retains the ultimate duty of confidence within the practice. That is acknowledged by staff as part of their employment terms and applies to accessing sensitive data (often about people with whom they may be familiar), and by the patient in their expectations of the relationship. This is very different from the distant and anonymised access of, for example, databases serving the pharmaceutical industry. It is unclear as yet as to whether patients regard this distant access of data and its potential for use/misuse with any real suspicion. Are we as patients aware or concerned that the level of data acquired might lead the unscrupulous to identify us? Will patients really choose non-disclosure of serious health concerns and issues, as the courts have already speculated?

From a technical viewpoint, all a GP has to do is undertake some way of making patients aware of the data extraction methods and advise them of any ‘opt-out’ procedures. This is rarely being done in person,
rather, by posters in waiting areas, messages on prescription sheets and a national leaflet drop supposedly to all households. What is less clear is that GPs whilst they can opt out of GPCS; they will not be remunerated for QOF work as this is processed through GPCS; an unlikely scenario therefore. Some GPs have already expressed moral objections to being an instrument of personal information access; a conscientious objection (CO). Perhaps they might consider that the CO terms (Clause 4) of the 1967 Abortion Act ought also to translate across to confidential information management.

At present, trust in doctors remains high despite well-profiled scandals such as that in Mid Staffordshire NHS Trust and less recently involving hospitals in Alder Hey, Liverpool and Bristol. However, some within the profession are warning that this almost inherent trust could sink as low as bankers. Certainly, patients might feel that in devolving their information elsewhere doctors, in this instance GPs, are to be mistrusted and the old concerns about patients withholding critical information in fear of its distribution become pertinent once again. O'Neill gives fair warning:

Mistrust could mushroom within states that do not create well-constructed and toughly enforced data protection systems… prevent unconsented access and use… Even where regulation is good, mistrust may grow if systems are opaque.

GPs cannot opt out of the care data process and have no involvement with what happens to the information next. Patients can ‘choose’ to opt out of care data but as has been shown demands for access to data can still be made under case law and statute; a facilitating choice. As for enabling patients to make that choice, it has already been established in case law that patients are entitled not only to information about medical procedures but also to have adequate time to consider their ‘options’ prior to consenting. Surely out of respect for maximising autonomy in a situation where this is and may well ought to be limited, the same principles might apply. The dissemination of the facts around modern NHS data sharing ought not to be left to notes and leaflets which may not be received or read through choice or due to disability. As McCartney points out, the national leaflet was ‘heavy on assumed benefits… but light on potential harms’. The technician, however, is unlikely to have the resources to enable detailed first hand explanations and as GPs they are unlikely to have the time. What is even less well explained is what will happen to (our) information once it becomes into the possession of third parties via the NHS and linked by virtue of patient care, research or market partnership and risks therein.

Concluding remarks

This paper seeks to identify the reality or otherwise of our choice as patients over the access to and use of our medical information given the rhetoric of choice in health policy and the draft towards privacy in law. Choices, if that is what they are, are increasingly limited. Rather than necessarily being a ‘bad’ development in the efficient provision of NHS care, what is lacking is transparency of activity in the management of our data.

As individuals, we seem of two minds. We are more than happy to share and share again personal, confidential, private you might consider, data with regard to finances along with commentary and information on what are sometimes our very personal activities; Facebook, Twitter and Instagram are prime examples.

The ‘genie is out of the bottle’; our medical information has been on the move for some time. It is only now when the data sets are being expanded, it has become a requirement for the medical profession to co-operate, and there is a more latterly developing public awareness that objections have arisen. It is the patient’s prerogative to expect judicious use of their data but more contentiously it is not their prerogative to opt out of its use completely if they are engaged with a tax-funded organisation such as the NHS.

What can be considered is that the ‘old’ relationship between doctor and patient under a relationship of confidence and trust probably sufficed at a local level to keep our medical conditions and disclosures protected. This is now the stuff that harks back to the era of old television programmes and writings from the early days of general practice. It did however, afford protections that are not longer available as a result of Article 8(2) of the HRA, the decision in Source Informatics and the inception of the HSCTA 2013. It is the Source Informatics position that still holds despite any debate over anonymisation, pseudo-anonymisation and the risks therein. If it is ‘anonymised’ it is available. Why do some protest so much? Privacy is an overblown concept, and confidentiality is already so diluted by our own actions let alone in law.

The issue of individual’s specific consent to the access, sharing and use of their data has had some discussion again rather late in the process. As reviewed elsewhere and in the context to treatment, it is a complex topic. Caldicott II emphasises ‘a data sharing model’ which engages the patient and gives them an awareness of what and how their information is used – so-called dynamic model of patient consent. McCartney says of the opt-out nature of care.data ‘…if people didn’t know they had an option, how could they exert the choice?’ The fact of matter is that in reality there is no choice. Maeduriane and
Pollock proposes the concept of the patient opting in to care data and related systems. At least this requires more actively engaging in the start of the process that utilises our information and has a much greater feel of respect for the person despite the fact that either can be over-ridden by case law and Statute. The patient does not really have a choice, and it is disingenuous to say they have. At best, they can express their preferences over their data. Trust requires transparency and shared decision making, and shared decision making makes for better information sharing. Without, there must be an enhanced possibility of a challenge to care data. Related information systems and the practitioners that use them in the European Courts under Article 8(1).

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References and notes
3. Ibid., p. 3.
5. Typical of many of the coalition Governments health reforms, it has taken time for a groundswell of opinion to form and raise concerns, in this instance about the unconsented sharing of patient information that could be considered confidential. A loose collaborative of the British Medical Association (BMA), the Royal College of General Practitioners (RCGP) privacy campaigners such as medConfidential became vociferous in its critiques of the NHS England information policy. The latter organisation describing the history of same as ‘hellishly convoluted’. http://medconfidential.org/2014/section-251-to-be-amended/.
6. Torjesen I I have shamelessly used the word from the following. Furure over data could jeopardise research. BMJ 2014, 348, g776.
7. See http://www.ic.nhs.uk/gpes and http://www.hscic.gov.uk/gpes: ‘GPEs is a centrally managed primary care data extraction service that extracts information from GP IT systems for a range of purposes [my italics] at a national level’.
8. See www.england.nhs.uk/caredata. The care.data dataset includes confidential medical information such as NHS numbers, dates of birth, postcodes along with prescription details and physiological indices. Data extracted along this pathway can be linked to personal confidential data from elsewhere such as hospital and social care environments.
10. These datasets are managed by the Health and Social Care Information Centre (HSCIC) whose establishment role and duties (and potential conflicts) are well described elsewhere. See George and Taylor M. Disclosure of confidential patient information and the duty to consult: the role of the health and social care information centre. Med Law Rev 2013, 0: 1–33.
12. See Montgomery v Lanarkshire Health Board (Scotland) [2015] UKSC 11 [75–76], [72] Their Lordships (Lord Kerr and Lord Reed) stated.
13. Pollock A, Roderick P and Booth P. Parliamentary Control over the Health and Social Care Information Centre: Proposed Amendment to the Care Bill and Briefing Note. London: Centre for Primary Care and Public Health, Queen Mary University of London and medConfidential, 2014, pp. 3–4.
14. After the submission of this article for publication (Nov 2014) in February 2015, the Nuffield Council for Bioethics published a comprehensive detailed analysis of the ethical issues associated with data management in health care and biomedical research. This put forward a number of ‘recommendations and precepts’ on the topic: See Nuffield Council for Bioethics. The Collection, Linking and Use of Data in Biomedical Research and Health Care: Ethical Issues. London: Nuffield Council, 2015, p. 198.
15. For some 20 years, there has been the clinical patient research data link (CPRD), until recently called the general practice research database. This encompasses in the order of 5 million longitudinal records at first obtained from general practice and now including hospital records. As well as being used for NHS purposes, the data once ‘de-identified’ (names, dates of birth and postcodes removed) has long been sold on to the pharmaceutical industry.
16. n. 1 above.
19. Ibid., p. 22.
25. Without reference to legal interpretations at this point in the article.
26. n. 15 above.
30. n. 20 above.
34. W v Egdell [1990] 1 All ER 835.
37. Ibid.
39. See n. 32 above. In A-G v Guardian Newspapers (no 2), Lord Keith stated, 
...as a general rule, it is in the public interest that confidences should be respected, and the encouragement of such respect may in itself constitute a sufficient ground for recognising and enforcing the obligation of confidence even when he confider can point to no specific detriment to himself.
40. See n 31 above. In Coco v AN Clark (Engineers) Ltd, Megarry J stated that ‘...three elements are normally required if, apart from contract, a case of breach of confidence is to succeed. First, the information itself, in the words of Lord Greene MR in the Salmana (Salman Engineering Co Ltd v Campbell Engineering Co Ltd (1948) 196(3) All ER 413 at 415), must “have the necessary quality of confidence about it.” Secondly, that information must have been imparted in circumstances importing an obligation of confidence. Thirdly, there must be an unauthorised use of that information to the detriment of the party communicating it.
41. Kennedy I and Grubb A. Medical Law. London: Butterworths, 2002, p. 1069. In making their point, Kennedy and Grubb drew an analogy with an action in libel or slander. They equated disclosure with publication of information and as such the individual has to be identified or is identifiable to someone else in the event of them having ‘particular knowledge’.
42. Ibid., p. 1072.
43. The author is grateful to the anonymous reviewer for suggesting this reflection on individual patient expectations in the differing scenarios.
47. Z v Finland (1997) EHRR 371. At para 93, the court stated that “the protection of personal data, not least medical data, is of fundamental importance to a person’s enjoyment of his or her right to respect for private and family life as guaranteed by Article 8”, and at para 95, with respect to the confidentiality of health data is a vital principle....It is crucial not only to respect the sense [bold – my addition] of privacy of a patient but also to preserve his or her confidence in the medical profession and in the health services in general.
50. Ibid., at [145].
51. Ibid., at [133].
52. Ibid., with Lord Nicholls [21] talking of non-disclosure as a function of the related individual’s ‘reasonable expectation of privacy’. Again, this appears to be a rather fluid concept.
53. Douglas v Hello! Ltd (No 3) (2006) QB 125. Lord Phillips MR at [53] indicating that in order to achieve Article 8(1) rights, the Court had to ‘shoe horn’ into an action for breach of confidence a claim for misuse of private information. The ‘information’ concerned photographs of a social non-public occasion rather than medical matters.
54. n. 27 above, pp. 10-11. General information is given to medical practitioners about disclosures required by statute such as those with ‘specific statutory requirements’, e.g., certain notifiable diseases, and to various regulatory bodies including the GMC. In addition, there is guidance over ‘disclosures to courts or in connection with litigation’.

55. Nathansohn V. Amendments to the Coroners and Justice Bill. BMJ 2009; 338: b985. Clause 152 would have permitted ministers ‘to remove or modify any legal barrier to data sharing’. In the explanatory notes, it reads,

This could be by repealing or amending other primary legislation, changing any other rule of law (for example, the application of the common law of confidentiality to defined circumstances), or creating a new power to share information where that power is currently absent.


62. See, for example, A G v Guardian Newspapers (No 2) [1990] 1 AC 105, [1991] 3 All ER 345. The so-called Spokane case.

63. See, for example, X v Y [1988] 3 All ER 648.


66. Article 2 provides that ‘Everyone’s right to life shall be protected by law...’

67. n. 65 above, para 116.


69. National Health Services Act 2006 c. 42 Patient information Section 251 Control of patient information.

70. n. 10 above, p. 16.

71. Ibid., pp. 15-18.


74. See, for example, http://www.england.nhs.uk/wp-content/uploads/2014/02/bull-10.pdf NHS England Who Pays? Information Governance Advice for Invoice Validation. Advises that under Regulation 5 CCGs and Commissioning support units (CSUs) are allowed to process Confidential Personal Data (CPD) for the purposes of invoice validation.


76. medConfidential describes itself as ‘an independent, non-partisan organisation working with patients and medics, service users and care professionals, drawing advice from a network of experts in the fields of health informatics, computer security, law/ethics and privacy’, http:// www.medconfidential.org/about/


81. Royal College of General Practitioners Curriculum 2010 revised August 2013 Statement 2.01 The GP Consultation in Practice.

82. n. 79 above, pp. 193-224.


88. Harris S. 'Data confusion', personal correspondence.


93. Abortion Act 1967 Clause 4 (1): no person shall be under any duty, whether by contract, or by statutory or other legal requirement, to participate in any treatment…to which he has a conscientious objection: […] As applied by the Courts currently the new data handling requirements are hardly likely to constitute treatment participation. See Regina v. Salford Area Health Authority (Respondent) ex parte Janaway [1988] 3 WLR 442; HA [1988] 3 All ER 1079 249. A moot point perhaps?


97. Smyth C. Doctors ‘could sink as low as bankers’. The Times, 3 September 2013, quoting Professor Ben Bridgewater, Consultant cardio-thoracic surgeon.


100. McCarty M. Care.data doesn’t care enough about consent. BMJ 2014; 348: g2831.


104. n. 99 above, Section 5, para 5.5, pp. 57–58.


106. n. 100 above.


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