# 6

# The Public Interest

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## 6.1 INTRODUCTION

This chapter provides an introduction to the concept of 'the public interest' in health research regulation (HRR). It considers two key ways that the public interest is constructed in HRR: namely as a legal device and through empirical evidence of the views of publics. To appreciate the scope of this concept, the public interest is set in its broader context, i.e. beyond HRR, highlighting that, historically, it has been a contested concept that is difficult to define in the abstract. Next, the public interest is situated within HRR, paying attention first to how it features in the HRR legal landscape and then how this is constructed through the views of publics (with specific reference to the use of identifiable health data for research). Both conceptualisations are analysed with reference to the key challenges and opportunities that they present before a holistic concept of the public interest in HRR is proposed and consideration given to how this may be operationalised in practice.

## 6.2 THE PUBLIC INTEREST: A CONTESTED CONCEPT

Although the public interest is fully embedded in HRR, it is by no means exclusive to this context. The following brief consideration of wider perspectives on this contested concept point to persistent debates not only on what the public interest 'is', but also to tensions as to how this concept should be understood. Appeals have been made variously to the values it invokes, the process it requires, and/or the views of (some or all) of 'society' at large that it reflects.[1]

Political and social scientists, philosophers and lawyers, among other disciplines, have contemplated this elusive concept without reaching consensus on its meaning or usefulness. During a period of scholarly interest in the public interest in post-World War II America, it was both lauded as 'a central concept of a civilised polity'[2] and dismissed as a concept so vague and ambiguous that it is no more than a rhetorical device.[3] This ambivalence can be seen in Sorauf's work in which, despite his scepticism, he initially concedes a 'modest conception' of the public interest that is rooted in 'our interest in the democratic method and its settlement of conflict by

[1] A. Sorbie, 'Sharing Confidential Health Data for Research Purposes in the UK: Where Are 'Publics' in the Public Interest?', (2020) *Evidence & Policy*, 16(2), 249–265

[2] S. Bailey, 'The Public Interest: Some Operational Dilemmas' in C. Friedrich (ed.), *Nomos V: The Public Interest* (New York: Atherton Press, 1962), pp. 96–106.

[3] G. Schubert, *The Public Interest: A Critique of the Theory of a Political Concept* (Glencoe, Illinois: Free Press, 1960).

orderly rules and procedures'.[4] He recognises too the potential function of the public interest as a 'hair shirt' that serves as 'an uncomfortable and persistent reminder of the unorganized and unrepresented (or underrepresented) interests of politics'.[5] Over time, however, his position hardens and becomes more negative. He later posits that the public interest promotes 'oversimplification', as it purports to "solve" the dilemmas of ... pluralism'.[6] Turning to the regulatory role of the public interest, Feintuck also points to a continued reluctance to define the public interest beyond what 'will vary according to time, place and the specific values held by a particular society'.[7] He characterises the public interest as an 'empty vessel' and argues for an account that looks 'to the fundamental value laden, democratic imperatives that underlie society: human dignity, parity of esteem, and the ability to participate actively in society'.[8]

Whether the public interest is best understood modestly as a procedural mechanism, ambitiously as protecting fundamental values in society including those that may otherwise be overlooked, or in utilitarian terms as the views of the majority, there is little doubt that this is a contested concept that is 'much used but ill defined'.[9] This chapter proposes that while there is need for further conceptual clarity here, there is also value to be found in such contestation and flexibility.

## 6.3 APPEALS TO THE PUBLIC INTEREST IN HRR

In HRR, the concept of the public interest is embedded in law and in policy, often as a counterpoint to individual interests. In medical research involving human subjects – including research on identifiable human tissue and data – consideration of the relationship between individual and public interests can be traced back to the original Declaration of Helsinki.[10] More recently, the legal mandate of the Health Research Authority (HRA) in the United Kingdom, as set out in the Care Act 2014, prescribes twin objectives to protect and promote the interests of both individual participants (and potential participants) and the interests of wider publics in safe and ethical health and social care research.[11]

However, reflecting the broader literature on public interest, Taylor notes in his consideration of genetic data and the law, that the public interest remains a 'notoriously uncertain idea'.[12] This chapter proceeds with an account of two key ways in which the concept of the public interest appears in HRR (with a focus on the use of identifiable health data for research), as constructed in law and through publics' views. It considers the key challenges and opportunities presented by

[4] F. J. Sorauf, 'The Public Interest Reconsidered', (1957) *The Journal of Politics*, 19(4), 616–639, 633.

[5] Ibid., 639.

[6] F. Sorauf, 'The Conceptual Muddle' Dilemmas' in C. Friedrich (ed.), *Nomos V: The Public Interest* (New York: Atherton Press, 1962), pp. 183–190, p. 189.

[7] M. Feintuck, *'The Public Interest' in Regulation* (Oxford University Press, 2004), p. 34, quoting A. Ogus, *Regulation: Legal Form and Economic Theory* (Oxford: Clarendon, 1989), p. 2.

[8] Feintuck, *'The Public Interest'*, p. 57.

[9] J. Bell, 'Public Interest: Policy or Principle?' in R. Brownsword (ed.), *Law and the Public Interest: Proceedings of the 1992 ALSP Conference* (Stuttgart: Franz Steiner Verlag, 1993) pp. 27–36.

[10] J. R. Williams, 'The Declaration of Helsinki and Public Health', (2008) *Bulletin of the World Health Organization*, 86(8), 650–652.

[11] Care Act 2014, Section 110(2) states: (2) The main objective of the HRA in exercising its functions is – (a) to protect participants and potential participants in health or social care research and the general public by encouraging research that is safe and ethical, and (b) to promote the interests of those participants and potential participants and the general public by facilitating the conduct of research that is safe and ethical (including by promoting transparency in research).

[12] M. Taylor, *Genetic Data and the Law: A Critical Perspective on Privacy Protection* (Cambridge University Press, 2012).

the public interest in each framing. Having identified the benefits and shortcomings of each, a holistic concept of the public interest is proposed, the relationship between the public interest as constructed within and beyond the law is examined, and consideration is given to how, in a more concrete way, public interest might be operationalised in HRR practice.

## 6.4 THE PUBLIC INTEREST AS LEGAL DEVICE

When health research is conducted on identifiable personal data, the public interest is a striking feature of the legal landscape. For example, in the realm of data protection, the public interest forms one of the routes to the lawful processing of personal data in health and social care research. Thus, the General Data Protection Regulation[13] (GDPR) provides a lawful basis to process personal data where this is a 'task in the public interest'.[14] Health Research Authority (HRA) guidance confirms that, for the purposes of the GDPR, this is the appropriate legal basis that should be used by public authorities, such as NHS bodies or universities, in order to process data for health and social care research.[15] In UK law, the Data Protection Act 2018[16] (DPA 2018) purports to add further detail to the interpretation of 'a task in the public interest', although concerns have been raised that the drafting of this legislation does little to add clarity to how this concept should be understood in practice.[17] A late addition to the Explanatory Note to the Act indicates, by way of an example, that 'a university undertaking processing of personal data necessary for medical research purposes in the public interest should be able to rely on [a task in the public interest]'[18], thus providing some guidance on the *context*, if not the *content*, of the public interest in these circumstances.

Two other prominent features of the health data legal landscape are: (i) the common law duty of confidentiality and (ii) the legislative regime which established the predecessor body to the HRA's Confidentiality Advisory Group (CAG). The common law duty of confidentiality provides that where confidential information is imparted to another person, in circumstances giving rise to an obligation of confidentiality, this must not be disclosed without consent or justification.[19] One such justification is where disclosure is 'in the public interest'. This duty, and its exceptions, apply not only in the context of the traditional doctor/patient relationship, but also where it is proposed that the information in question may be used for purposes beyond direct care, such as for health or social care research. The interpretation of this duty of confidentiality (and, importantly for this chapter, the meaning of the public interest) has

[13] Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC.

[14] Article 6(1)(e).

[15] Consent retains its ethical significance and legal importance under wider legal frameworks, but it is explicitly stated that: 'For the purposes of the GDPR, the legal basis for processing data for health and social care research should NOT be consent. This means that requirements in the GDPR relating to consent do NOT apply to health and care research'. Health Research Authority, 'Consent in research', (NHS Health Research Authority, 2018), www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/data-protection-and-information-governance/gdpr-guidance/what-law-says/consent-research/.

[16] Data Protection Act 2018, Section 8.

[17] Wellcome, 'Data Protection Bill – Second Reading Briefing for the House of Lords by the Wellcome Trust', (Wellcome, 10 October 2017), www.wellcome.ac.uk/sites/default/files/data-protection-bill-second-reading.pdf; 'Data Protection Bill – Lords' Committee Stage Day 1', www.wellcome.ac.uk/sites/default/files/data-protection-bill-lords-committee.pdf

[18] Data Protection Act 2018, Explanatory note to Section 8.

[19] The essential elements were established in *Coco* v. *A N Clark (Engineers) Ltd* [1969] RPC 41.

emerged as a result of decisions made on the facts of cases that have come before the courts. These judgements indicate, for example, that there is not only a personal interest in an individual's confidentiality being maintained, but also a wider public interest in doing so in order that patients (in general) are not discouraged from consulting with healthcare practitioners.[20] Case law, in relation to whether disclosure of deceased patients' records to a public inquiry was in the public interest,[21] recognises that the public interest (which was distinguished from 'what the public found interesting')[22] is multifaceted and can encompass both individual and collective interests. These include interests in: disclosure, maintaining the patient's confidentiality and maintaining confidence in the institutions under investigation.[23]

As with the legislation, there is no fixed definition of the public interest in case law; where this lies must be decided on the individual facts of each scenario. This perception of a lack of certainty led to concerns from some clinicians that routine activities, such as providing information to registries that collect and analyse data on specific diseases, might be vulnerable to challenge in the absence of specific consent.[24] These worries about the legality of such practices, among other matters, led to the enactment of legislation in England and Wales in 2001 that forms another key feature of the data sharing landscape, namely the establishment of the predecessor to the CAG. In summary, this legislation allows the Secretary of State for Health to make regulations to explicitly 'set aside' the common law duty of confidentiality for defined medical purposes, including medical research, where this is 'in the interests of improving patient care, or in the public interest'. These powers are now found in Section 251 of the NHS Act 2006 (as enabled by the Health Service (Control of Patient Information) Regulations 2002) and referred to colloquially as 's251 support'. In sum: where seeking consent is neither possible nor practical, researchers can obtain s251 support to use confidential patient information for medical research by make an application to the HRA's CAG. The effect of such an application is that, if granted, the researcher need not be concerned whether (in the admittedly unlikely event of litigation) a court would agree that their use of identifiable patient information without consent was indeed in the public interest.

In common with the broader literature on the public interest, the preceding whistle-stop tour of the public interest in law reveals anxieties around how this concept is interpreted in practice. It also speaks to the strengths and limitations of a narrow legal construction of the public interest decided on a case-by-case basis, but for which precedents can be established over time. These are explored further in the passages that follow.

We return first to Taylor's description of the public interest as a 'notoriously uncertain idea'.[25] It is of note that Parliamentary debate on the DPA 2018[26] on this topic resurrected many of the concerns around the public interest that had arisen some fifteen years previously, at the time of the promulgation of the CAG regime. These included the potential for the public interest to be interpreted widely to deliver 'sweeping powers'.[27] Nonetheless the CAG regime, which was first

[20] W v. *Egdell* [1989] EWCA Civ 13.
[21] *Lewis* v. *Secretary of State for Health* [2008] EWHC 2196, Paragraph 58.
[22] Ibid., Paragraph 59.
[23] Ibid., Paragraph 58.
[24] M. Coleman et al., 'Confidentiality and the Public Interest in Medical Research – Will We Ever Get It Right?', (2003) *Clinical Medicine*, 3(3), 219–228.
[25] Taylor, *Genetic Data*, p. 29
[26] For example, see *Hansard*, HL, vol. 785, col. 146, 10 October 2017; *Hansard*, HL, vol. 785, col. 1236, 30 October.
[27] These included the wide scope of the public interest provisions that provided the Secretary of State with 'sweeping powers to collect confidential data on named patients without consent' (*Hansard*, HC, vol. 622, col. 997, 26 February 2001, Earl Howe).

proposed as a temporary solution as the NHS geared up to apply a 'consent or anonymise' binary to its use of health data, has become an example of good governance and established itself as part of the data sharing landscape.[28] This can be attributed, in part, to a growing recognition from stakeholders in HRR – including researchers and publics – that consent is not necessarily the 'magic bullet' to legitimise HRR governance that it might once have been presumed to be. For example, Wellcome's research, as commissioned from Ipsos MORI, on public attitudes to commercial access to health data for research purposes found that, when considering data uses, 'a strong case for public benefit is the most important factor for many people: without it, data use by any organisation is rarely acceptable'.[29] This tends to suggest that while concerns about the uncertainty of the application of the public interest in HRR persist, it is a concept that also, in some ways, benefits from its inherent flexibility and its ability to adapt to changing interests over time.

A further critique that arises from this legal construction of the public interest is that this looks inwards to derive its legitimacy from its institutional origins and is disconnected from actual publics' views. For example, in the case of legislation – such as the DPA 2018 and the legislation underpinning the CAG regime – legitimacy comes from Parliament. Notwithstanding, the public interest in (legal) text tells us little about its context. Even when amplified by its Explanatory Note, the DPA 2018 does not elaborate on the legitimate content of the public interest in HRR.

Turning to case law, the public interest is conceptualised by the courts on the facts of each case, following precedents in previous decisions. This inward-looking legal construction of the public interest is consistent with the long established 'intellectual tradition'[30] within the law of invoking fictional persons to provide a barometer of what 'reasonable' members of the public would expect in any given situation. The paradigm is the fictional 'man on the Clapham Omnibus',[31] who in English law is deployed to represent the reasonable person. Elsewhere in the law, other fictional reference points include the 'right-thinking member of society' (in defamation law) or even the 'officious bystander' (in contract law).[32] It has thus been confirmed by the Supreme Court that: 'The spokesman of the fair and reasonable man, who represents after all no more than the anthropomorphic conception of justice, is and must be the court itself'.[33] This underlines why the law historically has not been centrally concerned with empirical evidence of the views of actual members of the public when it deploys the legal notion of the public interest in civil law cases.

However, this legal self-referential conception of the public interest in HRR is increasingly under pressure, as exemplified by the high-profile failure of care.data. As described more fully in this volume by Burgess (Chapter 25), this was an NHS England initiative that sought to make patient data available for specified purposes, including audit and research, in a format that was stripped of identifiable information. However, following widespread concerns about the scheme – including around its transparency and oversight – the programme closed in 2016.[34]

[28] G. Laurie et al., 'On Moving Targets and Magic Bullets: Can the UK Lead the Way with Responsible Data Linkage for Health Research?', (2015) *International Journal of Medical Informatics*, 84(11), 933–940.

[29] Wellcome, 'Public Attitudes to Commercial Access to Health Data', p. 1, referring to Ipsos MORI, 'The One-Way Mirror: Public Attitudes to Commercial Access to Health Data', (Wellcome Trust, 2016), www.wellcome.ac.uk/sites/default/files/public-attitudes-to-commercial-access-to-health-data-summary-wellcome-mar16.pdf

[30] *Healthcare at Home Limited (Appellant)* v. *The Common Services Agency (Respondent) (Scotland)* [2014], par. 2.

[31] Ibid., para 1.

[32] Ibid., para 1.

[33] Ibid., para 2.

[34] M. Taylor, 'Information Governance as a Force for Good? Lessons to be Learnt from care.data', (2014) *SCRIPTed*, 11(1), 1–8.

Here, a legal framework was in place to facilitate data sharing but, as argued by Carter et al.,[35] the social licence to do so was not. This failure underlines the message that 'legal authority does not necessarily command social legitimacy'.[36] It follows that where the law alone is unable to fully legitimise and animate the public interest, something else must fill this void. The following section suggests that a richer relationship between this legal concept and the views of publics could be a worthy candidate.

## 6.5 THE PUBLIC INTEREST AS THE VIEWS OF ACTUAL PUBLICS

The potential benefits of responsible access to health data by researchers, as well as the perils of getting this wrong, have led to a renewed focus on the public acceptability of data sharing initiatives and a growing body of literature that explores public attitudes towards sharing health data for research purposes.[37] Aitken et al. note the desire of stakeholders in HRR to optimise the use of existing data in health research and: 'the recognition of the importance of ensuring that data uses align with public interests or preferences'.[38] This commitment to using patient data responsibly is shared by funders, as exemplified by Wellcome's 'Understanding Patient Data' initiative, which works to champion responsible uses of data and improve stakeholder engagement around how and why data is used for care and research.[39]

Consider too the call in HRR for more and better public and patient involvement (PPI). The National Institute for Health Research (NIHR) recently issued 'Standards for Public Involvement in Research', which provide 'a framework for reflecting on and improving the purpose, quality and consistency of public involvement in research'.[40] In particular, Standard 6 on Governance states that '[w]e involve the public in our governance and leadership so that our decisions promote and protect the public interest'. Here, the role of publics is positioned not only as shaping and supporting research, but also as a means of legitimising HRR and grounding the broader public interest.

This approach has the benefit of being anchored to actual publics' views, something that is lacking from the narrow legal account set out above. In this way, it has the potential to provide at least some of the social legitimacy that was lacking in care.data. However, public engagement activities also attract criticisms of exclusivity and tokenism,[41] raising 'questions of representativeness, articulation, impacts and outcomes'.[42] Thus, to simply equate these outputs with 'the public interest' more broadly also runs the risk of reinforcing underlying inequalities in the delivery of a majoritarian account of the concept. Reports of instances of 'personal lobbying by

[35] P. Carter et al., 'The Social Licence for Research: Why care.data Ran into Trouble', (2015) *Journal of Medical Ethics*, 41(5), 404–409.

[36] Ibid., 408

[37] M. Aitken et al., 'Moving from Trust to Trustworthiness: Experiences of Public Engagement in the Scottish Health Informatics Programme', (2016) *Science and Public Policy*, 1–11; M. Aitken et al., 'Public Responses to the Sharing and Linkage of Health Data for Research Purposes: A Systematic Review and Thematic Synthesis of Qualitative Studies', (2016) *BMC Medical Ethics*, 17(73), 1–24; M. Aitken et al., 'Public Preferences Regarding Data Linkage for Health Research: A Discrete Choice Experiment', (2018) *International Journal of Population Data Science*, 3(11), 1–13.

[38] Aitken et al., 'Public Responses', 2

[39] 'About Us', (Understanding Patient Data), www.understandingpatientdata.org.uk/about-us.

[40] NIHR, 'Standards for Public Involvement in Research', (NIHR, 2019), www.invo.org.uk/posttypepublication/national-standards-for-public-involvement/

[41] J. Ocloo, and R. Matthews, 'From Tokenism to Empowerment: Progressive Patient and Public Involvement in Healthcare Improvement', (2016) *BMJ Quality and Safety*, 25(8), 626–632.

[42] J. Stilgoe and S. Lock, 'Why Should We Promote Public Engagement with Science?', (2014) *Public Understanding of Science*, 23(1), 4–15.

volunteers for pet causes'[43] point to the dangers of 'assuming that the perspectives of a small number of involved patients necessarily reflect the perspectives of a larger patient community'.[44] Indeed, McCoy et al.'s analysis of the recent NIHR 'Standards for Public Involvement' suggests that 'it is simplistic to assume that including public representatives on governance and leadership bodies will necessarily promote the public interest'.[45] They highlight the likelihood that the interests of differing 'publics' will, in any event, diverge, and call for more attention to be paid to *who* is being asked to contribute, *at what stage* in a research project, and *for what purpose*.

This is not, of course, to discount the important contributions that can be made to shaping and delivering responsible HRR through the thoughtful involvement of patients and wider publics.[46] However, whereas it is advanced above that the law alone is not enough to legitimise the public interest, this analysis also suggests that an additive approach to publics' views in HRR is also insufficient to provide a lasting and justifiable account of this concept. Something more is required.

## 6.6 THE PUBLIC INTEREST: A HOLISTIC CONCEPT

Taken together, the preceding examples illustrate the prevalence of the public interest in HRR and how this concept may be constructed both through the law and through the views of publics. On the one hand, the tendency of the law to approach the public interest as a legal test draws the criticism that this narrow notion of what purports to be in the public interest is wholly disconnected from the views of publics and can lack social legitimacy. On the other, to claim that the public interest can simply be extrapolated from the outputs of public involvement work is equally problematic. Nonetheless, despite this disjuncture, common themes emerge and, in this section, two further contributions to the debate on the role of the public interest are offered. The first is a proposal for a holistic concept of the public interest that is able to account for a plurality of interests and views. The second is that, despite the apparent impasse, legal and empirical notions of the public interest are not mutually exclusive. It is argued that these do bear upon one another and that if the public interest is to be effectively deployed in HRR, this relationship should be both acknowledged and made more overt.

The first proposal is to recognise that both the legal and empirical constructions of the public interest call for a conception of the public interest that is able to account for a range of diverse interests. In law, the potential for this approach is evident in an arc of case law that emphasises that the public interest is a multifaceted and flexible concept that is able to account for both individual and collective interests, including wider publics and institutional stakeholders. Similarly, the analysis above suggests that the value of public involvement is optimised when attention is paid to the multiple interests of differing patients and publics, including who is being asked to contribute, when, and for what purpose. This also tracks a move in HRR literature away from a narrow account of the public interest that pits individual interests against collective benefits. For example, Rid describes this 'pluralistic conception of public interest' as an account that is capable of recognising that multiple interests are in play.[47] Taylor's work also proposes

[43] M. McCoy et al., 'National Standards for Public Involvement in Research: Missing the Forest for the Trees', (2018) *Journal of Medical Ethics*, 44(12), 801–804, p. 802, quoting A. Prince et al., 'Patient and Public Involvement in the Design of Clinical Trials: An Overview of Systematic Reviews', (2018) *Journal of Evaluation in Clinical Practice*, 24(1), 240–253.

[44] McCoy et al., 'National Standards', 802.

[45] Ibid., 803

[46] See Burgess, Chapter 25, and Cunningham-Burley and Aitken, Chapter 11, of this volume.

[47] See A. Rid in A. Sorbie, 'Conference Report: Liminal Spaces Symposium at IAB 2016: What Does It Mean to Regulate in the Public Interest?', (2016) *SCRIPTed*, 13(3), 374–381.

that individual and public interests need not be balanced against one another, but rather that the need for legitimacy requires that each should account for each other.[48] Together, this forms the basis for a holistic concept of the public interest in HRR that is able to account for multiple interests and views. This approach does not, in the words of Sorauf, aim to 'solve' pluralism. Quite the opposite: it embraces the messy realities and subjectivities, both of the law, as broadly conceived, and of outputs from public involvement activities.[49]

The second contribution is to suggest that, despite the messiness, these accounts are not mutually exclusive and do, in fact, bear upon one another (though this relationship is far from clear). For example, I suggested earlier that shifting public views on health data sharing (and a move away from a 'consent or anonymise' binary) have contributed to the longevity of the CAG, which was originally proposed only as a temporary measure. Similarly, I have referred to how lobbying from the HRR community during the promulgation of the DPA 2018 led to an amendment of the Explanatory Note to clarify that 'a task in the public interest' is an appropriate route for public authorities such as universities to use when processing health data for research purposes. Lessons from care.data exemplify the importance of 'social licence' to the success of otherwise legal data sharing initiatives. In turn, there is an on-going need for deeper understanding of public acceptability to realise the potential of new and novel uses of health data.[50] Given the impetus to deliver clear and transparent governance of health data, it is proposed that this this relationship ought to be both acknowledged and made more overt, in order that it may be exposed to debate in HRR. Three concrete suggestions are made in this regard. The first is that the public interest, along with other concepts that operate at the intersection of public involvement and governance in HRR, should be examined to identify their potential to bridge the divide between the outputs from public engagement and the implementation of these in practice. The second is that initiatives such as CAG, where there is 'evidence' of the public interest being given effect to facilitate responsible HRR, should be further mobilised. The third is that instances where appeals to the public interest are made in HRR should be captured and articulated publicly, in order to promote transparency and accountability around how and why these have (or indeed have not) been justified.

## 6.7 CONCLUDING REMARKS

This chapter advocates for a holistic conception of the public interest, where interests are accounted for, rather than polarised. HRR governance has moved on from a 'consent or anonymise' binary and now needs novel and bold mechanisms that do not seek to over-play the role of legal mechanisms, nor suggest that public views alone can deliver good governance solutions. While the concept of the public interest remains contested and highly contextual, there is an increasing drive towards maximising the potential of this embedded concept in order to deliver a step-change in HRR.

[48] See M. Taylor in A. Sorbie, 'Conference Report', and Taylor and Whitton, Chapter 24 of this volume.

[49] Although outside the scope if this chapter, this holistic model also calls for scrutiny of the values in which it is grounded. Candidates may include, e.g. citizenship (Feintuck, *'The Public Interest'*) or solidarity (Kieslich and Prainsack, Chapter 5 of this volume).

[50] For example, health data, such as that held by the NHS, may be of 'immense value' to researchers developing artificial intelligence for use in healthcare settings. However, the question of how this value is realised remains 'a crucial one to get right because of the implications for public confidence' (Select Committee on Artificial Intelligence, 'AI in the UK: ready, willing and able?', (House of Lords, 2018), www.publications.parliament.uk/pa/ld201719/ldselect/ldai/100/100.pdf.