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Analysis

The value of healthcare data needs to be protected

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KEY MESSAGES

- **Data from healthcare systems hold value for improving healthcare delivery and some collaborations with the private sector could result in commercially successful products**
- **Established policies emphasise the need for collaborations with industry but concerns about data sharing remain widespread and confidence has been undermined by failures to safeguard data**
- **Collaborations using healthcare data should have the potential to serve the public interest, for example through providing access to useful technologies or the return of revenues for commercially successful ventures.**
- **Health systems and governments' must establish terms for sharing data informed by extensive public, professional and subject matter expert consultation**

29

30 **Contributors and sources**

31 This article was conceived by Stephen Bradley and Shivan Sivakumar who had become
32 aware of the issues of data sharing and the need to recoup value for patients and taxpayers
33 through their familiarity with innovations in cancer diagnosis. Bradley and Sivakumar shared
34 a concern that the value of discoveries that arise from the application of technologies like
35 artificial intelligence to patient data that is collected and curated by publicly funded
36 healthcare systems, should be captured for the benefit of patients and tax payers. Additional
37 background information on the policy context was obtained through discussion with
38 colleagues who have expertise in health informatics and review of relevant policy reports.
39 Sarah Markham initially provided comments on the manuscript, on the basis of that
40 contribution she subsequently agreed to become a co-author. Scott Hemphill contributed to
41 revisions of the manuscript.

42

43

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46 manuscript.

47

48

49 **Patient involvement**

50 A member of use MY data's Advisory Group provided feedback on the draft manuscript -
51 <https://usemydata.org/>. As a result of this we made several revisions to the text, including
52 inclusion of the Box. The paper was co-authored by Sarah Markham, who is a member of
53 the BMJ's patient panel.

54

55 **Conflicts of Interest**

56 We have read and understood [BMJ policy on declaration of interests](#) and have the following
57 interests to declare:

58

59 Stephen Bradley has submitted a grant application for a project which plans to evaluate the
60 performance of artificial intelligence systems in diagnosing lung cancer. He is clinical lead for
61 cancer for NHS Leeds clinical commissioning group. He receives PhD funding from CanTest
62 collaborative (Cancer Research UK C8640/A23385) and was a member of the executive
63 committee of the Fabian Society, a political think tank affiliated with the Labour Party
64 (unpaid). The publication costs of a collection of essays on health inequalities which he co-
65 edited for the Fabian Society were funded by the Association of the British Pharmaceutical
66 Industry and Lloyds Pharmacies. He has received funding from the Mason Medical
67 Foundation for a study on lung cancer diagnosis. The other authors have no competing
68 interests to declare related to the scope of this manuscript.

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The value of healthcare data needs to be protected

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Standfirst

Patient data held by publicly-funded healthcare systems can be harnessed to create discoveries that benefit health and the wider economy. But Stephen Bradley and colleagues argue that action is required to ensure value is recouped equitably for patients and taxpayers.

The threats to patient privacy from sharing of data have been well publicised. By comparison, the need to safeguard the value that can be generated from healthcare data has been largely overlooked. Monetary value can be generated through if technology, such as that generated from the application of artificial intelligence (AI) to data, is marketed commercially. Research involving patient data is subject to ethical review, but while these processes consider privacy implications they do not generally consider protecting the value of data nor are such committees well equipped to do so.

For cash-strapped healthcare systems, stewardship of vast reserves of data presents opportunities for innovative collaborations with industry. Aside from considerations over privacy, such relationships also hazard the loss of the value that may be generated from healthcare data to the benefit of private interests, The indicative market value of the data held by England's National Health Service (NHS) has been estimated at £5bn, if it were to be sold for commercial purposes(1). We contend that it is vital to ensure that the potential value that may be extracted from healthcare data is protected and that mechanisms are instituted to share revenues and/or access to new technologies that may be generated by private sector collaborations.

Controversial collaborations

A number of high-profile transactions involving patient data have demonstrated the need for accountability and transparency both in terms of the data shared and the value of what is received in return for patients and health systems. A collaboration between DeepMind (a subsidiary of Alphabet, owners of Google) and the Royal Free NHS Foundation Trust involved sharing patient data to create an app to identify acute kidney injury.(2) The project entailed sharing of a wide range of healthcare data on 1.6 million patients, was subsequently deemed to have proceeded without an appropriate legal basis.(3, 4) A memoranda of

118 understanding between both organisations set out the aspiration to establish a “broad
119 ranging” partnership, which for the trust would offer, besides bespoke software, “reputational
120 gain” and “place at the vanguard of developments in ... one of the most promising
121 technologies in healthcare”.(4) Since DeepMind is an AI company and the app simply
122 implemented an existing NHS algorithm, concern has been expressed that a motivation for
123 the agreement may have been to acquire data for machine learning research.(4, 5)

124

125 Another DeepMind-NHS collaboration has utilised AI in order to predict progression to wet
126 age-related macular degeneration through interpretation of optical coherence tomography
127 (OCT) scans, an application which has substantial promise in establishing more consistent
128 and efficient means to triage patients in busy eye clinics.(6-8) DeepMind has made its AI
129 model available to its NHS collaborator Moorfield’s Eye Hospital, but it has not been
130 disclosed whether this access is time limited and under what terms DeepMind will offer this
131 software in other NHS organisations or in other healthcare systems.(7)

132

133 The terms of a contract between NHS England and Amazon offered the tech giant access to
134 “all healthcare information” aside from patient records, apparently with nothing in return for
135 the health service.(9) Meanwhile, in the United States a partnership with the hospital chain
136 Ascension which gave Google access to the detailed health data for millions of patients
137 without their knowledge has been investigated by the Department of Health and Human
138 Services’ Office for Civil Rights.(10)

139

140 It is striking that in these cases the existence of data sharing arrangements between health
141 services and industry was only revealed following investigations by journalists. The resulting
142 discussion has tended to be framed in terms of consequences for patient confidentiality,
143 chiming with a critique of a business model which relies on extracting, combining and
144 commodifying personal data that has been described as ‘surveillance capitalism’.(11, 12).
145 Even assuming that processing of healthcare data will remain compliant with the more
146 stringent protections than those afforded to data which consumers have notionally
147 consented to share, the lack of recourse to scrutinise the terms of data transactions, or even
148 to discover that such agreements exist is troubling.(2, 13, 14) The repeated attempts to
149 institute routine sharing of English primary care data at scale in England, demonstrate that it
150 is not enough to simply demonstrate that such plans are not illegal.(15, 16) Public and
151 professional acceptance has been conceptualised as a ‘social licence’. Compliance with this
152 expectation requires that exploiting data for means other than it was collected must be
153 undertaken in service of the public good without disproportionate benefits for other
154 interests.(17)

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What is the policy agenda on collaboration using healthcare data?

In continuity with a longstanding emphasis on collaboration with private enterprise observed in many countries, the UK government’s strategy for the life sciences sector highlights the potential for the NHS to embark on partnerships with the business sector.(18, 19) Launched five years ago as a cornerstone of the government’s long term economic programme, implementation of the strategy has fallen short of its ambitions, with data sharing processes remaining inconsistent and unclear.(20)

In England, a recent review commissioned by the Secretary of State for Health and Social Care (‘the Goldacre review’) has called for these processes to be streamlined and clarified.(21) The report also advocates the creation of platforms through which healthcare data may be accessed. These Trusted Research Environments (TREs) would enable greater control over data to be maintained by rationalising and regulating the types of data being accessed and preventing wholesale transfers of data, with analyses undertaken within the TRE. The report acknowledges that while implementation of TREs can address privacy concerns “there is a need for a frank public discussion about commercial use of NHS data”.

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177 **Table 1:** Models of value sharing between health systems and private sector. Adapted from Ghafur et al.(22)

Agreement	Description	Potential Issues	Example
No value sharing	Health system shares data for free	Health system does not receive share of value of data	Amazon-NHS(9)
Free or discounted products	The product developed is provided to the health system organisation or to the whole of the health system for free or at a discount (for a defined or unlimited period of time).	No value captured from non UK income. If the product is discounted or free only for one organisation, other organisations within health service will have to pay	DeepMind-Moorfields(23)
Royalty/ revenue share	Health system receives a royalty or a portion of the revenue from products developed using its data.	Health system does not share ownership of the products being developed.	Sensyne Health- Oxford University Hospitals NHS Trust (also includes equity share)(24)
Profit share	Health system receives a royalty or a portion of the profits from products developed using its data.	Health system does not share ownership of the products being developed. Value captured will depend on the profitability of the company, rather than just on the top line revenues.	
Intellectual Property ownership share	The health system receives partial ownership of the intellectual property generated.	High cost and complication of the arrangement.	
Equity share	Health system receives a share of the equity of the company developing solutions from the data.	Unappealing to established companies.	Sensyne Health-Oxford University Hospitals
Fee for access	Health system receives a one-off payment in exchange for access to the data.	Depending on the pricing, this could generate very limited value for health system. May Penalise smaller companies that have less funding	Hospital Episode Statistics (HES) data from NHS Digital

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179

180 **What are the obstacles to protecting the value of data?**

181 When undertaking collaborations with commercial partners there are several factors which
182 mean that the value of health data may not be being adequately realised. Many healthcare
183 providers are likely to lack specialist expertise in commercial law and intellectual property.
184 This could render healthcare systems vulnerable to asymmetric negotiations that result in
185 rewards accruing to private sector collaborators, which are likely to have greater experience
186 in commercial contract negotiation and better resourced legal representation.(25)

187

188 Since agreements made with technology companies are often not made public there is
189 insufficient transparency to ensure that they deliver proportionate value to taxpayers and
190 health systems. The opacity of such arrangements has been likened to a 'one-way mirror',
191 through which technology companies are able to analyse and profit from patient data, but
192 which denies the public the right to understand how their data is being used and what if,
193 anything their healthcare system can expect to receive in return.(4, 26) By contrast, the need
194 for 'algorithmic accountability' has been emphasised in policy research on the subject, and a
195 recent public consultation has emphasised that the expectation of transparency is
196 paramount throughout the data life-cycle.(27, 28)

197

198 Polling and qualitative research indicates that there is broad support for sharing patient data
199 with commercial partners, but that the acceptability of such collaborations is contingent on
200 delivering demonstrable public benefit that does not disproportionately reward private
201 interests.(26) The understanding of what constitutes sufficient public benefit is challenging to
202 define and varies on a case by case basis. We contend that satisfying this test requires more
203 than the development of proprietary technology that could be used to improve patient care.
204 Where technology has been developed using patient data or co-produced using health
205 system resources then the resulting value should be returned through proportionate
206 mechanisms such as cost-free access to the technology or a revenue share for the health
207 service. (Table 1)

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209

210 **How should the value of data be protected?**

211 Failing to protect health data as valuable public assets risks making taxpayers pay both to
212 develop and later to use, novel technologies. This costly model of discovery is now
213 entrenched elsewhere in medicine. Notably, the pharmaceutical industry deploys assertive
214 pricing strategies for drugs developed from publicly funded research while scientific
215 publishers obtain research and editorial services from academics, before selling this back to

216 the publicly funded institutions which employ those academics.(29-31) Much focus has been
217 dedicated to highlighting and exploring potential remedies to these problems, including
218 greater regulation and more assertive involvement of the state in innovation.(32, 33)

219

220 The issue of safeguarding the value of healthcare data therefore resonates with wider
221 concerns about profit from public assets being diverted to private interests. Compared to
222 legacy industries like pharma, the nascent status of technologies such as AI presents a
223 window of opportunity to formulate regulations and norms to protect value. But these issues
224 are particularly complex with respect to healthcare data, not least because the multiple
225 organisations and individuals may be said to have contributed to its creation and
226 curation.(34)

227

228 Formulating how health systems should share rewards resulting from collaborations using
229 patient data is therefore far from straightforward. Innovations which have been created
230 entirely independently and are simply validated in a healthcare setting could be judged to be
231 analogous to devices or drugs, with the manufacturer retaining the prerogative to negotiate
232 on pricing without reference to the contributions made by the health service in validating the
233 technology. But, where health systems contribute significant resources to testing, such as
234 with the NHS Grail study, or where algorithms are validated or improved based on
235 performance, there may be a rational claim to some form of reimbursement.(35)

236

237 While most ventures using healthcare data will never prove profitable at all, there should not
238 be a presumption that harvesting patient data any innovation which may be commercially or
239 clinically successful will be acceptable. Nor should healthcare systems be expected to
240 underwrite the costs and risks of collaboration in the name of innovation. But there is a
241 strong case that healthcare services and the public research institutes should share in the
242 'upside' of any collaborations that do generate revenues, since they will also bear the costs
243 of efforts which do not prove successful.(36)

244

245 This might be achieved through arrangements such as healthcare systems, or the state,
246 taking an equity share in collaborative ventures.(22, 36) Alternative means of sharing value
247 more directly with patients who contribute data, rather than healthcare systems or the state,
248 have been envisaged including royalty payments to individual patients and creation of
249 independent community development funds for relevant populations.(11, 37, 38)

250

251 As highlighted by the Goldacre review, adequate consultation on these issues by
252 governments and health systems is overdue.(21) Creation of frameworks to guide

253 expectations of value sharing requires expertise and perspectives of ethicists, intellectual
254 property specialists and healthcare technology specialists, industry representatives
255 healthcare staff, patients and the public. Such consultations could include public deliberative
256 procedures such as citizen's assemblies. Some specific questions that could be considered
257 are presented in the Box. Experience, as well as numerous reports and consultations, have
258 emphasised that giving the public a say in how their data is used is crucial to establishing
259 and maintaining trust, without which the prospects of fruitful collaboration using healthcare
260 data are imperilled.(27, 39, 40) Failure to invest the time and resources in adequate public
261 and professional consultation to create a robust foundation for private-public collaboration
262 using health data is therefore likely to represent a false economy in the long term.
263

Box: Questions to address on collaborations using healthcare data

- What safeguards are necessary to fund costs for health services from collaborations, such as preparing data, to ensure resources are not diverted from delivering patient care?
- For the minority of ventures that return revenues, should these be returned to local health service organisations, or to the central health service, or to the nation's treasury?
-
- What kinds of partnership models are suitable for small and medium sized commercial partners versus those that are appropriate for larger companies?
- Should preferential terms apply for domestic companies, as opposed to overseas firms, as a means to foster wider benefits to society and the economy, such as employment and taxation?
- Should organisations which act as sub-contractors to health services, such as general practices in the UK, be permitted to negotiate value sharing collaborations independently?

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265

266

267 Healthcare systems need to invest in personnel with expertise in negotiating intellectual
268 property agreements to support those working for healthcare services who wish to use data
269 in pursuit of innovation. Such agreements should be made publicly available. Where
270 centralised expertise is available to support health systems to collaborate with industry,
271 organisations within those systems should be incentivised, or possibly even required, to
272 accept that support, rather than striking deals on their own.(41) Central scrutiny bodies,
273 such as the National Audit Office in the UK or the Government Accountability Office in the
274 US could be tasked with ensuring adequate value is returned to the public realm through
275 commercial partnerships.

276

277 **Conclusions**

278 Collaborations based around applying technologies like AI to healthcare data promise to
279 unlock new discoveries with both commercial and clinical value. But the patients have a vital
280 stake in determining how the value that results from such products is distributed and whether
281 it is reasonable for such collaborations to proceed at all. Neglecting these legal and ethical
282 frontiers in pursuit of innovation risks ceding valuable assets to private interests and could
283 prove a costly legacy for patients and taxpayers.

284

285

286 **Competing Interests**

287 Stephen Bradley has submitted a grant application for a project which plans to evaluate the
288 performance of artificial intelligence systems in diagnosing lung cancer. He receives PhD
289 funding from CanTest collaborative (Cancer Research UK C8640/A23385) and was a
290 member of the executive committee of the Fabian Society, a political think tank affiliated with
291 the Labour Party (unpaid). The publication costs of a collection of essays on health
292 inequalities which he co-edited for the Fabian Society were funded by the Association of the
293 British Pharmaceutical Industry and Lloyds Pharmacies. He has received funding from the
294 Mason Medical Foundation for a study on lung cancer diagnosis. He is employed as clinical
295 lead for cancer for NHS Leeds CCG. The other authors have no competing interests to
296 declare.

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