BioIndustry Association written evidence to the Science and Technology Committee's inquiry on data privacy

January 2021

Introduction

1. The BioIndustry Association (BIA) is the trade association for innovative life sciences in the UK. Our goal is to secure the UK's position as a global hub and as the best location for innovative research and commercialisation, enabling our world-leading research base to deliver healthcare solutions that can truly make a difference to people's lives.

2. Our members include:

   - Start-ups, biotechnology and innovative life science companies
   - Pharmaceutical and technological companies
   - Universities, research centres, tech transfer offices, incubators and accelerators
   - A wide range of life science service providers: investors, lawyers, IP consultants, and communications agencies

3. The BIA's members are at the forefront of innovative scientific developments targeting areas of unmet medical need. This innovation leads to better outcomes for patients, to the development of the knowledge-based economy and to economic growth. Many of our members are small, pre-revenue companies operating at the translation interface between academia and commercialisation.

4. The BIA welcomes the UK Government's vision for data use in the UK, as outlined by the recent National Data Strategy and draft 'data saves lives: reshaping health and social care with data' strategy. The BIA understands the Science and Technology Select Committee's interest in balancing data use with the public's right to privacy and welcomes the opportunity to submit written evidence. The following submission contains a summary of the perspectives of our members – primarily UK small to medium enterprises (SMEs) – along with real-world case studies.

The benefits of using data: improving our health and well-being

The sharing of data has always been fundamental to research and innovation, leading to ground-breaking drug discoveries or vital health innovations. For example, it was the use of patient data in the 1950s which showed the link between cholesterol and heart disease[1]. Data was then used to show that statins reduced the risk of death in people these heart problems[2]. Data has also helped improve the treatment of teenage depression[3] and prevent deaths from asthma in children[4].

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[1] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4525717/
[2] https://understandingpatientdata.org.uk/case-study/assessing-benefits-cholesterol-lowering-drugs
[3] https://understandingpatientdata.org.uk/case-study/improving-treatment-teenage-anxiety-and-depression
[4] https://understandingpatientdata.org.uk/case-study/tackling-preventable-asthma-deaths

Technology used to harness data for public benefit is developing at an exciting pace. This rapid progress is bringing new opportunities to improve our health and wellbeing. Some of the many benefits that can be realised through effective data use and sharing are:

- Better screening of the public to predict risk of disease, thus allowing for early interventions in disease progression

- Earlier and more precise diagnosis of disease, for example using Artificial Intelligence (AI) which can detect disease with more accuracy

- Analysing and modelling data generated from laboratory experiments to understand biological processes and drug interactions as part of the drug discovery and development

- Analysis of supply chain data and modelling to improve supply chain resilience, bringing down costs and delivering safer medicines to patients

- More targeted public health interventions to infectious or chronic diseases like COVID-19 or diabetes through epidemiological analysis of health data

These benefits rely on efficient flows of quality data within the UK's research and innovation ecosystem of publicly funded institutions (including the NHS), academia, charities and industry. These different players all contribute to the innovation behind beneficial health technologies. As an important part of the research ecosystem, SMEs rely on access to data to develop these cutting-edge health innovations [5]. For example, Benevolent AI[6] uses machine learning techniques to identify drug targets and patient populations, helping make "the right drug for the right patient". This relies on data sharing from multiple sources, which they used to identify Baracitinib as a treatment for COVID-19[7]. SMEs, therefore, rely on the sharing and use of data to discover and develop new health interventions.

Case Study: Jiva ai
AI can help clinicians in their decision making and reduce unnecessary interventions like biopsies.

Jiva AI puts usable AI technology in the hands of clinicians. The Jiva platform fuses data and models to create practical and explainable AI solutions. The platform can be used with minimal staff training, so it can easily be integrated into clinical practice.

Jiva technology has been used to interpret prostate cancer scans, which can be a very subjective process, leading to biopsies which may have been unnecessary. 80% of patients who have a biopsy get complications, which could include erectile dysfunction, rectal bleeding or even sepsis. Improving the diagnosis of scans will decrease the number of unnecessary biopsies, an immediate benefit to patients as well as the host clinical site.

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[5] https://www.bioindustry.org/policy/strategic-technologies/tech-bio.html
[6] https://www.benevolent.com/what-we-do
[7] https://www.benevolent.com/news/baricitinib-first-identified-by-benevolentai-as-a-covid-19-treatment-is-granted-emergency-use-in-india-in-response-to-its-escalating-crisis

Case Study: Precision-Life
Disease risk models built from large datasets can predict future diabetes complications, reducing healthcare costs and helping patients avoid life changing disease.

Precision-Life analyses large-scale patient populations to find combinations of genomic, epidemiological and other factors that drive disease within patient subgroups. Scientists and clinicians can then design effective precision medicine strategies tailored to each group. Using these insights in chronic diseases like diabetes saves costs as several effective interventions (drugs or monitoring) are already available. For example, monitoring glucose reduces these complications by 40% and blood pressure checks reduce renal failure by 80%.

Type 2 diabetes is a $1.75 trillion global problem, accounting for 10% of UK healthcare spending. 80% of that is spent treating complications of the disease, including cardiovascular disease, dementia, renal failure, glaucoma and blindness. Predicting future diabetes complications at the point of diagnosis creates a 3-5year window to delay or avoid these, thereby delivering huge cost savings for the NHS and improving patient care.

Technical barriers to using shared data

Technical barriers are practical issues that delay or prevent existing data being optimally used. These include problems like non-digital data sources, poor quality or unstandardised data, inaccessible data and incomplete or insufficiently linked data. Data should be collected under the FAIR principles (Findable, Accessible, Interoperable and Reusable) to avoid this.

Efforts to solve the technical barriers to data access are already underway through moves to curate public health data and move them to accessible trusted research environments (TREs). The recently published 'data saves lives' strategy makes valuable commitments to improve data architecture, establish TREs and consult on standards and interoperability[8] in the NHS. Similarly, the publicly funded initiative Health Data Research UK[9] is working to make public health data findable and usable. Other solutions, such as the use of representative synthetic data, would allow teams to experiment without needing to navigate governance or specialist environments. The BIA and its members are supportive of these efforts providing progress is made quickly and in collaboration with industry to avoid unintended barriers being created.

Governance as a barrier to data use

Governance barriers are those associated with the rules of accessing or using data. These may be legal or ethical requirements and are implemented both nationally and locally. While regulation is necessary, it can create a disproportionate barrier to SMEs, which have less financial resource or capacity for this type of work. In addition, the implementation of these rules is not always optimal or standardised.

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[8] https://www.gov.uk/government/publications/data-saves-lives-reshaping-health-and-social-care-with-data-draft/data-saves-lives-reshaping-health-and-social-care-with-data-draft#helping-developers-and-innovators-to-improve-health-and-care
[9] https://www.hdruk.ac.uk/

UK governance which regulates the use of health data is particularly complex, confusing and does not always protect the public's best interests. The complexity of the current system leads to errors or misunderstanding of the rules, both by the data custodians and those who seek to access the data. This has been demonstrated by innovators being given conflicting advice at different NHS trusts, for example. Resource can be wasted by heavy-handed interpretation of rules by research ethics committees (RECs), which has led to patients needing to re-consent for research projects in which they were already involved. These sorts of events risk undermining public participation and trust in the review process.

Data governance should be clear, easy to understand and proportionate to the risks. The BIA welcomes efforts by the joint NICE, MHRA and HRA initiative - the multi-agency advisory service - to simplify and streamline approaches[10]. A single front door approach would benefit SMEs and the public by providing a transparent system through which data access is granted. The BIA is particularly supportive of plans to streamline access at the proof-of-concept phase. The Government's 'data saves lives' strategy also plans to address issues with information governance. Plans for a revised information governance strategy and increased governance training is welcome. However, efforts to improve information governance should be developed in collaboration with industry and the public to make sure that the resulting frameworks work for all the stakeholders.

Impacts of reduced data use: impeding research and innovation

The resulting impact of these barriers is that the research and innovation process is impeded. Innovations or discoveries will take longer to reach the public, delaying potential improvements in health and wellbeing. In addition, barriers impact the companies' ability to grow, as too much time and resource is put into navigating them. A thriving biotech sector is a vital part of the UK economy, bringing wealth and jobs to the UK. Disincentives to work here also encourage companies to migrate abroad. Some SMEs have been put off using data from the NHS entirely and have established partnerships with data custodians in Europe. The Health Research Authority (HRA) recently conducted some research with innovators, which showed that this was a particular problem at the proof-of-concept stage; "*I wanted to do something in the NHS, but everyone I spoke to said 'go somewhere else because the NHS will kill your business'*"[11].

Reducing barriers to data sharing will speed up research and innovation and reduce the time that lifesaving treatments and interventions can be bought to patients. The BIA and its members are keen to support the refinement of existing data governance, to make the sharing of data both safe and impactful.

The BIA is happy to provide more evidence for the enquiry on data privacy. Contact Dr Emma Lawrence, Senior Policy and Public Affairs Manager at the BIA, on elawrence@bioindustry.org or 07880 009251.

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[10] https://www.hra.nhs.uk/about-us/news-updates/what-do-developers-and-adopters-ai-health-technologies-want-multi-agency-advisory-service-blog-carly-wheeler-policy-manager-data-and-ai/
[11] https://www.hra.nhs.uk/planning-and-improving-research/research-planning/how-were-supporting-data-driven-technology/sddr/