IET response to the Sudlow Review - 'Unifying Health Data in the UK' Consultation

About the Institution of Engineering and Technology (IET)

The IET is a trusted adviser of independent, impartial, evidence-based engineering and technology expertise. We are a registered charity and one of the world's leading professional societies for the engineering and technology community, with over 155,000 members worldwide in 148 countries. Our strength is working collaboratively with government, industry, and academia to engineer solutions for our most significant societal challenges. Professional guidance, especially across all technological sectors, is critical to good policymaking.

Our pool of knowledge and expertise spans diverse sectors, including but not limited to Health Systems, Clinical, and Biomedical Engineering. This vast scope positions us to constructively address the multi-faceted challenges and seize the opportunities in the realm of health data. Our commitment to technological innovation, engineering integrity, and public welfare are at the core of our work.

Executive summary

1. Standardisation and Interoperability

To unlock the full potential of health data in the UK, a standardised national framework must be established. This framework should enhance interoperability across different healthcare systems and facilitate consistent, quality data that can be efficiently utilised for healthcare improvement.

2. Centralised Data Management

The creation of secure, centralised data repositories is recommended to mitigate data silos, ensuring seamless integration of information from various sources. In combination with decentralised access through edge computing technologies, this strategy can provide local healthcare providers with efficient, secure data access.

3. Robust Data Security Measures

In light of increasing cyber threats, robust data governance and stringent security measures are crucial to health data management. This includes advanced encryption and anonymisation technologies and introducing an independent oversight body to build public trust and protect data.

4. Public Engagement and Transparency

Implementing health data initiatives requires broad public acceptance. Therefore, a commitment to public engagement, transparency, and education is necessary. This includes clear communication on data access, usage, and protection measures, which can enhance public trust and acceptance.

5. Investment in Digital Infrastructure and Skills

The future of health data management lies in digitalisation. Investing in high-speed networks, data centres, and cloud technologies is recommended. Fostering data literacy through workforce training will ensure the healthcare sector is well-equipped to harness the benefits of digitised health data.

Introduction

The IET is grateful for the opportunity to contribute to the independent review, 'Unifying Health Data in the UK'. This comprehensive review sets a significant foundation for crucial dialogues and transformative decisions around the future of health data management in the United Kingdom.

We stand on the threshold of a healthcare revolution driven by data. The potential of health data to redefine healthcare and research is immense, from the prospects of personalised medicine to predictive analytics. The UK, courtesy of the National Health Service (NHS) and its comprehensive, lifetime health records of over 65 million individuals, is uniquely positioned to capitalise on these opportunities. This potential was underscored during the recent COVID-19 pandemic, where swift and secure data linkage enabled the formulation of vital policy decisions concerning lockdowns, shielding, and vaccination strategies.

The IET's response to the 'Unifying Health Data in the UK' review presents our perspectives across four central themes: the current use of health data in research and healthcare, the barriers to health data unification in the UK, potential strategies to circumnavigate these obstacles, and the types of data that should be given priority to bolster research and healthcare. Furthermore, our response will provide insightful, pragmatic, and feasible solutions to the challenges currently impeding health data management in the UK.

We believe that harnessing the power of health data to transform the UK's healthcare landscape requires a concerted effort from all stakeholders - from engineering professionals, healthcare providers, and patient groups to policymakers and the wider public.

Q1. What are your views of the use of health data in research and healthcare as it stands today?

Health data presents immense potential for advancing healthcare services and medical research. Utilisation of health data can assist us in tailoring treatments to individuals, enhancing the efficiency of healthcare delivery, identifying diseases at earlier stages, and broadening our comprehension of diverse health conditions.

From a Health Systems Engineering perspective, health data contributes to enhancing processes, optimising resources, and improving the quality of healthcare. It also informs decision-making and policy formation, ensuring reliance on evidence rather than solely on intuition.

For Clinical Engineers, health data is crucial for the development and maintenance of devices, carrying out clinical trials, managing interfaces and integration, as well as ensuring regulatory compliance and safety. It guarantees the effective and secure communication of healthcare technologies, aiding in the enhancement and innovation of medical equipment and healthcare devices.

Biomedical Engineers use health data in their innovative design efforts, research and development activities, personalised medicine initiatives, public health interventions, and epidemiological studies. This data is crucial for understanding the needs of users, refining the performance of devices, studying the

efficacy of novel medical devices, modelling physiological systems, and creating new diagnostic algorithms.

Q2. What are the barriers to uniting health data in the UK?

Despite the numerous advantages identified in Q1, utilising health data presents several obstacles. These include the need to overcome data silos, ensure interoperability, maintain data privacy and security, ensure data quality and standardisation, adhere to regulations and managing transitions. These challenges require dedicated focus and innovative solutions to unlock the transformative potential of health data in healthcare fully.

i. Data Silos

A significant barrier to uniting health data in the UK is the existence of data silos within healthcare institutions. These silos hinder efficient data sharing and prevent a unified health data landscape. An illustrative example is the difficulty in seamlessly sharing patient information across hospitals, GP surgeries, and social care providers. The result can be duplicated tests, delayed diagnoses, or disjointed care plans. To overcome this, we recommend a nationally coordinated approach to establish data standards that promote system interoperability. Engineering solutions like federated databases could allow for decentralised control while ensuring that the data can be accessed and analysed collectively.

ii. Interoperability Issues

Health data's diverse formats pose interoperability challenges, with even simple data elements varying across systems. Engineering solutions like open standards, shared APIs, and middleware can aid data integration. Additionally, AI and machine learning could interpret and integrate disparate data. Edge computing could address real-time processing requirements, further enhancing the utility and accessibility of health data.

iii. Data Privacy and Security

The 2017 WannaCry attack highlights the critical need to balance data accessibility and privacy in healthcare. Solutions like homomorphic encryption allow data analysis without revealing the actual data. Furthermore, blockchain technology, as discussed in the IET's 'Blockchain for Healthcare' report, ensures robust security, and creates transparent, unalterable audit trails. Both strategies promise significant enhancements to the protection and use of health data.

iv. Data Quality and Standardisation

Standardisation is vital for integrating health data. Currently, the way health data is recorded can vary dramatically. For instance, one clinician might record patient weight in kilograms while another uses pounds. Standardisation would entail the development of national guidelines for data recording and classification. The IET advocates for an inclusive process in developing these guidelines, involving healthcare providers, patients, data scientists, and engineering professionals.

v. Regulatory Constraints

Compliance with GDPR and the UK's Data Protection Act can pose limitations on data sharing. Although these regulations are necessary, they can also create perceived barriers. Transparent, streamlined, and regularly updated regulatory environments, coupled with advanced AI tools for automated compliance checks, can help foster an environment where data sharing and privacy protection coexist.

vi. Public Trust and Perception

Without public trust, a unified health data system is unfeasible. Communication plays a critical role here. For instance, during the 2016 care.data program, public concern was heightened due to perceived inadequacies in communication about the scheme's opt-out provisions. Improved transparency about data

use, clear opt-out options, and comprehensive public consultations can build and maintain public confidence. Education initiatives, particularly in schools, can empower the public to make informed decisions about their data.

vii. Infrastructure and Resource Limitations

Unifying health data is resource intensive. Both technological infrastructure and human resources are required. In addition to public funding, public-private partnerships could play a pivotal role in providing necessary resources. For example, collaborations with tech companies could provide access to advanced analytics platforms, while partnerships with academic institutions could provide training for data management personnel.

Q.3 - What are the solutions for unlocking these barriers and realising the potential of health data in the UK?

i. Development of a Standardised Framework

The IET's 'Digital Advantage' report provides a compelling case study of the NHS implementing the FHIR standard, thereby giving weight to Recommendation 1 of the report. Advocating for a legislative mandate compelling trusts to use nationally agreed standards could speed up the adoption of these standards.

A significant obstacle in unlocking the potential of health data lies in its heterogeneity. The data gathered across various regions, healthcare providers, and systems frequently lack consistency. In response to this, we propose the development of a standardised, national framework. This approach would enhance the interoperability, quality, and consistency of health data.

The proposed framework should be developed in consultation with a wide array of stakeholders, including healthcare providers, patients, data scientists, and policymakers. Starting points could include established standards such as FHIR or CDISC. However, a unique, tailored approach may be necessary to truly represent the UK's health ecosystem in its entirety.

This could entail creating standardised data entry forms, developing unified coding systems, and implementing comprehensive data sharing protocols. This way, we can ensure an integrated and effective system of health data that serves the needs of all users.

ii. Building Secure, Centralised Data Repositories

The second aspect of our proposed solution involves the establishment of secure, centralised data repositories. This system could address the prevalent issue of data silos by integrating data from all sources into a unified, manageable entity. The potential benefits of this approach are clearly illustrated by Estonia's centralised digital health system.

However, it remains essential to maintain decentralised access to data. Thus, a hybrid solution that combines a central repository with edge computing technologies could provide secure, efficient data access for local healthcare providers. This approach would equip providers to deliver timely, personalised care while also ensuring effective data management at the national level.

iii. Ensuring Robust Data Governance and Security

According to the IET's 'Digital Advantage' report, following the 2017 WannaCry ransomware attack, only one out of England's 236 NHS trusts fully met the Cyber Essentials Plus standard. One of the report's policy recommendations involved commissioning a data security team to assist NHS trusts in meeting the Cyber Essentials Plus standard, introduced in response to the 2017 WannaCry ransomware attack.

This highlights the urgent need for robust cybersecurity measures and reinforces the crucial role of a dedicated data security team in each NHS trust. Furthermore, it emphasises the significance of trust in the management of health data.

To safeguard privacy and sustain public trust, we propose the establishment of robust data governance structures and the implementation of stringent security measures. The adoption of advanced technologies such as encryption, anonymisation, and secure multi-party computation is also recommended for enhanced data protection.

In addition, we suggest the establishment of an independent oversight body to monitor these practices, thus providing an additional layer of assurance to the public.

iv. Public Engagement and Transparency

Achieving unified health data is not just a technological challenge; it also requires public engagement and transparency. We advocate for a multifaceted approach that incorporates consultations, surveys, and educational initiatives to cultivate public acceptance. Transparency should be deeply ingrained in the system, answering key questions such as:

- Who has access to the data?
- How is the data utilised?
- What protective measures are in place?

Regular reporting on data usage, audits, and security breaches can enhance transparency. Finland's 'My Kanta platform', which allows citizens to see who has accessed their data, offers a practical model to consider.

v. Investing in Digital Infrastructure and Skills

In alignment with the IET 'Skills for a Digital Future 2023 survey', and its emphasis on the importance of workforce transformation, we recommend investing in digital infrastructure and fostering data literacy among engineering and health professionals. This can be accomplished through ongoing training programmes, apprenticeships, and partnerships with universities, thus ensuring that the workforce is equipped to navigate the increasingly digital landscape of healthcare.

Digital infrastructure serves as the backbone of a unified health data system. Therefore, investments should focus on high-speed networks, data centres, and cloud technologies.

Moreover, the development of digital skills within the workforce is vital. Government-backed training for current health professionals, coupled with STEM encouragement for future generations, can help cultivate and maintain a competent, digitally literate workforce.

vi. Policy Innovation

In line with the IET's recommendation in its 'AI for Drug Discovery' report, which advocates for the introduction of legislation permitting researchers to utilise anonymised health data, the IET encourages policy innovations that ease data sharing, such as the implementation of data trusts or data cooperatives.

Innovative policies can pave the way for the ethical sharing of health data. Data trusts, for example, can manage and distribute large datasets while ensuring privacy, security, and fairness. They present a democratic and transparent approach to handling health data, complete with explicit rules governing usage and access.

Canada's Vector Institute is at the forefront of employing data trusts and serves as a viable model for the UK. Through adopting and adapting such initiatives, it is possible to create an environment that supports responsible and effective data sharing for the greater good.

vii. Promotion of Public-Private Partnerships

Public-private partnerships can stimulate innovation while sharing costs. Private companies with technological expertise can significantly contribute to the development of efficient and secure health data systems. However, checks and balances need to be established to prevent potential conflicts of interest, ensuring both equitable access and privacy protection.

The Genomics England partnership stands as a valuable example of effective public-private collaboration. It illustrates how private sector expertise can be harnessed to achieve public health goals. In this case, Genomics England partnered with various private entities to sequence 100,000 whole genomes from NHS patients, a milestone in precision medicine. This partnership not only accelerated technological advancements but also upheld ethical standards, ensured patient data security, and allowed the NHS to retain data control.

Such an example can serve as a model for future collaborations, demonstrating how the synergistic combination of public oversight and private sector efficiency can produce impactful outcomes in health data management.

viii. Role of AI and Machine Learning

AI and machine learning technologies are powerful tools for health data analysis. From predictive modelling to precision medicine, these technologies can extract actionable insights from vast health datasets. However, the development of clear ethical guidelines is essential to govern the use of AI and machine learning applications. These guidelines could draw inspiration from those already in place for clinical trials, ensuring responsible and ethical use of these advanced technologies.

Q4. What types of data should be prioritised now to be made available to support research and healthcare?

In response to the question of what types of data should be prioritised to support research and healthcare, as a multidisciplinary engineering and technology charity, we recommend the prioritisation of the following seven types of data:

i. **Electronic Health Records (EHRs)**
EHRs provide a comprehensive account of a patient's medical journey, encompassing medical history, diagnoses, treatments, allergies, radiology images, and laboratory results. Projects like the '100,000 Genomes Project' in the UK demonstrate the vast potential of EHRs in research and clinical care when combined with genomic data.

ii. **Genomic Data**
Personalised medicine, driven by genomic data, is revolutionising healthcare. Integrating genomic data with traditional medical records can substantially enhance disease prediction, treatment, and management. This approach has seen success in treating certain cancers and genetic disorders.

iii. **Imaging Data**
Medical imaging data, such as MRIs, CT scans, and X-rays, can augment our understanding of diseases, enable more accurate diagnoses, and facilitate AI-based diagnostic tools. For example, machine learning algorithms, trained on extensive imaging datasets, can assist in early detection of conditions like lung cancer or brain tumours.

iv. **Real-Time Monitoring Data**
Wearable technology provides continuous, real-time health data outside of clinical settings, enhancing patient care management, particularly for chronic conditions. The growing importance of telemedicine during the pandemic has underscored the invaluable nature of such data.

v. **Social Determinants of Health (SDOH)**
Factors such as income, education, employment, social supports, and housing significantly affect health outcomes. Integrating SDOH with clinical data can promote more holistic care strategies, as illustrated by initiatives like Public Health England's 'Wider Determinants of Health' tool.

vi. **Patient-Reported Outcome Measures (PROMs)**
Patient experiences and perspectives offer valuable insights into the efficacy of healthcare services. PROMs can drive improvements in service delivery and patient experience, enhancing patient-centric care models.

viii. **Pharmacy Data**
Detailed records of prescribed medications, adherence, and pharmacy-based interventions can inform treatment effectiveness and potential drug interactions, optimising medication use and enhancing patient safety.

By prioritising these types of data, we can best support the ongoing evolution of research and healthcare delivery.

Conclusion

In conclusion, the IET recognises the immense potential and value of unifying health data in the UK. As a multidisciplinary engineering and technology professional engineering organisation, we are committed to addressing this endeavour's technical and ethical challenges, leveraging our collective expertise to drive innovation and uphold the highest data governance standards. Realising the full potential of unified health data requires a holistic approach that combines technological innovation, robust policy frameworks, public engagement, workforce upskilling, and secure, interoperable infrastructure. Our proposed solutions, ranging from the establishment of a standardised data framework to the promotion of public-private partnerships, underscore our commitment to fostering a secure, efficient, and patient-centric health data ecosystem. As we navigate this journey, prioritising data types such as electronic health records, genomic data, and real-time monitoring data will be crucial. These datasets will fuel advancements in research and healthcare delivery and offer valuable insights into disease prediction, personalised treatments, and health outcomes.

Moreover, it is essential to maintain an ongoing dialogue with the public and foster a culture of transparency. Public acceptance and trust are vital for the success of any initiative concerning health data. Hence, we advocate for establishing robust governance structures, rigorous data protection measures, and a strong emphasis on public engagement and education. Lastly, we recommend continued investment in our digital infrastructure and cultivating a digitally literate workforce. Equipping our health and engineering professionals with the necessary skills to navigate this digital healthcare landscape will be paramount to successfully implementing unified health data in the UK. We hope the insights and recommendations outlined in our response will contribute constructively to this critical review. The IET remains committed to working alongside all stakeholders to unlock the potential of health data, with the ultimate goal of enhancing healthcare outcomes for all individuals in the UK.

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