Data saves lives: reshaping health and social care with data
Chartered Society of Physiotherapy
Consultation response

The Chartered Society of Physiotherapy (CSP) is the professional, educational and trade union body for the UK's 60,000 chartered physiotherapists, physiotherapy students and support workers.

The CSP strongly welcomes the intention of the NHS data strategy. We believe accessible high quality data is essential in order to:

- Understand population level needs in order for services and workforce to be planned effectively
- Know who is and isn't accessing services so that services and systems can address barriers to access and redress health inequities
- Stratify need and assess risk so that services can be targeted to have maximum impact
- Drive service quality improvement
- Deliver the commitments contained in the NHS Long Term Plan

As advocates for evidence-based and digitally-enabled health care, often working at the interface between healthcare settings and sectors, we and our members are very conscious of the frustrations that result from fragmented infrastructure and initiatives, particularly from the significant national AHP data deficit. The proposed unified approach, addressing questions of interoperability and data integration, is an essential step forward. We advocate for a holistic view of health and care data: across sectors, healthcare disciplines and geographies. We believe that the NHS data strategy should aim to support appropriate data sharing between the devolved nations of the UK.

The coronavirus pandemic has precipitated transformative developments in health informatics, and shone a light on current weakness in current data infrastructure – for example, the shocking gaps in data about the needs of residents in care homes that became evidence in the first part of 2020. The pandemic has also, particularly in the course of the vaccine roll-out, clearly shown the need to build trust among patients and health care professionals, to support confident participation in healthcare.

The development of trust must be central to the data strategy. It demands not only the optimistic presentation of the opportunities of health data sharing, but respectful recognition of legitimate concerns, and thoughtful acknowledgement of the risks and how they can be mitigated. We would like to see this given greater prominence in the data strategy, through plans for consultation, data governance, and for an independent review body.

We too, at the CSP, are actively developing our own data capabilities, for the continued health of the organisation, and to provide leadership in the digital transformation of the profession we serve. We aim to see physiotherapy staff and patients become confident and skilled participants in data-enabled healthcare. Our digital health motto of "Collect well; Use well; Share well" reflects the multiple, essential roles that our members play in health data systems. The draft data strategy gives hope of great progress in technical data infrastructure. Its success will depend on developing holistic data literacy to match.

Summary of CSP recommendations

- We believe that the data strategy should go further to build trust in health data sharing among the public and health and care professionals. The draft strategy does a good job of

presenting the opportunities, but must also acknowledge the risks and set out measures to mitigate them.

- The strategy should acknowledge the UK-wide dimensions of health and care needs, workforce planning and development, research and infrastructure, with a plan to support and encourage appropriate data sharing between the devolved administrations.
- The success of the strategy depends on building data literacy throughout the health and care workforces, and at every stage of the data supply chain: creators, stewards and users. We recommend that the development of technical infrastructure must be accompanied by a plan for data skills training, in pre-reg courses and throughout the established workforce. Doing so would bring about a change in data culture from something we must collect to something we want to collect.
- Data governance is the foundation of all data lifecycle activities. We would like to see the plan for unified data governance given due prominence in the next iteration of the strategy.
- Data infrastructure must be designed from the outset to reflect the needs and the contributions of the physiotherapy workforce and other allied health professions across all settings and sectors
- Development and genuine innovation should be incentivised according to strategic need: to deliver the NHS Long Term Plan and support reset and recovery after the pandemic. This relies on addressing the gaps and weaknesses within current data systems in order to drive service improvement and better commissioning to meet population health needs equitably.
- The NHS must address legacy underfunding of core ICT infrastructure, ensuring adequate and equitable provision of computer hardware, mobile devices and internet connectivity for staff to play their full roles as collectors, stewards and users of data.

1. Bringing people closer to their data

1.1 The commitment to engaging patients with their data is central to the success of the data strategy. It is also among the most challenging aspects as it depends not only on the efforts of the NHS to provide accessible information and tooling, but on the data literacy and health literacy of citizens. The implementation of the NHS data strategy could provide a focussed opportunity for the government to develop initiatives that build the UK's 'data citizenship', to the wider benefit of National Data Strategy objectives.

1.2 The draft strategy makes reference to legal controls on how health data can be used – we believe these should be treated as a minimum rather than a goal for ethical data stewardship. Data technology and regulation are fast evolving, and there must be an ongoing commitment to keep participants in health data systems up-to-date with, and accountable to emerging requirements. Even experienced developers may need additional support to negotiate the complexities about meaningful consent, and Data Protection Impact Assessments, implicit in health data processing.

1.3 The CSP recognises and promotes the potential for public good in health data sharing, but we believe that it must be an equitable and inclusive good. There are additional sensitivities about information sharing in some healthcare disciplines, such as addiction and sexual health, and among some communities, such as travellers or immigrant communities. It is essential to understand and address the legitimate concerns that may deter such patients or their healthcare professionals from data sharing in order to secure the inclusivity and representativeness of the data resource.

1.4 We welcome the suggestion that PROMs should be included in future datasets. It is essential that all relevant professions have input into the selection of relevant PROMs, to support patient management, service evaluation, service planning and benchmarking. We would also welcome the addition of Patient Reported Experience Measures (PREMS) and an assessment of Quality of Life (eg EQ5D) to this dataset. The creation of a robust, longitudinal dataset will support future research and modelling for population health needs assessments.

2. Giving health and care professionals the data they need to provide the best possible care

2.1 The success of the strategy depends on building confident data literacy among participants at every stage of the data supply chain: to understand the purpose and value of data collection, responsibilities to data stewardship and sharing, and as data interpreters and decision-makers. However, the annual UK Allied Health Professionals survey continues to highlight a lack of confidence in such data skills. The implementation of the NHS data strategy must be supported with a plan to train for role-appropriate data literacy, not only among pre-registration physiotherapy students but throughout the established workforce.

2.2 A rationalisation and clarification of the rules and guidance on information governance will be welcomed by CSP members. The legal and ethical responsibilities of data collection, stewardship and sharing can be daunting, particularly where staff lack training or confidence in their data skills. The data strategy offers the perfect vehicle to establish unified data governance, and to encode data policy into data standards and infrastructure, supporting data stewards to share data confidently and within the rules.

2.3 Many CSP members provide rehabilitation in community and social care settings, and in the private and independent sectors. Despite contributing to an essential function of our healthcare infrastructure, they have often found themselves outside the target of digital health developments, obstructing their access to the data they need to provide the best possible care, but also their ability to share data with other health professionals. It is critical to the overall success of the data strategy that physiotherapists and other allied health professionals, in all settings, are considered from the start, as first-tier players in data supply chains. Any additional considerations for the governance of cross-sector data sharing, or data standards and technology patterns, must be intrinsic to data design. For example, the increasing use of a “rehab prescription” is an important component of needs assessment and treatment programmes that will be poorly represented in data models designed for primary care settings.

3. Supporting local and national decision makers with data

3.1 Data-driven cultures rely on decision makers, data contributors and data subjects trusting the quality of data assets above their own opinion. While we welcome the promise of investment in data skills, we query the sole emphasis on “analytical and data science capabilities”, which must be balanced by investment in data management capabilities addressing every stage of the data supply chain.

3.2 We very much welcome the ambition to improve the supply of data for planning and monitoring of services and developing needs. The CSP’s experience of such exercises has shown that weaknesses occur where data modelling fails to reflect the permeability of real-world boundaries, such as between higher education and the healthcare workforce, or the NHS and private practice.

3.3 Similarly, there are significant challenges in connecting data sets from different administrative regions, in order to understand geographical disparities in care needs, workforce pressures and training. We are particularly keen to understand how, and where, physiotherapists move through their training and careers to support with workforce planning. We would like to see this data strategy lead a framework for UK-wide sharing of clinical evidence, workforce and health education data.

3.4 We have also found that information relating to need, provision and outcome is not consistently collected, undermining planning and service development efforts, such as our work in Community Rehabilitation. The unified data strategy gives a framework to build on

good practice and innovation, such as the Dorset Intelligence & Insight Service pioneered by Dorset Clinical Commissioning Group.

3.5 Efficient reporting and dashboards are not, in themselves, sufficient for optimal understanding. Role-appropriate data literacy must be cultivated among the clinicians and managers who use, analyse, evaluate and interpret the data, and who action its insights, as well as among data stewards. Dashboards and reporting are at their most effective when they are co-designed with their specific user group. In short, as a professional body we respect the professional data skills, but we also recognise the need to invest in data skills throughout the workforce, including CSP members.

4. Improving data for adult social care

4.1 We acknowledge and welcome the ambition to build a connected view of the health and social care data ecosystems. CSP members have keen insight into the necessity and the challenges of data exchange between health and social care. Without this the value of health interventions to reduce demand on social care (and vice versa) is not visible, and cannot therefore be used to design services to have maximum impact. We believe that data strategy in general benefits from 'ecosystem thinking'. Data modelling for health and social care must also keep in view intersections with education and workforce development, local and national government, and other more peripherally related systems.

4.2 Given the explicit reference to adult social care, we question the omission of any reference to children's social care, and also those transitioning from children and young people's service to adult services.

5. Empowering researchers with the data they need to develop life-saving treatments, models of care and insights

5.1 As researchers ourselves and representing clinical researchers, the CSP has a keen interest in promoting the safe exchange of data and insight. We note, however, that this chapter is somewhat lacking in context while we await the findings of the ongoing Goldacre review.

5.2 We note that many concerns about the data available to researchers relate to issues much earlier in the supply chain, including quality assurance, data integration, or lack of trust among some patient communities, which may lead to systematic gaps in data assets. In addition, by working with clinicians and clinical researchers it will be possible to identify comprehensive datasets for use by clinical and research teams, which should include collection of Patient Reported Outcome Measures (PROMs), Patient Reported Experience Measures (PREMs) and Quality of Life (QoL) measures.

5.3 Co-designing data systems with healthcare researchers is an opportunity to learn from the advanced practices in data management that have been pioneered by research communities. Genomics, for example, has well-developed principles and protocols of data publication under embargo, which encourage open and additive research while protecting intellectual property.

6. Helping colleagues develop the right technical infrastructure

6.1 We welcome the promise of a unified and strategic approach to data infrastructure. Our digital health community has often been disappointed by the outcomes of data developments that have been fragmented and sometimes at cross-purposes. The NHS data strategy offers a critical step towards putting that right.

6.2 We believe that the implementation of unified data governance is an essential precursor to effective data design. We hope to see a plan for data governance laid out clearly in future iterations of the strategy. The unified architecture, data standards, and metadata design provide opportunities to encode and implement the data governance policies, providing support and a safety-net that will give greater confidence to participants at all stages of the data supply chain.

6.3 We urge that data modelling and architecture take a broad view of both use cases and supply chains. In particular, we hope to see the allied health professions properly consulted and reflected in data and systems design from the outset, rather than shoe-horned, later, into data models built for medics and nurses. Similarly, standards and architecture patterns should be designed for use in community healthcare settings and beyond the public sector.

6.4 The earlier fragmentation of data infrastructure has led to variable degrees, by sector, organisation and discipline, of technical debt. This applies to data literacy as well as data technology. We believe that the overall success of the data strategy will depend on equitable support for the development of technology and skills across the health data ecosystem, as weaknesses in one area may limit the value of the resource.

6.5 One of the biggest obstacles to data collection and use by our members has been the chronic underfunding ICT infrastructure across the NHS. Many staff have limited access to computers or mobile devices to support their work, or make do with obsolete hardware and inadequate broadband or mobile data connections. These issues must be remedied first, before we can progress to make real use more ambitious data technology. To focus on AI and advanced analytics while staff are crying out for single sign-on and reliable wi-fi risks neglecting the quality of the data resource, and entrenching the divide between professions and sectors in who has the resources they need to provide the best possible care.

7. Helping developers and innovators to improve health and care

7.1 Anecdotally, there is a view that the NHS makes it hard for developers to engage, with moving demands and limited resources. We believe that the unified approach and open standards set out in chapter 6 will go a long way to build confidence. Similarly, we believe that a unified approach to data governance would offer a trusted and authoritative point of reference on matters of health data policy.

7.2 Finally, the introduction of this data strategy gives a framework for the development of healthcare technology according to strategic need. Recent years have seen the launch of many data services associated with GP practices, such as ordering prescriptions and booking appointments, but relatively little that supports physiotherapists and their patients. We hope that the data strategy will be used to incentivise genuine innovation and the filling of gaps, rather than proliferation of similar products.

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