Foreword

We are in the midst of a data revolution. More data is useful, but opening data – in other words making it accessible to a wider array of appropriate audiences can yield even more important results. Evidence suggests that giving patients access to their own healthcare records can increase healthy behavior and improve decision-making. Giving providers access to comparative performance indicators across hospitals and physicians increases cost-efficiency in the healthcare system. Giving researchers access to clinical data improves medical outcomes. Giving the public-at-large access to nationwide prescription data and hospital performance increases choice, empowerment and accountability. These are just some examples of the value behind making health data more open and accessible, into what we may collectively call shared data. Through making data more accessible, while also ensuring privacy and confidentiality, NHS England has committed itself to spur a revolution in health care, through increasing patient power, saving lives, and greatly improving quality of treatment.

Three key objectives lie at the core of all our work:

▸ *Transparency:* The safe sharing of data and information between clinicians, patients, and the public.

▸ *Participation*: Supporting patients and citizens to take more control of their health and care and fully engage in the design of local services.

▸ *Interoperability*: The development of seamless digital records across all care settings, based on open standards.

Since April 2013, NHS England has undertaken a number of initiatives to achieve all three objectives. These include: The scheduled launch of care.data in 2014, an initiative designed to address gaps in the information currently held by the NHS and to promote seamless data flows across NHS departments; the publication of comparative provider outcomes; and the introduction of the "Friends and Family Test," a measure of patient satisfaction based on the number of patients who would recommend hospital inpatient and A&E services to friends and family, and associated free text feedback.

All these initiatives have gone a substantial way towards helping us understand the potential impact of making data accessible. Through these investigations, we have gained a better sense of what works, and what does not. To take our efforts to the next level, we are adopting a more systematic approach to the way we use and evaluate the effects of open data. To do so, we need methods to measure the impact of open data and to analyze the specific circumstances under which it is most (or least) effective. In other words, we require a roadmap that will guide us in our efforts to build on existing successes and applications.

This report, prepared by the GovLab, a global action research network, goes a considerable way towards establishing such a roadmap. It lays the foundations for a substantive research agenda that can help health and care services advance their objectives and, at the same time, deepen interaction with open data, as well as enhance patients' and providers' experiences. I am particularly pleased with the report's emphasis on establishing *metrics* of success and *methodologies* to collect the data required to support these metrics. Metrics are critical in evaluating success and failure. They are essential to helping us understand what we do right and where our work needs refinement or improvement.

The report's broader emphasis on establishing an organisation-wide culture of learning (what the authors call an Open Data Learning Environment) is also invaluable. Ultimately, a successful application of open data can come only from a transformation of the way we use information across departments, hospitals, providers, trusts, and other agencies and institutions. Data transparency requires coordination and commonalty of purpose, and it obliges us to cut through existing silos. The proposed Open Data Learning Environment is an important step towards achieving this goal of systematic and organisation-wide transformation.

It is my belief that making data more accessible, in an appropriate manner, will ultimately revolutionize the delivery of health and social care in England and around the world. I see this transformation occurring in years, not decades. This report represents yet another milestone in our efforts to ensure that NHS England will be at forefront of this global transformation.

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