

## The importance of health and civic data to the Government's growth agenda Summary of themes and action points

### Summary

This note sets out the main themes and proposed action points at the Future Health policy roundtable – sponsored by Janssen – exploring the importance of health and related data to the Government's economic growth agenda. The below is a non-exhaustive summary from the discussion from Future Health held on 1 December 2022.

The views and contents of this note are those of Future Health and are not attributable to any individual participants.

### Introduction

Huge progress was made in generating, sharing, and using health data in the first two years of the Covid-19 pandemic. However, this initial momentum has stalled, and the current Government and NHS policy landscape is confusing and cluttered with organisations, initiatives, and disconnected priorities.

The agility and data fluidity seen during the pandemic has been lost. The UK is falling behind in phase 2 and 3 clinical trials. With financial investment tight and winter pressures on NHS services rising a new operating model is urgently needed that takes friction out of the system.

### What is needed now

- Narrative – a federated approach to data and analytics is the right way forward – but the Federated Data Platform narrative and focus need to shift to the 'purpose' of the platform, its benefits to patients and the operation of the service. The key ingredient for a thriving federation of NHS intelligence and data-intensive innovation is trust – the trust of the public, who are the data subjects, and to whom data controllers are ultimately accountable. The UK Government can only liberate the potential of health data – for NHS improvement and economic growth – with the consent of the UK population.
- Power – Power must be devolved – this requires two things. First, clarification is needed on existing legislative responsibilities to enable Integrated Care Systems (ICSs) to press ahead with collecting and analysing the data on the population health needs of their areas. During the pandemic the Control of Patient Information (COPI) notice supported this. But the withdrawal of COPI has slowed progress. ICSs need to be the master data controller within the NHS. Clarification in the Hewitt Review of ICSs, a statement from DHSC and/or NHS England or a short guide of best practice information governance in the new NHS structures or some combination could be the method for ensuring this. Second, the centre needs to be more cohesive in its approach. A national data-action council co-ordinating the priorities from various agencies and working to empower ICSs could be a helpful and sharper force. This should have a

Vaccines Taskforce style ethos of speed, energy and partnership, rather than a more typical Whitehall Committee structure

- Skills – Data (science, engineering, and management; or more broadly informatics) skills must be properly valued – ICSs should have a data-action lead on their board (CCIO/CDIO). NHS data analysts need to be brought out from the fringe and into core planning and delivery at ICS level. Future workforce planning needs to ensure these roles are invested in and scaled up
- Investment – Investment in health data infrastructure should not be seen as exclusively about extra NHS funding. More needs to be done to secure other sources of public funding for NHS data infrastructure, through for example Government backed uplifts in science research funding through universities. The UK also needs to fix its clinical trial model. It is too slow and bureaucratic to recruit patients to trials. A template trial contract should be adopted which can be adapted by individual ICSs and NHS Trusts. Nationally, a federation of clinical trials intelligence across ICSs, linked to recruitment performance indicators, could speed the set-up of trials, and improve recruitment and retention. Improving the clinical trials environment will bring investment into health systems and have a wider regional economic benefit
- The future – The immediate priority is to clarify data policy priorities, devolve responsibility and tackle pressures. Consistent and multi-year investment must also flow to support the ambitions of wider population health and longitudinal data spanning different care settings beyond the NHS as well as wider public health data. There is a need to not only focus on the sick population but on ways to grow the 50-55% of the healthy/well population, and its importance to regional economies and social wellbeing. Civic, cooperative approaches to mobilising data into health innovation deliver impacts and attract public support for data-sharing, with tangible local benefits.

### **What this would deliver**

Implementing the above would help with:

- Building a clearer set of national priorities and a more cohesive centre on health data policy
- Empowering ICSs with the right mandate, skills and expertise to use data to tackle short term service pressures and build foundations for population health management approaches
- Creating new alliances, partnerships and investment in UK health data infrastructure and research
- Improving patient and public confidence and involvement in NHS data-action, pulling through the relevant data and digital innovation into civic clusters of improvement in care services coupled with economic growth and allied research
- Providing certainty on long term investment in data infrastructure that supports population health and ambitions for more preventative healthcare

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