

Available manifesto commitments towards more trustworthy uses of data for health – medConfidential

The current Government has effectively privatised medical data analysis by requiring that all new large NHS data projects across England incorporate a ‘private sector’ partner to handle data analytics; citing ‘delivery’ and ‘scalability’, [every one](#) of the seven new ‘Digital Innovation Hubs’ will hand richly-detailed, patient-level data to the private sector. **Patients should always know how data about them is used, by whom, for what purpose, and what the outcomes are.**

Transparency commitment: Tell patients how their data has been used. NHS Digital already has a working mechanism that enables them to tell an individual patient how NHS Digital has used data about them – however, you currently have to write to NHS Digital for them to tell you. This mechanism could be rolled out *almost immediately* via NHS.UK and the NHS app, so that every patient could see many of the ways in which data about them is used for purposes beyond their own direct care – and, as a consequence, every patient could see how the NHS uses data about them to improve medical research; seeing outcomes and being able to *know* that their data was part of that research. Critically for trust, where patients have opted out, they will be able to see how their wishes are respected. Only with full transparency and accountability can greater access to GP records for research be met.

AI / research commitment: A ‘public option’ for NHS AIs. The UK’s world-leading research base has an ‘open access’ policy to make published outputs available for the benefit of all, not just those who can afford to pay to use them; we should do the same for NHS funded AIs. To avoid another round of tech company [monopolies and profiteering](#), the £250m NHS AI budget already announced should ensure a competitive market by underwriting a public option of [NHS AI tools](#). Such NHS tools, using the AI budget, would give the technical and clinical F2s falling out of the NHS a way to contribute to the NHS.

Prohibition: ‘Policy makers’ should not use patient-level data for ‘funding’ decisions.

The current Government’s [plans for NHS legislation](#) include using individual patient records for ‘funding’ decisions made at national level. Such use will undermine both public trust in the use of data for research, and public confidence that what they tell their doctor might affect the funding their hospital receives. Use of patient-level data for such decision making should be prohibited; properly generated custom statistics are more than adequate.

Single strike. The Care Act 2014 made provision for regulations that would, amongst other things, enact a ‘single strike’ sanction for abuse of NHS data. Despite public claims of ‘safeguards’ being in place, these regulations have not been laid (or written), even when [NHS Digital’s own audits of data recipients prove](#) contracts – and, in some instances, the law – have been breached...

Improve the opt-out process for families. In a way that maximises the amount of information available for commercial ‘partners’, and by a deliberate decision of the current Government, any family must express their opt-out ‘per person’ (i.e. individually online for adults, and via paper forms by post for children) rather than as a family registered at the same address being able to express their wishes in a single step. This is easy to change, and it is the right thing to do. The current process makes any Government supporting it look like it prefers to disadvantage families with children – and leaves it open to suspicion of an attempt to suppress family choice and reduce opt-outs through deliberate bureaucratic overcomplication.