DSIT consultation on data intermediaries

medConfidential would not oppose more guidance being published (options 4 & 7), but assess that any legislative change would have fundamentally creepy unintended consequences (options 1, 2, 5 & 6). If an intermediary was viable, it would already be lawful – the law is not the barrier, but it is a convenient scapegoat.

The consultation assumes data must be copied to be useful, but on-device AI makes copying unnecessary, so DSIT was envisaging a world that's already ending. We cover related topics in a post written after a DSIT (as was) roundtable on this consultation.

The consultation seems to believe that "data brokers" and "information intermediaries" are substantively different – they are de facto interchangeable, even if it may be temporarily convenient for one to suggest otherwise. The need to find a more profitable business model will push these organisations into exactly the activities DSIT is assured, in meetings, they will never touch.. Assurances get broken by cheats. We would draw DSIT/DCMS's attention to the entire chapter of Goldacre Review for DHSC entitled "The challenge of privacy in health data" which applies far beyond health data.

OpenBanking is not generalisable

The consultation isn't about consent – all the positive use cases discussed are things that are already legal today; it's about allowing data flows in all aspects of your life that you wouldn't say yes to if they had to ask you. DSIT has internalised that although the law says you should be able to see data about you, Government, the NHS and the private sector simply ignore that, because it is convenient to keep data subjects as literal subjects of decisions made by others.

The first movers are always those who'll most benefit with least friction. OpenBanking was used by landlords to creep on their tenants, because positive new business models take years. If there was a positive example of where the model would work, it would headline the consultation. Instead it's akin to "smart data" which generally degrades to copying data behind your back for someone else's financial gain.

If DSIT wishes to insist that the methods of OpenBanking should be applied to the notion of data copying, please copy the balance of the HM Treasury Contingencies Fund into ours…

Examples

The NHS has had information intermediaries for 30+ years, which demonstrates that new legislation is not required – there's even an extra line in the NHS data price list for them. The comparative size of that charge shows the work they create.

Invariably, those intermediaries aim to allow things others do not as they have to show commercial viability and turn a profit, and that becomes a race to the bottom, which invariably blows up. Swathes of the Goldacre Review for DHSC are on how to clean up that mess (a topic we go into slightly more in our response to the other DSIT consultation running simultaneously with this one).

Fourth parties willing to become an intermediary or simply pay an intermediary must want something they can't get directly. When someone wants to do something profitable, they find a way.

When a pharmacy started acting as an intermediary and selling its customer list, the first people in the queue – the convicted fraudsters – would never have got through NHS vetting. When eugenicists wanted to do their genomics work, they went to UK Biobank not the NHS/GeL. There will always be pressure to break promises to individuals in search of profits, especially when, without that juicy new contract, the data broker will suffer adverse consequences – Genomics plc expects Genomics England to break their promises to patients about insurance use because it will make Genomics PLC money (Q123).

Whenever the NHS has a hiccup, the large health charities again reassess whether their committed supporters could contribute data directly. The answer is always that not enough of them will do so to matter — unless there is a direct benefit to the individual, in which case the project could happen today anyway. Optional volumes will never support a stable service. But the pressure to make data flow to intermediaries without people's active choice, awareness or permission will be endless — and that is the point at which toxic and perverse incentives abound.. Viability only comes with defaults at population scale, as most people have no idea this happens. 5% of people have expressed an NHS Data Opt Out, but if you poll people upwards of 20% of people say they have.

"Research" is not a regulated activity – it covers anything anyone wishes to claim

Bona fide academic research is good, but forcing all people to make data available against their wishes, as the watered-down NHS Data Opt Out proposes, undermines all intermediaries and all data use. There are many data-sharing schemes where the assumption of those working on them is that no one would ever object to any decision that is made, so there's no need to tell people and no need for an opt out. "Smart Data" is the euphemism.

Public perceptions of this initiative will be based on the most toxic behaviour that the proposals that flow from it allow.

Individuals, data subjects, must be able to see how data about them is used (especially by intermediaries and their subsidiaries)

The burden of managing and implementing choices must be entirely placed on the intermediaries. They will complain that without cheating or subterfuge they'll make less money – maybe that's an admission that they don't have a legitimate business model and the Department will then be responsible for cleaning up the mess.

The NHS introduced information intermediaries after a quasi-corruption scandal resulted in the first one being created as a face-saving measure, and then former employees at new companies asked for that same non-exclusive arrangement. The NHS has since spent a decade closing them down again as they broke the rules to avoid failing, and failed anyway.

Similarly, the “Zoe” app that gained prominence during the pandemic thrashed around for a business model, asked multiple times for bailout from the NHS, and degraded to selling ‘food supplements’ to the worried well – the same business model of the former US website “Infowars” run by Alex Jones.

DSIT seems to want to repeat this approach. It is entirely unclear why.

If an intermediary was viable, it would already be lawful – the barrier is not the lawful parts.

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