

The Spending Review¹

1. Data use is necessary and useful, but also allows people to do things with inadequate thought or for their own narrow benefit and with wider harms. In government, such mistakes make *everything* done with data harder. **Data use across Government must be fair and just, safe, and transparent.**
2. Just as a Department chooses what to digitise, it is necessary for the spending review to examine what they did not digitise.² Similarly, Departments will focus on ‘fraud’, and a desire for announcements,³ which – in financial terms – is dwarfed by Departmental error.⁴ Those choices are driven by culture, not the public purse.
3. Debates about data operate best when all parties are able to express *and hear* the full range of views, and where clear governance lines exist around decision-making boards. UPD, for example, may act as cheerleaders for medical research and forget to help patients understand their dissent choices – but with their assured independent funding and governance, they do have a long term vision. Many things that happen where a UPD doesn’t exist in the rest of Government tend not to happen in health, where the ecosystem is more durable.
4. In the rest of Government, opportunities for constructive challenge and genuine dialogue with projects are often minimal; catastrophes (or fear of them) inevitably dominate discourse, and decisions are too frequently made for short-term reasons.⁵ Just as silos can create disasters that harm cross-NHS working, silos in government – and a lack of whole government scrutiny from outside but adjacent to government (apart from our free time) – undermine nearly all data sharing plans, but especially the good ones, because there are no trusted actors to tell the difference.⁶
5. We make three cross-Government points:
 - 1) **Digital savings get undermined by Departmental choices;**
 - 2) **The Spending Review should aim to uncover data hoards before they leak;**
 - 3) **Citizen confidence in data saves money over the spending round period.**

¹ Most of this was written in February 2021, but not published until June 2021.

² Or us, e.g. in Annex 5: <https://medconfidential.org/2020/universal-credit/>

³ In particular, the cover of Annex 3: <https://medconfidential.org/2020/universal-credit/>

⁴ Annex 3: <https://medconfidential.org/2020/universal-credit/>

⁵ For example, *why do the [registers of data sharing projects under Part 5 of the Digital Economy Act](#) not link to the paperwork for those projects (hosted on GOV.UK)?* The argument from the Cabinet Office (from an ex-DCMS part of GDS) that GOV.UK can not link to materials hosted elsewhere on GOV.UK is not credible. That some regressive Departments do not wish to publish proactively, i.e. most of them, means they also block any step that would distinguish between those Departments which do publish proactively (e.g. HMRC) and those that do not.

⁶ It is not for us to interrupt others while they make our life far easier by perpetuating the absence of a ‘Rest of Government’ replica of Understanding Patient Data, such as an independently-funded ‘Understanding Everything Else’.

6. Institutional cultures are also apparent in digital choices. Sometimes organisations demonstrate an “institutional ignorance”⁷ of the effects⁸ of their choices, but even when the Home Office facial recognition algorithm was found to be racist,⁹ it *still* chose not to fix it.¹⁰ These institutional problems persist.¹¹ Nudge is an excuse to do nothing.¹²

Digital Savings get undermined by Departmental Choices

7. One *single* ‘missing link’ on GOV.UK is estimated to have cost taxpayers £50 million¹³ over the course of the spending period. The Home Office has an online method for migrants to update the details they are required by law to maintain with the Home Office.¹⁴ However, until earlier this year,¹⁵ if you were to look at the GOV.UK guidance on ‘how to report a change of circumstances’,¹⁶ you would not be signposted by default to the digital service – instead the vast majority were directed to a PDF form¹⁷ to print out and post.
8. Despite the Home Office (and GDS) being made aware of the missing link, Home Office still failed to properly fix it,¹⁸ due to structural and institutional flaws at the Home Office.¹⁹ The Home Office enacted laws which required people to use the form or be *at risk of deportation*, but it appears no-one at the Home Office was responsible for the form.²⁰
9. Estimates of the cost of this ‘missing link’ to HMT and taxpayers vary, but the £50 million estimate still doesn’t account for any of the wider costs to those lawfully residing in the UK, not to the civil service and the public purse. It is only an estimate as the Home Office has confirmed that it doesn’t follow HMT guidance on costing.²¹
10. There are other forms like this in Government.²² The V62 car registration form was the most downloaded form on GOV.UK in 2020, and was downloaded from GOV.UK over one million times to be posted back to DLVA.²³ HMRC’s Child Benefit form²⁴ was also downloaded around one million times in the year – putting an additional and unnecessary

⁷ <https://www.bbc.co.uk/news/uk-politics-51961933>

⁸ <https://www.bbc.co.uk/news/technology-48222017>

⁹ <https://www.bbc.co.uk/news/technology-54349538>

¹⁰ <https://www.newscientist.com/article/2271078-uk-still-using-racially-biased-passport-tool-despite-available-update/>

¹¹ <https://medconfidential.org/2017/the-home-office-secretive-invasive-and-nasty/>

¹² See (late June 2021) Annex 6A: <https://medconfidential.org/2020/universal-credit/>

¹³ This estimate derives purely from the cost difference between a government Department receiving a form on paper and receiving a structured submission via a web form – assuming that the submissions in their systems were processed identically, and that they are correct. The Home Office is correct to say it follows the same process for both, but the estimate was based on the fact that it would. Similarly, HO does not assess the cost or burden on those who fill out the form; this was purely the cost of *one step* in processing.

¹⁴ <https://visa-address-update.service.gov.uk>

¹⁵ https://www.theregister.com/2021/02/01/gov_uk_web_link_50m_taxpayers/

¹⁶ <https://web.archive.org/web/20210201105519/https://www.gov.uk/change-circumstances-visa-brp>

¹⁷ <https://www.gov.uk/government/publications/notification-of-change-of-circumstances-form-mcc>

¹⁸ https://www.whatdotheyknow.com/request/home_office_internal_response_to

¹⁹ https://www.whatdotheyknow.com/request/home_office_internal_response_to?nocache=incoming-1771405#incoming-1771405

²⁰ Not for the first time.

²¹ https://www.whatdotheyknow.com/request/cost_of_transactions_ukvi_update#incoming-1680412

²² The figures in this paragraph are based on GOV.UK figures:

https://www.whatdotheyknow.com/request/the_most_downloaded_pdfs_from_go#incoming-1749359

²³ Other sites also host a copy of the form; these figures relate only to downloads from GOV.UK

²⁴ It has multiple variants.

burden onto parents of newborn children who, in the vast majority of cases,²⁵ need do nothing other than fill in the form and post it back.²⁶ Both^{27,28} of these forms used 1m+ times per year would appear to be ‘low hanging fruit’ where the *status quo* creates significant cost to the public purse, and unduly burdens citizens, without any clear justification.²⁹ Service redesign may be needed to address hidden issues, but there also has to be the *desire* to design the service with a focus on user needs. No evidence has been provided to suggest this is the case.

11. In an attempt to minimise the estimated cost, the Home Office showed it internally counted the cost of retyping a form submitted on paper as being the same as a digitally submitted form,³⁰ despite both GDS and the Treasury repeatedly showing otherwise. (The latter clearly involves fewer steps,³¹ even if it is ‘the same process’.) Also, one inevitable result of the Home Office retyping paper forms is typos – which means the Home Office sometimes threatens to deport entirely lawful residents, simply because Home Office itself made a typo.³² Throughout this example, the Home Office has demonstrated a level of unwavering confidence in its own processes that would make even Dunning and Kruger blush.³³

Uncover expensive or risky ‘data hoarding’ by Departments

12. Departmental costs are only increased by risks from data, especially where policy is not aligned across different Whitehall silos.³⁴
13. Where Departments share data, the Memorandums of Understanding or data sharing agreements should be published *proactively* on GOV.UK. Where Departments cannot or do not provide a GOV.UK link to their data sharing arrangements, those are the areas likely to have potential for greatest concern and biggest risk to public funds.
14. Similarly, and given the track record of the former Chair of OfQual and CDEI,³⁵ any Department business case that relies on unpublished advice should be subject to additional scrutiny, to avoid history repeating itself again.³⁶ Therefore:

²⁵ There are some newborns for whom additional documentation is required.

²⁶ The “digital” approach requires specific Adobe Acrobat software, which the author does not have and so cannot tell how badly it works (or doesn’t). We note for completeness that this “PDF first” approach was the preferred choice of the large ‘Systems Integrators’ and the ecosystem of consultants who did not wish to see GDS created nearly a decade ago. The worst pollution of bad Government IT leaves a long-lasting legacy for those who have to deal with it; in this case, the parents of newborn babies...

²⁷ DVLA doesn’t keep track: https://www.whatdotheyknow.com/request/cost_of_transactions_via_the_v62

²⁸ HMRC doesn’t keep track: https://www.whatdotheyknow.com/request/cost_of_transactions_for_ch2_for

²⁹ See Annexes 5D and 5E: <https://medconfidential.org/2020/universal-credit/>

³⁰ See the 5th February e-mail from Home Office on page 3: <https://www.whatdotheyknow.com/request/737505/response/1771405/attach/4/FOI%2063241%20Annex%20A%20PDF.pdf>

³¹ Which the Home Office itself confirms on page 7 of Annex C to the request above.

³² <https://www.theguardian.com/uk-news/2017/sep/26/leave-uk-immediately-scientist-is-latest-victim-of-home-office-blunder>

³³ Kruger, J., & Dunning, D. (1999). Unskilled and unaware of it: How difficulties in recognizing one's own incompetence lead to inflated self-assessments. *Journal of Personality and Social Psychology*, 77(6), 1121–1134. <https://doi.org/10.1037/0022-3514.77.6.1121>

³⁴ c.f. Annex 1 on UC RTI between DWP/HMRC: <https://medconfidential.org/2020/universal-credit/>

³⁵ <https://medconfidential.org/wp-content/uploads/2021/02/2021-02-CDEI.pdf>

³⁶ <https://twitter.com/medConfidential/status/1357037423172141061>

In the Spending Review:

- **where Departments rely on their own data, they should explain what data they have used and how;**
- **where Departments rely on data from elsewhere in government, they should publish what data they have used and how.**

There is no harm in doing either, and the best (large) projects may do both – but there *are* costs where self-interested decisions are made due to Departmental infighting.³⁷

15. Departments making business cases must be expected to explain what data they use in those ‘businesses’; how it is acquired, stored, processed, and deleted.
16. Bureaucracies like to hoard, and bureaucracies do not like to rely on other bureaucracies which can change their mind about access, or change their system and processes for access, or which can make decisions that are out with the acquiring Department’s direct interests. It is simply not in a Departmental directorate’s own interest to delete data when it sees itself as being dependent on that of others.
17. There is no reason for DWP to build a ‘shadow medical record’,³⁸ other than the fact it doesn’t trust the NHS to provide it with data – which it doesn’t. DWP largely ignores what information the NHS does provide, as shown by the overturn rate in PIP tribunals. Modelled on the understanding between the GP profession and the insurance industry for accident reports, while reflecting the need to encourage early treatment and full candour between a patient and their doctor – any harm to which would cause even more, longer term NHS health costs – any claim for any additional health data by DWP should explain exactly what assessment is needed, and what the results of that assessment can be.
18. That 10% of DWP decisions end up in a tribunal³⁹ is a large cost to the public purse from DWP’s intransigence; also HMCTS and NHS resources, providing information that DWP first ignores and then providing the same information again for the Tribunal.⁴⁰ We note there is no digital appeal process for DWP decisions,⁴¹ and that much of the justice system and the Government’s implementation of digital courts are optimised not to save public money, but to offer greater institutional comfort vs smaller levels of citizen support.⁴²

One current extreme example within the data linkage policies of Cabinet Office and ONS, from the APIs listed in the ONS / GDS API list,⁴³ it is *policy alone* that prevents ‘end of life’ FHIR API in many hospitals⁴⁴ being connected to DWP’s

³⁷ For example, DWP’s business case for having its own identity infrastructures.

³⁸ https://www.theregister.com/2019/02/19/dwp_health_data_tool/

³⁹ <https://www.bbc.co.uk/news/uk-49891159>

⁴⁰ DWP says only 5% are successfully overturned; with a success rate of 50%, this means 10% of cases go to hearings.

⁴¹ <https://pt2.works/blog/2020/04/02/universal-credit-report/>

⁴² <https://www.thelegaleducationfoundation.org/articles/tlef-statement-on-hmcts-response-to-its-digital-justice-report>

⁴³ <https://www.api.gov.uk>

⁴⁴ <https://www.api.gov.uk/nhs/end-of-life-fhir-api/#end-of-life-fhir-api>

medical API⁴⁵ in a way that can influence care.⁴⁶ As we say, this is an extreme example, but it is of precisely the kind the ONS / GDS API site claims it seeks to facilitate – and is further one in⁴⁷ which the Home Office would have interests,⁴⁸ and where all of the Whitehall incentives misalign.

19. As such, and despite Government policy for government digital services, the proliferation of identity services may repeat.⁴⁹

Citizen confidence in data use saves public money in the longer term

20. The model of “PFI for data”⁵⁰ will offer no better value in the long term than the original PFI scheme, and it will undermine public trust in the data infrastructure of Government.
21. In 2014, had NHS England agreed to tell each patient how the NHS and others used data about them, and what their choices were, then NHS data would not have suffered such a controversial five years.⁵¹ And the (Palantir) systems that were scrambled into place for the pandemic would instead have long been established. Within DHSC, NHSX is now set to repeat those same failures.⁵² NHS Digital meanwhile, in its ‘online’ dissent process, chose to require that families with dependent children print out and post back a form to express data choices *for dependent children living in the same home*.⁵³ That programme then went off the rails.⁵⁴
22. When a specialist data controller states, with reasons, why data sharing is harmful, the undeserving recipient should not be encouraged (or funded) to work around them – there are reasons why enforced SARs are illegal.⁵⁵ The National Data Guardian for Health and Social Care acts as the final referee on decisions in health that fall under Caldicott Principles 7 and 8. In the rest of Government, that process seems to be being done by journalists and the media – and those Ministers who are capable of accepting criticism and improving policy based on feedback...
23. It is an optimistic, self-serving fallacy within NHSX and DHSC that citizens / patients / service users care less about how their data is used than they did in 2014. Government itself may (want to) understand more, but so does everyone else. Government just wants the public to care less.
24. The lesson learned from the pandemic seems to be that Departments should build dashboards and even more databases. This approach will fail. As with COPI notices in the

⁴⁵ <https://www.api.gov.uk/dwp/get-medical-details/#get-medical-details>

⁴⁶ <https://www.itv.com/news/2021-03-18/widower-learned-in-wifes-final-days-do-not-resuscitate-order-had-been-made-without-consent>

⁴⁷ <https://www.independent.co.uk/news/uk/home-news/nhs-letter-newborn-baby-eight-day-old-identity-documents-free-healthcare-right-violet-nik-horne-latha-london-north-west-trust-a7955211.html>

⁴⁸ <https://www.ukauthority.com/articles/home-office-plans-to-step-up-use-of-apis/>

⁴⁹ Annex 2A: <https://medconfidential.org/2020/universal-credit/>

⁵⁰ See second half of <https://medconfidential.org/2021/shared-care-records/>

⁵¹ <https://medConfidential.org/2021/children>

⁵² <https://medConfidential.org/2021/shared-care-records>

⁵³ Page 1 <https://medconfidential.org/wp-content/uploads/2021/04/CAG.pdf>

⁵⁴ <https://medconfidential.org/2021/medconfidential-bulletin-11th-june-2021/>

⁵⁵ <https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/right-of-access/can-we-force-an-individual-to-make-a-sar/>

NHS, the lesson *should* be that it requires institutional knowledge to know who has the canonical data, and how it can be got – when there is a demonstrable and legitimate need that is in citizens’ direct interest. There will always be a temptation to grab all the data ‘just in case’, which will result in many unreliable datasets full of mostly one thing.⁵⁶

25. The only really effective mitigation for this is for citizens to know how data about them is stored and copied,⁵⁷ and – as Government heads further and further down an AI ‘rabbit hole’ – how the data is processed.⁵⁸
26. An individual official, a DG, or a project team may think they can hoodwink the public, and for the duration of their time in post, or even a whole spending period, they may even be right. But the price comes due eventually, and it is always more harmful and costly in both the short and the long term – especially when a ‘whole of Government’ approach is taken. Often that is not the individual civil servant’s⁵⁹ remit, or even the Department’s.⁶⁰
27. It is understandable why a Department might forget or ignore the humanity of the people it serves or services. Just as Treasury staff could not advocate HMT policy if they knew how many children would go hungry as a result, Departments institutionally blank the fact that they are dealing with real, living people with real and often complicated lives.⁶¹
28. DfE sees the ‘unit of management’ as being the school – forgetting all too often that every *data point is a child*⁶² with their own experiences, most often a family, and rights; yet the monster factory⁶³ of Government makes harm the expected outcome.

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⁵⁶ <https://twitter.com/ekoner/status/1362323807260848134>

⁵⁷ <https://medconfidential.org/2015/implementing-data-usage-reports/#gdur>

⁵⁸ <https://medconfidential.org/2020/analysis-and-inputs-reporting/>

⁵⁹ cf. <https://www.youtube.com/watch?v=QEJ9HrZq7Ro>

⁶⁰ <https://twitter.com/medConfidential/status/1357037423172141061>

⁶¹ cf. our case studies of Home Office processes earlier in this document.

⁶² <https://privacyinternational.org/blog/1318/national-pupil-database-not-open-data>

⁶³ Systems of DWP UC core report: <https://medconfidential.org/2020/universal-credit/>