medConfidential's Comments on the Powers in the Digital Economy Act (Part 5)

medConfidential welcomes the mid-point Review of the Digital Economy Act powers. For a modern framework, under legislation passed 3 years ago, it is notable how some parts of it have been used – and how other parts have not been used.

The Codes of Practice (as laid) did not begin well. In the debate in the House of Lords, the Government strongly defended its use of the old and outdated 'data science ethical framework' rather than the then-current 'data ethics framework'. After defending the indefensible with bluster and passion at the Despatch box, the Codes were corrected for formal publication.

We welcome the data teams' approach of doing the right thing, eventually – but note that it would both be easier on them, and improve public trust, were HMG not to try quite so many 'alternative approaches' first.

Codes of Practice and the Registers

medConfidential welcomes the publication of the Registers, and we note the significant amount of work by GDS and DMCS on delivering the infrastructure to publish them. The requirement in the Code that each relevant Register is updated *before* data sharing begins should help ensure some degree of public confidence in data sharing. This approach should be replicated by <u>all</u> data projects; there have already been demonstrations of the sort of problems that can arise when it isn't.²

However, the availability of the paperwork needed to *understand* the Register has been highly variable at best – some published, some entirely withheld. The new Registers page³ should have an additional "documents" tab, which contains all of the published applications and minutes for each entry in the Register.

Publication of papers and minutes on the same basis as the Register is what the Registers and paragraphs 142-144 of the PSD Code of Practice⁴ (and equivalents in the other Codes) were designed to do; this has been systematically undermined by the Secretariat's failure to comply with good practice under the oversight of the Review Boards – both in its failure to

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https://www.gov.uk/government/publications/digital-economy-act-2017-part-5-codes-of-practice/code-of-practice-for-public-authorities-disclosing-information-under-chapters-1-3-and-4-public-service-delivery-debt-and-fraud-of-part-5-of-the-di#register-of-information-sharing-activity

¹ The strength of the Government's defence from the despatch box on referring to the old Framework was matched only by the completeness of its u-turn in the published Codes where the new one was used. We welcome HMG doing the right thing, even after insisting strongly it will do the exact opposite: https://www.theyworkforyou.com/lords/?id=2018-06-25b.68.4

² https://www.whatdotheyknow.com/request/adr_uk_projects

³ https://registers.culture.gov.uk

publish minutes and, in the case of fraud and debt, an initial decision that suggests minutes would not even be kept.⁵

Many parts and agencies of Government assume that 'errors' by citizens are deliberate and intentional 'fraud', yet it is considered unusual to similarly conflate the 'errors' we detail in this document with 'fraud' – solely because they are the deliberate actions of Government...

Missing numbers

We note that 'fraud' is the Government term for an error by a (poor) citizen, whereas there appears to be no use of powers to detect and understand 'mistakes' that benefit richer citizens – or those which in any way benefit Government over any citizen.

All figures on 'error' by Government are missing,⁶ because the institutions behind Windrush, mid-Staffs, and other such data-driven mistakes clearly believe that the data upon which they make decisions are accurate – and that therefore their decisions are infallible; the defence of the 'institutionally ignorant'.⁷

Chapter 3 & 4 – Fraud, Debt, and Government errors

Based on the number of rows in the project Register, the Fraud and Debt powers are doing *something* – although the determination of efficacy is a matter for the subject specialists, and has been obfuscated from public view. We have elsewhere described aspects of the fraud and debt work in the Cabinet Office as akin to "ghost hunting and unicorn farming".⁸ There is no information for the public to be able to know whether these projects are any better. Or, put another way: for the powers that appear to be being used the most, there is the least information available on *why* decisions are being made.

Despite medConfidential following up for well over a year with the Secretariat about publishing the minutes and decision-making paperwork alongside the Registers, this has still not been done – beyond a few sample documents that may be scattered across the website of any public body that applies. Progress has been repeatedly claimed without Cabinet Office (which operates the fraud powers) having delivered anything other than smoke, mirrors, and more mistakes.

- Where, for example, is the page containing the documents which formed the *basis* for entries in the Register?
- Or does the 'transparency' required of these powers operate on the assumption that, for every project, citizens must simply trust that a public authority has published the same document that HMG actually approved, and that it remains in force over time?

⁷ https://www.dailymail.co.uk/news/article-8128851/Windrush-report-finds-Home-Office-officials-institutionally-ignorant-race-issues.html

⁵ https://www.whatdotheyknow.com/request/debt_and_fraud_information_shari

⁶ https://www.missingnumbers.org/

https://medconfidential.org/wp-content/uploads/2020/01/2019-09-unicorn-farming-CO-fraud.pdf

- Does HMG expect each document to be FOled individually?
- How can anyone know whether the document released is the same as the document the Review Board and Ministers believe they approved?
- For bodies covered by the GOV.UK single site, why aren't those documents available centrally?
- For bodies with their own websites, why does the Government expect citizens to find them on each site, based on the limited information within the DCMS-run registers?

Chapter 7 – Statistics

The issues we raise across the other areas of Government – especially those regarding research – will eventually infect UKSA and Official Statistics unless actions are taken to resolve issues *at source*, rather than merely defending statistical data from the missteps of wider Government data usage.

Misuse of research is the 'canary in the statistical coal mine', and one against which UKSA will find itself in a weak position to defend.

Chapter 2 – Identity Database powers

There is an explicit statutory ban on using the civil registration powers for building an identity register. Despite this, UKRI and ESRC funded a project¹⁰ to use citizen juries and opinion polling on how to best persuade the public of the value of a population identity register for research, using a variety of those DEA powers...

It is believed by DCMS that the powers of the Digital Economy Act are unknown, which may be partially true. What this project made clear is that the statutory safeguards in the Act are as unknown (or ignored) by those who believe they understand the powers, as the powers themselves are unknown or understood by those who could use them for legitimate purposes.

Chapter 1 - Public Service Delivery

In 2019, **zero** projects were proposed by central Government in this area – demonstrating that the promises and claims these powers were needed that were made to the public, civil society, and Parliament during the passage of the Bill were not entirely true:

"As I said right at the beginning, the reason we do not want to wait ... is that we want to use these powers to help people."

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⁹ The answer to this appears to be yes. Which we will do so, and ask for what discussions those bodies have had with DCMS about why DCMS is transferring work it should do in the Register of data sharing onto those other bodies.

¹⁰ Project outline: https://warwick.ac.uk/fac/soc/ier/people/pelias/, plus more details: https://warwick.ac.uk/fac/soc/ier/research/esrcpopulationlab

¹¹ https://www.theyworkforyou.com/lords/?id=2018-06-25b.68.4&s=%22As+l+said+right+at+the+beginning%2C+the+reason+we+do+not+want+to+wait%22#q77.1

There may have been an intent to help people, but it appears few people were helped by the PSD powers. The urgency claimed to Parliament was non-existent, and Ministers were misinformed by their civil servants (most notably the data team that is now at DCMS).

During the passage of the Act, given concerns about how these powers might be used, and that they might facilitate excessive data use beyond initial purposes, powers to access data held by the Department for Health and NHS were excluded. (N.B. This exclusion only covers health data collected for purely health purposes – not all health-related data.)

Despite only the *Scottish* Government having actually used the powers that are already available to all, there was nonetheless a push to widen the scope of these unused powers to include NHS data¹³ despite clear statements made to Parliament that concerns about flaws in the Code were irrelevant *because health data was excluded*.¹⁴

Had there been an evidence-informed debate, that would be one thing. But here instead is DCMS talking¹⁵ at the Institute for Government meeting¹⁶ in February of this year:

medConfidential: Do you think extending these powers to health data is a good idea?

DCMS: There are no moves right now to make medical records part of the DEA. **medConfidential:** If you read the PSD board minutes, they are looking at it? **DCMS:** OK, those are true, that's something ... acting on that is something not being done at the moment.

It is unclear where the first answer sits in the "fraud and error" spectrum.

The mid-point Review, at that time due to be published around a month after medConfidential was given that answer, is expected to want more powers for those writing the Review, without any meaningful consultation with civil society. DCMS has stated that it has 'consulted stakeholders' for that Review – by implication, one can only conclude that the Department does not consider medConfidential a stakeholder.

While Government claims to talk to itself, the Departments don't exactly tell each other everything. All too often, one part of Government will tell another only what it thinks the other should know, and only that which it judges the other will not object to hearing – and accuracy and truth fall down the gaps covered by these 'secrecy blankets', while everyone hopes it'll be someone else's problem by the time it gets noticed.¹⁷

¹² Ibid.

¹³ See top of page 2: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/
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¹⁵ https://youtu.be/KpvaJ-sGkaY?t=4750

¹⁶ https://www.instituteforgovernment.org.uk/events/data-bites-8-getting-things-done-data-government

¹⁷ https://www.whatdotheyknow.com/request/adr uk projects

Those statements to Parliament about the immediate utility of the PSD powers were not deliberately false; they were just wrong – i.e. error, not fraud. If this assessment were being made by DWP, however, the civil servants involved would be sanctioned and punished for saying something they believed to be true.

The civil service term for other Departments snuggling their comfort blanket is "missed use" and its practice has spread beyond the Cabinet Office.

That there were zero Public Service Delivery projects in 2019 raises one other question: where did the Departments' data work go? Departments always have data projects, they just aren't necessarily doing them under PSD powers. Since data work clearly continued, but the new powers weren't used, which powers were used?

Chapter 5 - Research

Akin to the horse gorging on oats in the hope that some will pass through for the sparrows, the implementation of research powers appears to be entirely supplicatory to Departmental interests.

Background

Describing our core NHS and social care work, we say that "medConfidential works with patients and medics, service users and care professionals; draws advice from a network of experts in the fields of health informatics, computer security, law/ethics and privacy; and believes there need be no conflict between good research, good ethics and good medical care."

The same is true for good research using data in the 'rest of Government' as it is for good research in health.

The cases other government Departments make, as to why they should be able to access health data demonstrates both the legitimacy of medConfidential's interest, and the pollution of *bona fide* medical research by policy-based evidence-making in Departments that cite for themselves and their activities the same justifications as for legitimate medical research.

This ongoing pollution of intent should concern all sectors, and appears to already be taking hold behind the blanket of civil service secrecy that pervades the implementation of the Digital Economy Act. The research powers have a different framework for transparency than the other powers in DEA Part 5, and this framework is being opportunistically leveraged by Departments.

'Administrative Data Research UK' (ADR UK), a subdivision of the research councils (UKRI), is the primary mechanism for the increasing use of DEA research powers across the rest of Government. This is through choice, not necessity.

¹⁸ https://medConfidential.org/2020/missed-use-and-misuse

In law, it is the data controller who determines the manner of processing of data, i.e. the one who approves any particular project, and Departments do have a legitimate interest in pursuing research, in line with their public task – both of which are largely unaffected by the DEA powers. (Departments *may* use them, but that is for convenience rather than necessity.)

It is entirely within a Department's interest to achieve its own aims, which may legitimately include research. But where it cannot justify such work internally, to be funded from its own budgets – and especially since it may be easier to secure academic funds than going for Departmental budget sign-off, with its inherent political challenges – some find it far easier to spin a line to ADR UK / UKRI than to convince (or compete for funds within) their own Department.

Recommendation for changes in practice in use of the DEA research powers

medConfidential has three recommendations for changes to current practice:

- Substantive details of <u>all</u> projects must be published, on the same terms as any other UKRI project or investment and all outputs should be published online, in compliance with UKRI's open access policy. ADR UK should not continue to offer Departments a *quid pro quo* of secret funded projects for more data; if Departments want their data projects to be hidden from the public, they definitely don't get to use academic research funds to do so. (What may be lawful is not always ethical, and can reflect badly on both parties.)
- To avoid Departments using ADR UK as a 'slush fund' for new projects they could not justify internally, ADR UK must not fund any more than 49% of direct costs (and 0% indirect) for civil service staff on any project that has a project end date within 2 years of the end of the project grant. In other words, academic funds should not usually be spent on Departmental staff delivering new projects which have a fixed time frame, and which do not result in research outputs. To be clear, this exclusion would not cover an academic funding contribution towards ongoing Departmental business and public task that delivers defined, increased benefits to academia, where the Department makes a prior commitment that the business will become part of the ongoing business of the Department.¹⁹

¹⁹ For further avoidance of doubt, this formulation is designed so it would block, e.g. the MoJ 'Data First' project, while allowing other investments by ADR UK that are properly structured. ADR UK can invest in academic data processes within Departments, but those processes must exist *before* and *after* the project – even if the project transforms such a process. (The early 2019 public commitment to reform the MoJ DAP is something that would be entirely supportable within this framework, see bottom of page 3:

https://www.whatdotheyknow.com/request/535603/response/1285640/attach/4/FOI%20181127019%20Mr%20Phil%20Booth%20reply%20Thursday%2027%20December%202018.pdf)

 In the same way that academic researchers are expected to disclose related projects, in <u>all</u> cases when it funds non-academics, other projects worked on by staff funded by ADR UK must be disclosed to ADR UK – both in the application process and during the grant itself.

More widely, Departments already have wide powers for data processing, and DCMS is attempting to rewrite the rules (again) with its 'Framework for Data Processing by Government' – which is neither open to civil society input or comment,²⁰ nor likely to improve matters. medConfidential expects to review these recommendations when the Framework leaks out.

Perverse financial incentives within Government

Policy-based evidence-making in a research process defined by a Department and funded by a Department, but conducted by an outside contractor who has no discretion to produce research outputs is not research. If Departments are not willing to put up cash for work they allegedly want to do, then they clearly don't want to do it enough.

"Good" data projects require no obfuscation or funding shenanigans; projects that resort to such tactics are cause for concern for exactly the same reasons that those tactics were chosen in the first place. Similarly, Government Departments funding academic research activity is not new, and there is no problem in principle with research within a public task.

But if it is research then it must be able to provide the right answers to the following: are the *outputs* public? And are the project *proposals* public, as for all genuine research projects?

ADR UK may see short term benefits from facilitating Departmental work, and is clearly willing to fund it – but combine this with the secrecy of these and other ADR UK powers, and with the unresolvable problem of data projects continuing after the original funder has stepped away,²¹ and stakeholders' original intents can emerge.

Departments can contract academics to do work, and ADR can help find and even fund them – but ADR should not be using academic funds to do borderline (or outright) non-research work commissioned by a Department. The academic process is far from perfect – note the population register above – but it is multipartite. Academic funds going to a central government Department (via ADR UK / UKRI) to do work on its public task, as defined by that Department or another, looks like policy-based evidence-making of the most blatant form, hiding behind a figleaf of research powers.

Consequences

²⁰ https://twitter.com/GavinFreequard/status/1225737991504c703488

²¹ https://www.newscientist.com/article/2231423-nhs-may-use-peoples-phone-data-to-predict-mental-health-issues/

What is treated as "missed use" by one Department is a deliberate decision to avoid toxic consequences by another; public task gives only limited protection, and the 'presumption of sharing' within the Digital Economy Act is a process that fails when Departments don't tell each other what they actually want to do in practice.

In the civil service 'art form' of telling people only what you want them to know, and only what you want them to hear, relationship to reality can be entirely left aside. This is not, however, a uniquely civil service trait – the academic papers written to justify the DeepMind / Royal Free project's continued use of data (after it had been ruled unlawful by the ICO) were the epitome of jurisdiction-hopping of the most blatant kind, ²² constructed in a way that would have done the most dodgy proponents of civil service misdirection proud.

It is a truism that if one government Department cannot expect to know the true intent of another, it is unreasonable to expect the public to do so.

We do not suggest that the project approvals process at ADR UK made the 'wrong' decision based on the information they were given – as with other funders, they do the best they can with the information they have at the time. But, unlike academics, government Departments do not expect to be held accountable for what they tell grant-giving bodies.

Unfortunately, the information funders have at the time may not be sufficient to make decisions that, in retrospect and with additional information, prove to be entirely wise. As a funder, it is almost impossible to know what will or has happened after a funded project ends – or in adjacent projects, with the same staff, in the same offices, working on 'two projects' that are ostensibly and externally funding a barrel full of wine, while adding an internally-funded teaspoonful of sewage...

Each individual decision, taken in isolation, may be deemed defensible – at the time it was taken, or even in retrospect. However, public confidence in the use of data comes from an *overall* assessment of actions and powers, takes a dim view of secrecy, and prefers evident results to excuses.

medConfidential, May 2020 coordinator@medconfidential.org

https://medconfidential.org/whats-the-story/health-data-ai-and-google-deepmind/

²² See 'July 2019' line: