Available next steps to *safely* make GP data available for research and planning (which fits [in one tweet](#)[1])

> *"...**it's a shame that not more was learnt from that incident** [care.data] **to essentially prevent what has happened again in this situation**. So yeah, I think there has been a loss of public trust over that, and certainly again..."*

> NHSx surrogate on BBC Newsnight, 22/6/21:
> https://twitter.com/BBCNewsnight/status/1407463790006968320

People are still opting out, and will continue to do so. More with every partial (mis)step.

That harm will continue until the Government clearly announces that *every* patient <u>will</u> have more information than they do today, *before* the GP data programme goes live.

Once that promise has been made, no-one will need to opt out – for now – as they can be sure that they will be given more information to make a better, more informed decision tomorrow. And no-one need keep scanning twitter for an eminently-missable tweet from NHS Digital; everyone can know they will be proactively written to.

As they should have been, in the first place. Back in 2014...

GPs (and practice staff) should be properly informed, supported *and supportive* first, and only then should the public comms begin in earnest.

A independently-chaired, multi-stakeholder advisory group[2] – covering research and research funders, the profession, other Colleges (notably RCPysch), health charities, pharma,[3] and NGOs like medConfidential and UseMyData – should be convened to keep everyone honest, and to stop any one stakeholder saying one thing in private and something different in public.

That group and process will allow the time to fix everything else, and it is really now the only way to get all of the various NHS and health charities, and [research charities](#), on board to – explicitly and in public – support what the new GP data programme does.

That support, *and their logos on the posters*, ensures that it is in their own interests to make sure the programme is good. And that will in turn reassure the public.

(Of course, should any [shortsightedly](#) ignore [harmful aspects](#), then their reputations will likely be affected...)

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[1] Plus https://docs.google.com/document/d/1wo3QKI1kNZaosyXGPQ-gyxDD-2gG3sIHJIXbKQLVIp8/edit

[2] Suggested membership, on the model of CDAG - the care.data Advisory Group, 2014-16 - here: https://docs.google.com/document/d/1oEf0_TSTk3s9BxYhqpz3wpFZMxDHegXlq3EObuv9c6E/edit - if you would like access to this document, please request it.

[3] Who were notably absent from the membership of the care.data Advisory Group, but who inserted their lobbyists nonetheless.

What needs to be done?

1) End dissemination of patient-level ([personal](#)[4]) data

- At risk of equivalising patients with lab rats(!), the world of animal research welfare uses a maxim[5] it calls the 3Rs: "Replace, Reduce, Refine". (See here for a [longer version](#).[6])

- Going beyond the announcement of GP data being TRE-only, Secretary of State to Direct NHS Digital that **data sharing for planning and research[7] will be TRE-only**, and the HSCA 2012 powers of dissemination are repealed in the forthcoming HSC / NHS Bill.

- Automating efficient and effective **data minimisation** by NHS Digital must be on the critical path to increasing safety in use of patients' data. This has never been meaningfully resourced, and some of the solutions to this require *collaborative* solution design, not mere temporary resources.

- Were NHS Digital to continue disseminating data once someone's dissent to their GP has been coded, NHS Digital cannot know what data remains accurate. NHS Digital may hold 'historic' data, but if a Type 1 dissent code is added, that record will be truncated – and so cannot be relied upon for analysis.[8] A Type 1 opt-out or a National Data Opt-out (since NHS Digital does not currently know that a Type 1 has been implemented[9]) should result in the **deletion of the patient's historic data** held by NHS Digital.

- The ICO is now clear that anonymisation and pseudonymisation are dissentable under DPA, so a digitally-managed dissent choice must be available without burden on care providers or patients. In practice, this should be an **effective** National Data Opt-out, unless DHSC chooses to create *another* opt-out which patients will have to express *again* to avoid data about them being disseminated when they previously requested it not to be.

2) Fix the dissent process...

- ...following [all of the steps in this document](#).[10]

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[4] https://docs.google.com/document/d/1CPxv6vCGS3Qp6jPyrEdCobctpxHnTDleFGO0IMojf8o/edit

[5] https://www.understandinganimalresearch.org.uk/animals/three-rs/

[6] https://docs.google.com/document/d/19xicAtDLJZsCGAik_7McWwWrMUBM581WP9NOP1cqWh0/edit

[7] In the sense this phrase is used to cover all purposes beyond direct care, not just these two particular use cases.

[8] https://twitter.com/medConfidential/status/1400026794267275265

[9] The easiest way to resolve this would be to state by policy and then in law in the forthcoming health Bill, that a National Data Opt-out means that data will not leave the GP practice for purposes beyond direct care without specific informed consent for that purpose alone (e.g. UK Biobank).

[10] https://medconfidential.org/wp-content/uploads/2021/06/intial-note-to-Opt-outs-Review.pdf

3) Build for trustworthiness, including transparency

- Implement [all of the Immediate Steps in this document](#)[11] and commit to and begin delivery of the steps for the Medium Term.

- Make sure whatever is done is something *everyone* can understand.[12]

- This will include some steps which will be required from the changes proposed in **the data strategy which has made this *even more* confusing…**

When the stakeholder group is content that the programme is ready – or that any remaining objections are unreasonable, *and the organisations are willing to publicly say so* – then the GP and after that the public information campaigns can recommence.

3A) Institutional Governance

- NHS Digital: Return to NHS Digital the independence and discretion that NHSE/x took from it after care.data, which HSCIC always had. (And even care.data went better than GPDPR so far, as a result.)

  - Replicate the Partridge Review with a report by *two* NHS Digital non-execs on what happened. (Likely Ben Goldacre on medical ethics and data aspects, and a second NED covering decision-making and institutional governance.)

  - NHS Digital functions, especially those covering it as the statutory safe haven, must be outside the reorganisation powers of SofS in the forthcoming Health and Social Care / NHS Bill

- Rebuild the data functions in whatever NHSE/x becomes; this probably needs an experienced DHSC, NHS, and data lead, at DG level. (There's an obvious candidate currently outside of DHSC who has risen to DG.)

The measure of success of an NHS programme is how many different parts of the NHS and how many NGOs are 'throwing elbows' to get their logo included in the documentation and the slides. This programme has one *third party* logo anywhere near it: ours.

A reset should be used to build a replacement GP data programme that organisations around the NHS ecosystem would want to be *seen* to be involved in, and which every family in the country *should* want to be involved in.

medConfidential, 29th June 2021

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[11] https://docs.google.com/document/d/17OuT7BeqpFYSPdXFHR0s6BleZ--k6cAwqJLhkFG72bQ/edit#

[12] https://twitter.com/medConfidential/status/1398314695195516931