



coordinator@medconfidential.org

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Dear Ming, AGD,

The [AGD minutes](#) from 12th June 2025 should prompt extreme concern in anyone with an interest in NHS England's handling of patient data. Also this week, [your FDP programme has acknowledged](#) previous deceptions, entirely in line with the culture of HDR.

Item 5.1

Item 5.1 of the meeting covers the first time AGD is given evidence to make an informed assessment of HDR's decision-making. **The key finding is AGD could not support a majority of the projects**, despite HDR's assurances, perhaps because HDR's researchers were told by HDR that the "Covid-19 only" requirements could be ignored by researchers and HDR would deceive others for HDR's benefit, and AGD saw straight through that in a way NHS England never did, which shows the importance of AGD.

We understand the researchers involved answered the questions they were asked, and we have so far seen no reason to believe they did anything other than fill in the forms they were given with honesty and integrity. It is HDR's leadership that told them what to do, or what not to do, not the institutions or individual researchers. HDR is an [accountability sink](#).

HDR is actively running an unknown (to the public) number of projects running which may or may not have been listed on one of several HDR websites, meaning NHS England has failed to ensure NHS England's obligations of transparency are met. The AGD minutes imply what we have understood to be true: that every project HDR approved internally was given access to all data HDR had – including all GP data. All 100+ projects were given access to GP Pandemic data without any PAG/Profession review as NHSE agreed would happen, including for projects that commenced after COPI relaxations had ended.

1. The Data Uses Register [says](#) that the HDR project did not have "sublicensing" permissions – why was it able to make delegated decisions about data access when the public were told it could not?
2. Are HDR held to the same standards as other applicants? Is this borne out in practice or simply an administrative fiction?
3. Will NHS England disclose each project individually in the data uses register, disclosing for the first time which data was made available to which project?
4. What did the GP Professional Advisory Group say about those projects which use the Pandemic GP dataset? Were PAG even asked?

5. Will all HDR projects be suspended pending full and complete AGD/PAG review?

Failures in NHSE's Data Governance and Decision Making

NHSE claims the data controllers are the universities for reasons we do not understand and which do not reflect reality. If that it is true, it is unfair to blame 16 major universities¹ for HDR's decisions. As each project goes through AGD, each project should disclose in the AGD minutes where individuals are employed, any conflicts of interest, all institutional involvement, and each project is given their own silo in the SDE without access to data they do not need and do not have permission for.

6. Given the lists of universities in the consortium aren't consistent, which is correct according to HDR and which according to NHSE? Are either consistent with where the researchers granted access by HDR are actually employed?

Those disclosures should be checked by NHS England against NHS England's records of what data was accessed and used inside the SDE.

HDR's own "[ways of working](#)" documentation states that decisions are made internally, seemingly at the discretion of the Director of the HDR BHF Data Science Centre. However, neither BHF nor her employing institution are listed as a formal HDR consortium member, raising questions of both governance and conflict of interest.

7. As they aren't in the published lists, will HDR confirm in writing to AGD that it is correct that no one from the University of Edinburgh or the University of Dundee had *any* access or participation in any remit? Will that written confirmation be made public in the AGD minutes to ensure it is not immediately disproven?
- a. Is it credible that there was no participation of these two major HDR institutions in the consortium?²

The public has a right to clarity. Given the shared culture, shared staffing and shared vision, of HDR, of Biobank, and of HDRS, the future of patient data risks being discredited before HDRS even begins. At the launch of the HDR/Sudlow Review the author claimed Biobank have "[one of the best systems](#)" for getting data out in "[days](#)", this after they had sent data to eugenicists, and Biobank continue to insist that long bankrupt companies are actively running projects on their platform.³

8. Does AGD have any advice to NHS England on the "patient involvement" claims of HDR and Biobank?

¹ By our count from some NHSE statements. Other documents about the consortium say different figures and include non-university organisations. Future AGD minutes may wish to clarify the exact state of affairs.

² Given that [HDR largely funnels resources to cronies](#), it is not immediately or objectively credible that they were not involved. That does not make it the case, but it does require investigation. Or, as HDR has done so far, perhaps the truth will come out via a press release instead.

³ Our letter to both on this topic: <https://medconfidential.org/wp-content/uploads/2025/06/biobank5.pdf> – AGD may have a variety of interests in knowing NHSE's answer to the questions asked in that letter and in the documents footnoted.

Lack of Transparency in the Data Uses Register

It has long been noted on [TheySoldItAnyway.com](https://www.theysolditanyway.com) that the NHS England Data Uses Register does not show the periods over which data was accessed within the TRE. This structural omission hides the scope of data use, and facilitates abuse. The decision makers inside what will soon be the Department of Health in England did once again what was in their short term interests and kept the public in the dark.

We're aware NHS England has had fixing the omissions of the release register on the ToDo list for years and never delivered until the failure mired the organisation in scandal.⁴

9. Will AGD recommend urgently improving the process of creating the Data Uses Register to show per-project, per-month data access for all projects active in the SDE?
10. What safeguards now exist to prevent similar blanket access by others?

There should be a shared evidence base where everyone can agree what happened with data, even if reasonable people can disagree what *should* have happened. HDR and NHSE England have deliberately subverted this evidence base for their own temporary gain.

While some may assume HDR acted competently and honestly, the evidence increasingly suggests otherwise. HDR's governance appears modelled on a culture of opacity that mirrors Biobank and the worst behaviours seen during the pandemic.

It is unclear if the broad access granted in items 5.2 and 5.3 is any different to the secretive and unaccountable access DHSC's "Private Office - Data Science" team enjoyed under the previous Government (we understand that PODS no longer exists as an unit, and instead all of DH/E will get access to the [34 datasets](#) PODS had access to). The public will not know how DH/E has processed what DH/E agrees elsewhere is their identifiable personal data.

Item 9 appears to grant discretion for similar opacity outside of Government, allowing NHSE to keep both AGD and the public in the dark. If a project gets access to data for a purpose, those purposes must appear in the data uses register, otherwise the register is incomplete. Such approvals must filter through to the data uses register somehow or the shared culture of HDR and Biobank will become the shared culture of HDR, Biobank, and DH/E.

11. Where a project is approved by NHSE under the process agreed by AGD in item 9 of the minutes, will it appear anywhere in public?

⁴ And then some officials in DH/E blame medConfidential for their own failures. Various units inside the Department of Health in England will only do anything after a scandal, and so the scandals keep happening because DH/E refuses to do anything without a scandal... [Decision Making](#)

Behaviour, Culture, and the Path Forward

12. How do DH/E's assurances about promises in the HDR fiasco align with assurances about promises being made for OpenSAFELY?
13. How can the proposals for HDRS progress with any public confidence while the primary proponents are mired in a scandal of dishonesty and coverup?

Given the unfixed deficiencies in the data uses register, and the DH/E culture of opacity around uses of data (exemplified by items 5.1, 5.2, and 5.3) that AGD were asked to approve,⁵ then all of the good work of Understanding Patient Data and so many others for so many years has been shredded by the secrecy and short term greed of HDR and NHSE. Again. The ethos of Baroness Mone is strong at HDR and biobank and perhaps HDRS.⁶

As DHSC found with the PPE procurement trusting a Peer of the Realm, assumptions of probity can be subverted by those who are willing to lie or cheat. Access to NHS patient data is a privilege, not a right. If HDR's catastrophic abuses (or Biobank's) do not meet the threshold for the consideration of "single strike" powers, is there no abuse NHS of patient data so harmful that the Department of Health in England will issue sanctions? Perhaps NHS England only enforces policy upon those it feels it can bully into submission (e.g. patients who don't want their data abused by such ghouls – instead DH/E continues to insist that patients' who have opted out must have their supplied for research, even when honest legitimate ethical researchers do not want to use data of people do not want their data used).

medConfidential has a draft of a complaint for the ICO over DH/E and HDR's choices in the processing of identifiable and sensitive pandemic-only GP data, but would hope DH/E is in a position to put into the public domain *all* the facts about who / what / when / why rather than participate in HDR's coverup, a coverup which will fail piece by piece, possibly in a series of Politico newsletters.

Yours sincerely,



Phil Booth, medConfidential



Sam Smith, medConfidential

Cc AGD, AGD chair, AMRC, BHF, DHSC, HDR, JGPITC, MRC, NDG, UPD, WT.

⁵ And did.

⁶ For completeness: each of Baroness Mone, HDR, and Biobank all deny any wrongdoing.