Academy of Medical Royal Colleges

Mr Matt Hancock, Secretary of State for Health and Social Care
& Parliamentary Undersecretary Lord James Bethell
Department for Health and Social Care
39 Victoria St
London
SW1H 0EU

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Academy of Medical Royal Colleges

10 Dallington Street
London, EC1V 0DB

T+ 020 7490 6810
www.aomrc.org.uk

Dear Matt & James,

Recommendations about GP DPR – The General Practice Data for Planning and Research (GP DPR) patient data sharing programme and an agreed pause in roll-out to 1st September 2021

Thank you for asking me to comment on the current situation regarding GP DPR and to offer my personal recommendations as to how best the current short pause can be used to engage the medical community and help deliver this important initiative.

I do not claim to be an Information Technology or Information Governance expert, but I have substantial related knowledge and experience. Additionally, I have canvassed the opinions of a number of experts and interested parties to further inform my views and have been struck by the great degree of consensus as to both the assessment of the problem and the potential solutions.

For clarity, however, my focus has been on establishing the views of the medical community and not patients or other special interest groups. This letter is therefore based on those conversations and sets out my personal assessment of:

- **The immediate challenge to the roll-out of GP DPR**
- **A set of mitigations and solutions to overcome those challenges and which should command the support of the GP community**
- **Comments on the communications issues**
- **Some thoughts on the wider collection of health data**

Please also note, I am sending this just after publication of the Health and Social Care Data strategy and in advance of a rapid review being conducted by Dr Ben Goldacre (due to be published later this year). Both have direct relevance to this letter and consequently, I am very happy to discuss further anything contained herein in the light of those reports.

The immediate challenge to the rollout of GP DPR:

The past few months have seen a flurry of interest in the direct issue of the GP DPR initiative but has also led to a wider discourse about use of, and access to, patient data throughout health

and social care. There is no doubt that a broadly negative media, and suspicious or conspiratorial social media, have amplified existing anxieties and done little to encourage balanced dialogue, so we are at an inflection point with groups who shout loudest being heard the most.

The 8 June 2021 announcement of a brief pause in roll-out of the GP DPR replacement of General Practice Extraction Services (GPES) has been helpful in that it has allowed us to take stock and reflect on the mood of the public, healthcare professionals and the research community. It also helps us to establish what is achievable by 1 September 2021 and what action can be taken in the longer term as GP DPR evolves.

I will not further rehearse the background to the current situation or speculate on why we reached this point, but it is certainly unfortunate that several years of hard work, which included comprehensive engagement with the General Practice IT Group comprising representatives of many interested parties has culminated in such a tense impasse.

GP DPR is not the wrong solution. Medical leaders unanimously recognise the fact that access to rich, robust and extensive health data is essential if we are to tackle the growing challenges faced by the health service and the RCGP/BMA joint letter to NHS Digital exemplifies this. However, even if GP DPR is the right solution, if it does not have the support of the medical community in the first place, it cannot hope to have the trust and confidence of patients in the second.

Thus, our principal challenge is to establish the immediate actions required to regain the trust and confidence of the medical profession, so that doctors (mainly General Practitioners) can act as positive advocates to patients when it comes to allowing the data that is held about them, to be used for planning and research purposes.

If this attempt to restore trust is not swift and seen to be underway, then opposition will only grow, until the point where so many people opt out, the value of the dataset itself is diminished.

By any measure, the greatest challenge today is one of perception and trust and the increasingly commonly held belief that personal data will be; sold for profit to commercial organisations, will identify citizens individually, will be hacked or will be used for other inappropriate means.

A set of mitigations and solutions to overcome those challenges:

There are four steps that should be taken to overcome the perceptions or misconceptions as outlined above, which continue to be propagated by pressure groups and which are rapidly becoming a mainstream view so must be tackled now:

1. Doctors and the public need reassurance that their data will only be accessed by those with permission and for a reason that is agreed with those that hold the data.

Doctors need to be convinced that the data will be held at specific locations, and that those accessing the data are subject to scrutiny or can be overseen and subject to audit when required.

The Trusted Research Environment (TRE) model of the type operated by the Office for National Statistics fits offers these characteristics and has operated successfully for almost two decades without any loss that of data which, is arguably, equally as sensitive. A TRE has the widespread support and acceptance of the research community and operating one effectively shuts down claims that the data can be sold or used without public consent or scrutiny. A rapid impact study to establish any unintended consequences of moving to a 100% use of TREs should be launched, but this should not delay announcing the commitment to proceeding.

2. Data security should be enhanced beyond simple pseudonymisation.

A technical solution that goes further than this first level of security should be introduced to ensure patients cannot be routinely identified and that integrity of data is preserved. Dr Ben Goldacre's OpenSAFELY TRE achieves this, by providing an open-source trail of who has accessed the data and for what purpose, in addition to publishing all the code required to obtain data. This is an exemplar of what can be achieved in a modern, fit for purpose TRE and is widely regarded, even by the most sceptical as the new standard. I recognise that in some exceptional circumstances patient identifiable data is necessary and additional security measures should be put in place to safeguard patients in these very rare cases, but these need to be explicit to patients and their doctors.

3. Simplify the opting out procedure, which by common consent is complicated and confusing.

This can cause suspicion that it is deliberately designed to inhibit patients opting out. The process and language used to describe the two types of opt-out needs to be rapidly reviewed and then the differences made simpler, clearer and easier to understand. Data collected prior to a Type 1 opt-out being implemented needs to be explicitly part of the opt-out and all opt-outs need to be easier to implement centrally. Then that fact that this has occurred should be heavily promoted.

4. Enhance data security and signal that this has been done.

The recent ransomware hack of the Republic of Ireland's health service data, despite not receiving huge media coverage in the UK, has only served to heighten these concerns – irrespective of the subsequent measures; the data store of any health data must be as secure as technologically possible, and assurances given to the public that this is the case.

Once these four steps have been taken, or at least are seen to be underway in some form, a comprehensive communications campaign should begin to reassure doctors and patients that concerns they have raised have been listened to and acted upon.

There is common agreement that while the current situation is not necessarily caused by poor communications, this is nevertheless 'a substantial communications problem' and one that can be remedied with extensive and effective communications once the proposals above are acted on. This is not the place to set out a full-blown communications strategy, however, there are some over-arching principles, which have acted as a common thread in the numerous conversations I have had with key stakeholders in recent weeks.

Comments on a new GP-DPR communications strategy:

- The medical community is trusted far more than politicians or healthcare managers. So, if a patient's GP can explain the merits, value and importance of GP DPR collection, patients are less likely to opt-out. Any communications campaign should leverage the medical profession as a trusted source and leverage the current climate of support for the NHS as a national resource and for which there is shared ownership.

- There is a relatively small community of health data experts – they are respected and articulate. This group needs convincing first, and steps must be taken to keep them on board throughout the current interregnum and beyond. Delays in publishing the Data Protection Health Impact Assessment (DPIA) around GP DPR have not helped their confidence. They need to feel enfranchised and part of the solution, and then should explicitly act as advocates for an amended system.

- The above does not apply to pressure groups, whose views do need to be recognised and acknowledged, but not allowed to become too influential.

- Any communications strategy and planning must be tested with frontline clinicians and patients to ensure that the final 'scripts' are accessible to their target audience.

- Polling by Healthwatch reveals that while there is high awareness (57%) of GP DPR collection, understanding of the issue is low. Only 19% of those polled said their understanding matched an NHS Digital video on the subject. Any national marketing campaign should have this lack of understanding at its heart and focus on the benefits of health data and give examples of how anonymous and personal data is used in everyday life.

- The NHS is a trusted brand, never more so than at present, it should be at the front of any patient facing marketing campaign.

There is also, by common consent, a growing belief that the current situation is beginning to bear a resemblance to the 'Care.Data' launch in 2013 with its repeated pauses leading to its abandonment three years later. For this reason, the current pause should not be extended beyond 1 September 2021, but at that point a new plan should be put in place.

Instead, I would encourage you to press on with a GP DPR type approach to collecting data, but give a commitment not to disseminate any data under the new arrangements until the four mitigations (set out above) are established and a reasonable and realistic timeline for their implementation is set out. This should assuage the concerns of health data experts and General Practitioners.

I am assured that ONS could provide a minimum viable proposition for the TRE by 1 September and Dr Goldacre could replicate his OpenSAFELY model soon after. The opt-out refresh and simplification of the process could also be announced on 1 September, but then implemented in the coming months. Data security announcements could also occur on 1 September.

Some thoughts on the wider collection of health data:

The recent furore has only served to play to a vexatious narrative that 'politicians are not to be trusted with our data'. Given the vast potential good that comes with appropriate use of NHS data to improve healthcare, then it is important that Government be seen to be working tirelessly to 'get this right, this time'.

I strongly recommend that a completely independent oversight group is immediately established to ensure good governance and help reassure the public about the purposes to which their data are being used, and the impact that this has both directly and indirectly on the care they receive. It is not to be the panel that makes operational decisions on requests for data. It should do this in a wholly transparent and easily accessible way, which serves to allay the fears of all but the tiny minority who are opposed to data collection and dissemination for any purpose. It should comprise more than independent data and IG experts and GPs, but also include informed patient group representatives, behavioural scientists, ethicists, clinicians and communications professionals.

The data oversight group should be tasked with continually reviewing:

- The appropriateness or otherwise of TRE's and ensure they are compliant with modern data processing and management methods. From early conversations it has been made clear to me that at least one TRE must be very **straightforward to use,** so that legitimate medical research is not hindered by lack of access to highly expert programmers. Several TREs are regarded as "notoriously difficult and user unfriendly" at present, which is why legitimate researchers are fearful of this change. It does not have to be this way. At least one TRE must be **comprehensive** enough to allow highly sophisticated analysis, linkage to other trusted TREs and data manipulation, so as not to hinder advanced research. Every TRE must be **transparent** so that everyone can be assured that all who access the data are doing so for legitimate reasons and that the outputs are truly anonymous. This could involve publishing all requests, all code and all outputs.

- Security of the data, which continues to cause doctors and patients concern. The NHSD database is a potentially highly valuable target for hackers and has enormous 'ransom'

value to criminals. Thus is it imperative that data security standards applied to all of NHS data is subject to the most intense testing and scrutiny possible, to international standards. If any deficiencies are identified, immediately resourcing urgent fixes and whatever solutions are required becomes essential. If the underpinning database is hacked and the data released, then all the other security measures cease to be relevant or meaningful.

- Opt-out procedures to ensure a balanced approach is taken and decisions about whether or not to opt out are taken from a position of knowledge and informed choice. There is considerable work to be done in this area and is likely to require ongoing review.

- Whether best practice on data management and information governance is being followed, as international standards and methodologies evolve.

- Whether key audiences and stakeholders are being kept informed and involved, as the health data system develops beyond just primary care. Currently, ownership of communications around the benefits of health data collection is fragmented, with no single accountable body charged with delivering the message. If this is not consciously addressed, then issues will continue to flare up over coming years.

Concluding comments:

I trust that this letter has provided some constructive suggestions and insights and I am pleased to have been offered the chance to help progress the work.

It is clear from the many conversations I have been able to have in the last few weeks that we have a remarkable opportunity to lead the world in our use of health data to tackle the many challenges we face. However, we will only be able to achieve this if we commit to working to a 'gold standard' on matters relating to security, governance and transparency. It is right that the GP DPR pause is utilised to ensure that from 1 September 2021 this important initiative can fully meet those high standards.

The Academy of Medical Royal Colleges is committed to working with your teams and all key stakeholders to progress this issue and I will personally continue to do whatever I can, while remaining independent and constructively challenging. Please do not hesitate to contact me again to further discuss these issues.

Kind regards

Professor Helen Stokes-Lampard PhD FRCGP FLSW
Chair, Academy of Medical Royal Colleges

Cc: Mr Matthew Gould – CEO NHSX
Mr Simon Bolton - CEO NHS Digital
Sir Simon Stevens – CEO NHSE/I

Appendix A – list of stakeholders I have directly consulted with:

- **AoMRC** – Leaders of several Medical Royal colleges and Faculties, in addition to senior AoMRC staff
- **NHSX & NHS Digital** – a wide range of senior executive members (clinical and non-clinical)
- **RCGP** - Prof Martin Marshall (Chair), Dr Marcus Baw (Chair of the RCGP IT Group & Chair of AoMRC Health Technology group, and member of the Faculty of Health Informatics), members of RCGP policy team
- **BMA GPC** – Dr Farah Jameel, Dr Mark Sanford-Wood and other senior members of the BMA including from their policy unit
- **DataLab, Oxford University,** Dept of Primary Care Health Sciences - Dr Ben Goldacre
- **National Data Guardian** – Dr Nicola Byrne
- **NAO** – Sir Ian Diamond (Permanent Secretary, CE and National Statistician), Prof Alison Pritchard (Deputy national statistician for Data Capability)
- **NHS Assembly** – Prof Dame Clare Gerada (Chair)
- **UK Biobank** - Prof Sir Rory Collings, Naomi Allen
- **Healthwatch** – Jacob Lant, Chris McCann
- **Genomics England** – Chris Wigley, CEO
- **Notable individuals** - Dame Julia Cumberledge, Prof Sir Cyril Chantler, Mr Michael Lewis

Additionally, dozens of GPs, doctors in training and hospital consultants with an interest in this area approached me to provide their views. I am grateful to all these people and organisations for their time, insights and resources. The views expressed in this letter are however, my own and do not imply agreement by any of those named above.