

GDPR's evolution in their own words – quotes from documents released by NHS Digital

This paper describes the evolution of the General Practice Data for Planning and Research (GDPR) programme, as told through the programme's [own documents](#), which medConfidential has republished after receiving them via a number of Freedom of Information requests.

[care.data \(v1\)](#) commenced in 2013 and collapsed in 2016. In official statements about GDPR in the summer of 2021, NHSX and NHS Digital told the public it was “[a new system, designed over the last three years](#)”. In contrast, the Australian Parliament was correctly told by the architect of care.data that, “[Just to be clear, there was no sense in which this was an abandoned project](#)”.

The Programme Board papers themselves show that the process was actually more like five years long – i.e. the programme that would come to be named GDPR picked up directly from care.data – and also show that other public statements were not entirely true either.

2016

1. On July 6th 2016, the Government announced that [the care.data programme would close](#).¹ The final regular meeting of the care.data Programme Board was held in its usual scheduled meeting slot in September 2016.
2. In the same regular meeting slot the following month, on 19 October 2016, [the Programme Board for what would later be named the GDPR programme² met for the first time](#), stating:
 - a. “*The minutes of the **previous meeting** were agreed as an accurate record*”, i.e. this is and was clearly understood to be a continuation of the same board.
 - b. “[*the*] Board has **previously recorded a decision that the working assumption for the business case is that patient consent will be handled in a central platform, rather than at practice level. Should this assumption prove to be invalid it would have an impact on the new service.**”
3. In the board meeting³ held on 24 November 2016, [the minutes say](#):
 - a. “***discussions around this topic are NOT to be discussed with the wider organisation***”, i.e. NHS Digital.

¹ <https://www.gov.uk/government/speeches/review-of-health-and-care-data-security-and-consent>

²At this point, the board was renamed the ‘GPES Interim Strategy Board’ – the explicit purpose of which was to continue with the implementation of “GP Data For Secondary Uses”.

³At this point, the board was renamed the ‘GP Data Implementation Board’ but, for consistency, we refer to it as the GDPR Programme Board throughout this document.

- b. “NHSE currently want 100% of data for non-payment extracts, **no data with type 1 objections applied**”, i.e. NHS England wants all patient objections to be disregarded.
- c. “The chair asked for ‘**Appointments**’ to be changed into ‘Capacity utilisation’” – the latter being a far less contentious way to describe the collection of GP appointment data, which had already attracted [controversy](#).

2017

- 4. Possibly reflecting the mandated secrecy from the rest of NHS Digital in the previous minutes, the [January 2017](#) meeting seems to have taken place in the Leeds office of a global law firm.
- 5. And the [March 2017](#) minutes point out two massive gaps in the use cases until then:
 - a. “additional examples for the use case document (**missing research agenda and winter pressures**)” – both of which seem extraordinary oversights for a programme that had by this point already been going for 3 years at least.
- 6. Contrary to the reason that would be given on GDPR’s launch, the minutes from the [July 2017](#) board meeting state:

*“REDACTED answered that there was **no intention for GP Data to replace GPES data feeds**.*

The aggregate data feed from GPES will still be necessary for payments.”

2018

- 7. In [January 2018](#), the programme expected work beginning in March 2018 to continue without involving GPs, over 2 years after the programme started. At this point, it was also not expecting [sensitive codes](#) to be copied, and recognised the need to understand patient views:

*“REDACTED updated the board on the status of the GP Profession engagement. The next meeting with the profession is planned to take place in March. However, **the BMA are still not willing to engage** until the Memorandum of Understanding (MOU) issue is resolved. The MOU in question is between NHSD, DH and the Home Office which states that NHSD will pass non-clinical information to the Home Office for immigration offences. The BMA sees this passing of the information to be unethical and therefore will not engage with NHSD until it is resolved. This is a major issue for the programme as it has prevented formal engagement with the BMA on the Standard GP Dataset,”*

p4: “REDACTED raised a risk around patients’ attitude to data sharing and the programme needs to work together with NHSE to align communications,

*as there should be **reactive communications and mitigations ready for when the health media hear about this programme.***

*See also "Delivery Strategy", p5 and "Dataset Approach", p6: "...currently the programme is **not planning to flow sensitive codes.** However, this stance will be re-evaluated following release of the conclusions of a public consultation, which completed in January 2018."*

8. And in [March 2018](#), the minutes suggest the programme was being fundamentally changed:

*"REDACTED queried the use of a legal Direction as set out on page 9. REDACTED experience was that **Directions are usually used to mandate NHSD to collect or deliver a service, rather than state what the service must look like. This may be first time a Direction has been used in this way** and it was agreed that REDACTED should conduct further engagement on this" – in determining "what the service must look like", DHSC or whoever issued the Direction would be directly determining the purposes and means by which patients' data would be processed.*

9. The minutes from [June 2018](#) list a key area of work which was never issues, or issuable:

"Another key area of work is approval of the dataset as an Information Standards Notice (ISN)"

10. And, despite appearing as an item on the [November 2018](#) agenda, there was no public consultation on GDPR "core communications materials":

"Readiness assessment and endorsement of core communications materials to commence public facing consultation"

2019

11. In [February 2019](#), someone had a very good idea – but this never happened, and unnecessary confusion was caused (and persists) as a result:

*"There was a need to **describe the work of the constituent [GP Data] programmes and projects as a whole, including the Local Health and Care Record.**"*

12. By [April 2019](#), at least some communications lines had been worked out... showing that at even this stage the Board knew there were problems:

*"7.3. REDACTED agreed that **there were going to be flare ups in the media** and SoS permission would be needed to proceed with any **counter messages to mitigate these.***

7.4. Regarding GDPR, REDACTED advised that the organisation could offer a baseline reassurance to the public that the GP Dataset would incorporate anonymous data flows. Additionally, the fact that HSCIC had rebranded itself to be NHS Digital was very important.

7.5. Redacted also recommended that the programme **shouldn't overplay any differences with care.data**, which was also co-branded with the BMA/RCGP."

13. The [June 2019](#) minutes show the start date for beginning to extract patients' GP data had been "re-baselined" to October / November 2019:

*"REDACTED explained that in March 19 the GPDfSU [GP Data for Secondary Uses] delivery plan had been **re-baselined to start data flow from October / November 2019, assuming appropriate stakeholders' engagement had happened.**"*

And confirmed that – contrary to the way the programme would later be presented to the public – GDPR was being driven not only by NHS Digital, but NHS England, NHSX and DHSC:

*"By now, the project should had [sic] completed planned workshops, including the final combined session resulting in **agreeing the content of the dataset**"*

*"GP Dataset was an evolution from GPES and aspiration for the future to improve Data quality and safety. In addition, **the initiative was not coming in isolation from NHSD but included colleagues from NHSE, NHSX, DHSC.**"*

14. And yet a month before the intended start date, in [September 2019](#), there were still a number of significant concerns. Also several conditions – which show that NHSX was very much in the driving seat:

*"3.2. REDACTED advised that two NHSX sponsored sessions, held in July and August, were reassuring re positive collaboration with stakeholders. **The main concerns involved the possibility of data re-identification, and establishment of relevant governance / oversight.***

3.3. The support from Secretary of State (SoS) had been received under the following conditions:

- Achieve clarity regarding the data controller position; NHSD to be a sole data controller*
- **NHSX must have joint supervision** of the communications and engagement work*
- **NHSX oversight** of this work via SRO*
- **NHSX oversight** of data anonymisation work via Data Processing Services programme SRO"*

2020

15. As reported in the board meeting in [January 2020](#), three days before Wuhan locked down. It has since become clear what “NHSX data policy colleagues” decided to suggest to Ministers, and where well-considered decisions were undone by NHSX:

*"3.4. REDACTED reported ongoing conversations with the **NHSX data policy colleagues, who would deliver a briefing to Ministers on 29 January.** REDACTED stated there was a need to **identify Ministers' appetite** regarding a large, general data campaign"*

Also p2: *"3.9. REDACTED updated on discussions held with the **National Data Guardian representatives and also Understanding Patient Data, which recommended a more sequenced approach** during the Discovery Phase (starting with GPs and Practice staff, followed by patients and then to flow data)."*

16. From [31st March 2020](#), after the country had gone into lockdown due to the pandemic:

*"3.3.2. On 11 March, a meeting had taken place at leadership and comms levels to ensure that the **programme communications set out a broader GP data usage context**, provided by NHSX; considerations involved: transparency, commercial uses of data, media attention and work on a strategy to handle comms in the media. **An agreement had been reached not to commence engagement with practices until the Covid-19 response period was over"***

17. And yet by [September 2020](#), when some in Government were thinking the pandemic was over, Ministers had reverted to going ahead with the GP data collection – while NHSX was clearly in charge:

*"The Programme intend to issue a briefing, from the NHS Digital Chief Executive, to seek their [BMA & RCGP] endorsement. REDACTED happy with the approach, but asked to have sight, **referencing the interest at ministerial level that GPDfPR was receiving"***

*"3.1.2. In September the programme was advised by NHSX that they had been prioritised and that the work should now be progressed. The scope of the programme is unchanged, but the **plans must be condensed, as delivery is still expected by the end of the financial year"***

A critical (“key”) planned pilot stage with a limited number of GP practices was completely dropped:

*"4.2.3. REDACTED asked the board to note a key difference with original plan the programme was working to in March is that there will be **no discovery phase, however the scope for delivery remains the same.** The programme had planned to flow data for a limited set of practices, to test the*

data. While this pilot stage will not now take place, the programme will apply the same philosophy of 'start small, learn fast'."

And the start date was re-set (again), with concerns voiced that the public might find out about the programme when the Data Provision Notice was published:

*"4.2.7. In the Governance swim lane, REDACTED drew attention to the delivery of a new Data Provision Notice (DPN). The aim is for it to be issued by the end-November 20, **for collection to commence in early / mid-January 21**. A risk is recognised that when the DPN is submitted to the Data Coordination Board (DCB) the programme will become visible in the public space, due to the publication of their board minutes. The communications team are aware of this and will factor it into their plan."*

*p4: "4.2.16. REDACTED queried the communications approach and asked if inclusion on the DCB minutes the formal mechanism for the announcement of the GPDfPR data collection would be. REDACTED thought that it could be unwise to use the DPN or DPIA as a method of notification to the public **as this has the potential to be perceived poorly by public stakeholders**"*

Crucial details also surfaced about the programme's use of patients' GP data for purposes beyond the scope of Research and Planning:

*"4.2.18. A discussion then took place around Type 1 Opt Outs, NDG and the profession, in the context of the GPDfPR data collection being used for purposes other than planning and research. **JG stated the programme should look at the 'direct care' use cases** with REDACTED adding the need for alignment with the NDG. **JG also asked the team should not use the DPIA alone as a way of communicating, as this might not be understood by the average person, because it is a technical document...***

*4.2.19. JG said the best strategic advice for the programme, is to collect wholesome [sic] data once and use this multiple times by NHS Digital, to minimise burden on the system and practices. **The project should not miss the opportunity to consider all the direct support use cases of the data and not only Type 1 Opt Out planning and research and this discussion needs to take place.** Using all the use cases known within NHS Digital from request submitted for data request, she urged for a discussion to examine the possibility of an expanded roadmap ... REDACTED agreed that **the narrative around data has changed significantly** and this should not be ignored."*

18. By following month, [October 2020](#), the deadline for having uploaded the data of every patient registered with a GP in England is set for the end of March 2021:

*"...suppliers provide 1% of data a day building to **a full set of data by day 100, which will be the 31st of March 2021**. Some suppliers will load their historical data before the 100 days, but no supplier should go beyond the deadline of the 31st."*

New developments emerge around the longer term use of GP data already collected by NHS Digital, including the fact that the (amended) DPIA for GPES has not been submitted to the Information Commissioner's Office:

*"3.1.10 GPES is meeting the needs of direct care. **Discussions with Open Safety [sic] have commenced to come up with the future operating approach will be and NHSX and Digital need to be involved with these discussions...**"*

*Also, next item: "JG mentioned that **engagement with the ICO has dropped off the agenda. The programme has not gone back to the ICO with the GPES DPIA and the programme needs to submit this as soon as possible**"*

19. The minutes of the [December 2020](#) Programme Board meeting confirm that critical documents are still only in draft:

The *"**Draft Direction has been shared with DHSC**"* – a month before the 'go live' date, after over 4 years of work.

*p3: "Data Provision Notice (DPN) and Data Privacy [sic] Impact Assessment (DPIA) are **moving into final draft**, ahead of formal reviews commencing. Expected readiness for publication mid-January. **This will also be shared with the profession to review before the publication**"* – despite the very next item acknowledging *"**Formal support with the profession has still not been attained.**"*

They also confirm that 10 Downing Street has been taking an interest:

"6.1.2 Influencing factors delaying the formal engagement and approval from the profession are:

- *COVID Vaccine work taking Priority.*
- *Data Request from 10 Downing Street, via DHSC requesting Practice Level data from January 2019.*
- *An updated position where positive discussions have taken place within 10 Downing Street and DHSC*
- *A new agreed plan to move forward, which will now be used to re-approach and engage the profession."*

And that the start date has been slightly pushed back. It is unclear what is meant by a "pilot scheme" at this point – certainly one never took place:

*"**25 January should be when data begins to flow and when the pilot scheme can commence.**"*

20. The minutes of the meeting of the once-again-renamed “GP Data Portfolio Board” in [January 2021](#), two days after the last meeting’s 25 January ‘go live’ date, show that GPD(f)PR still hasn’t secured the support of the profession, i.e. BMA and RCGP:

*"3.4.2. REDACTED provided an update using their slide pack 3.5 - GPDfPR January Update. **The key update related to the support of the profession, citing the nuance between ‘direct care’ and ‘supporting direct care’.**"*

"Jackie Gray (JG) stated her full support for the GPDfPR and requested as much notice as possible for support would be greatly appreciated."

21. And in [February 2021](#), a full month after the Board had expected the programme to begin extracting patients’ data, GPDPR was relegated to a single item in “Any Other Business”:

*"8.1.1. **GPDfPR: not discussed today.** We are in process of taking the new service live, should be complete over next two weeks. We will need governance (go/no go) support to make the decision before the service is live. **This decision will be made outside of the Board. The Board did not object.**"*

You can follow what happened next in our What’s the story? summary, [“GP data 2021”](#).