

Equality and Social Justice Committee

Senedd Cymru
Cardiff Bay
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20 April 2023

Data justice and use of personal data in the Welsh NHS

Dear Chair

GPC Wales, the representative body for general practitioners in Wales, are very interested in the committee's short inquiry on personal data in NHS Wales. We welcome your interest and work in this developing area and would like to provide the committee with an insight as to the complexities and risks on this important matter from a GP perspective.

Firstly, I would like to make clear that we are wholly aligned with the theoretical concept of safe and legal access for patients to their own medical information. The GP record is widely acknowledged to be the most consistent and life-long patient record in the health sector.

1. Current situation regarding Data access

Patients can currently access a limited dataset of their medical records - potentially including Medication data, summaries of conditions and other functionality like appointment booking - via MyHealthOnline (MHOL) or the NHS Wales App, if their practice is part of the ongoing beta testing stage.

They can obtain their full medical record via Subject Access Requests (SAR) under GDPR. GPs have 28 days (or 84 in complex cases) to comply with SAR requests.

However, there are challenges with this as the all-encompassing GP record often contains data which needs removal or redaction.

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It is not uncommon to find data within a patient's record which might breach the data rights of third parties, for example:

- misfiled documents
- references to family members or neighbours
- telephone numbers of relatives
- complex child protection documents containing lots of third-party data, often of a highly sensitive nature.

Before GPs can share these data with the data subject (i.e., the patient) they must ensure that all third-party references are redacted or removed (in the case of a misfiled document). Redaction is currently largely manual and incredibly labour intensive – with many GPs personally having spent hours redacting single instances of multi-volume records in response to SAR requests.

This results in GPs often being required to use valuable time for these tasks that could otherwise be used for delivering direct patient care.

2. GP data controller role and potential sanctions

Under GDPR regulations, GP partners (who hold GMS contracts) are considered as the data controllers for any data that they hold about their patients¹.

Therefore, if GPs breach GDPR regulations they are **personally liable** to be reported to the Information Commissioner's Office (ICO) who can investigate and sanction. The potential sanctions from the ICO range from advice, public criticism, and ultimately financial sanction, of which the current maximum levy is **30million Euro or 10% of annual turnover**. As this is a criminal levy, GPs are unable to gain indemnity insurance for this through the state-backed General Medical Practice Indemnity (GMPI) scheme or the Medical Defence Organisations. Therefore, while breaches of GDPR may be a low-level occurrence risk prospect, they would have catastrophic potential for individuals and practices- and ultimately patients- with personal bankruptcy and collapse of practices being very real prospects

GPs must of course also consider the Common Law Duty of Confidentiality.

GPs need to be sure that only the patient themselves can access the record via appropriate safeguards. If not, GPs face regulatory risk from the GMC. Family member access for sensitive information would be highly difficult to grant given these obstacles.

3. What needs to be in place to proceed with safe patient-level record access in Wales?

It is our view that plans for full record access would probably have to be on an 'OPT-IN' and informed consent-based model, itself probably highly labour-intensive.

¹ See also BMA guidance 'GPs as data controllers under the General Data Protection Regulation' (March 2018) www.bma.org.uk/media/1827/bma-gps-as-data-controllers-under-gdpr-november-2019.pdf

GPC Wales would therefore require the following to comply with wider patient-level records access:

- Support and resource to redact (prior to GDPR, SARs were chargeable which mitigated this)
- Effective technological solutions on redaction to reduce this burden (this is still a long way off, with similar schemes being proposed in NHS England more than four years ago but still not having been delivered)
- Legal change to remove the risk under GDPR (this is no less complex post-Brexit)
- Information Governance reassurance around properly authenticated access to the NHS app
- Opt-in consent to engage with resourced time to discuss ramifications

If all the above were granted, a staged approach of patient data access would still be necessary to satisfy the risk concerns of data controllers. One potential starting point would be with prospective records (i.e., those going forward) only being accessed initially.

Much of the data which would be available to patients is extremely complex and often requires a medical degree or training to appropriately interpret it. Access to such data without the appropriate knowledge or support can, in our experience, often result in additional concern and anxiety for patients. This is a very real outcome which should be considered as part of any further action in this area. We are reassured that the NHS Wales app, currently in public beta testing phase, will only proceed with summary record access once a GP practice has enabled the functionality. We strongly advise that only summary and coded data including vaccinations, would be in scope for the NHS Wales app until all these issues are addressed to our full satisfaction before allowing full record access.

4. What is happening in England?

In England, the multi-year GP contract signed in 2019 included a clause to turn on patient access to records via the NHS England app from 1 November 2022 on the promise that redaction software would be in place.

This technological solution has not yet become available, but NHS England has proceeded with the mass switch on despite the major concerns of practices, LMCs and GPC England.

The outcome has been that many GPs in England have chosen to delay their involvement at this stage as they do not feel ready. The BMA has recently [issued guidance](#) on how to do this.

Lessons can be learnt from England, and therefore any actions in Wales must see GPs being part of the process so that they feel confident and ready to support these changes.

5. Data use for Health and Social care planning

Finally, sharing patient level data is going to be vital in ensuring a data led planning process for NHS and Social Care in the future. Developments such as the **National Data Resource** (NDR) and the SAIL databank are welcome in acting as a repository to enable efficient and accurate planning and research to take place. This can only function when confidential patient data is shared and linked to other data sets in Primary Care, Secondary care, and Social Care.

This requires data governance and safety to be engineered into the process from the outset and an honest debate with the public held so they are aware their medical records will be used for this purpose with safeguards and individual confidentiality maintained.

To date, SAIL has demonstrated itself to be a trusted research environment with effective safeguards and processes allowing safe access to data, leading to high levels of GP practice engagement. However, GPs have seen little tangible use of SAIL to benefit their populations directly given that level of engagement to date. **This should be addressed by Welsh Government (as the funding body) to mandate usage for NHS planning purposes where necessary.**

The processes to use these data sources for the NDR are being developed. However, to date we feel that progress has been made without the commensurate Information Governance Safeguards and necessary legal changes to satisfy GPC Wales that the risks to GPs in sharing data have been sufficiently mitigated.

The need to override the Common Law Duty of Confidentiality for GPs as data controllers needs to be lawful and explicit, as without this, attempts to enable data sharing from Primary Care are doomed to fail.

This also in our view requires a large-scale information campaign and consultation process with the Welsh public, similar to that undertaken during the presumed consent Organ Donation changes. We feel it is of similar importance and of similar transformational value to the NHS in the longer term.

Should the committee require any further information or feedback on this matter either now or in the future, GPC Wales remains ready and willing to support your work.

Yours sincerely



Dr Ian Harris
Deputy Chair,
General Practitioners Committee Wales