

Jenny Rathbone MS

Chair of Equality and Social Justice Committee

By email only

22 December 2023

Dear Ms Rathbone

### **Inquiry into Data Justice**

I am writing to you in your capacity as Chair of the Equality and Social Justice Committee and, in particular, in relation to the Committee's inquiry into data justice. The work of my team, and the expertise we hold on the issues being scrutinised, may be of use to this inquiry, and may also help inform any future work the Committee may undertake.

The ICO is the UK regulator of the UK General Data Protection Regulation (GDPR) and Data Protection Act 2018 (DPA), and has an office in Cardiff dealing with the interactions between our remit and public affairs in Wales. I am responsible for that office, and my team works alongside health and social care bodies in Wales to help them ensure that data privacy and information rights are built into their data processing activities. We also engage with Welsh Government officials to help them ensure that new policies and legal measures are developed in accordance with the legislation we regulate.

The below comments are offered in respect of the key issues that have been scrutinised by the Committee thus far. They are designed to give the Committee our regulatory perspective on these matters, in particular with reference to personal data processing in Welsh health and social care sectors. Where appropriate, further detail is provided through links to information and guidance published on our website.

### **The role and remit of the ICO**

Where proposed legal measures developed by Welsh Ministers - including primary and secondary legislation, statutory guidance or ministerial instruction - mandate or provide for personal data to be used in new or different ways, Article 36(4) of the UK GDPR requires that prior consultation with the ICO must take place. Comments and views that we convey during the consultation process

must be taken into consideration as the measure is implemented. Guidance for legislators on Article 36(4) has been published by the UK Government<sup>1</sup>.

The identification of privacy risks contained within legislative proposals is our key objective during the Article 36(4) consultation process. This helps to prevent legislative measures being passed which provide a high risk to the data protection rights of individuals impacted by the proposals.

Our experience of Article 36(4) consultations has taught us that identifying and mitigating risks at an early stage of the development procedure is beneficial to all parties involved. For example, identifying a flow of data between organisations in the initial phases of developing policy can allow for effective data sharing measures to be put in place prior to the commencement of the measure.

Outside of the legislative framework, organisations that determine the purposes and means for personal data processing ([data controllers](#)) are required under Article 36(1) to consult with the ICO on any high-risk processing activities they are seeking to undertake. If we are concerned that the risks of such processing are not mitigated to a sufficient degree, we can consider using our regulatory powers to prevent the processing from taking place. By way of example, we have previously issued a formal warning to a Welsh organisation that was unable to mitigate risks that we highlighted within a proposed processing activity.

The Committee can therefore have some assurance that the existing UK legal framework for data protection requires independent and regulatory scrutiny of proposals to use personal health and social care data, and that the matters addressed in this letter will be considered by us as part of that work.

## **Transparency around the use of data**

Transparency is enshrined in data protection law, with individuals having a right to be informed under the UK GDPR. Our own research<sup>2</sup> has also highlighted that transparency is a precedent to individuals becoming empowered through information. The provision of clear information about how health and social care bodies will process the personal data of the citizens of Wales is crucial in engendering the trust necessary for effective service delivery.

As part of our upstream engagement work, we have been involved in discussions with Welsh Government and health and social care bodies around initiatives such as the Data Promise and National Data Resource. Both of these initiatives appear

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<sup>1</sup> [Guidance for legislators on Article 36\(4\)](#)

<sup>2</sup> [Data Lives Year 1 Report \(ico.org.uk\)](#)

to be good opportunities to provide information to the citizens of Wales as to how their data will be collected, used, stored, shared and kept secure.

We would expect that measures designed to provide data transparency provide this information in a clear and practical way, and in line with obligations provided in Articles 13 and 14 of the UK GDPR. We will continue to provide advice and guidance to Welsh Government and health and care bodies in relation to this subject.

The purpose behind any new processing of personal data is of fundamental importance for data protection compliance, as the purpose will almost always determine which of the lawful bases specified in the UK GDPR should underpin the processing. The specific information rights available to individuals will depend on the lawful basis being relied upon.

Legislative measures dictating new collection, sharing, analysis or other processing activity should therefore have a clear and specific rationale as to why they are being developed, and that rationale must be conveyed in any subsequent transparency information. Failure to do may result in a 'data grab' of personal information, where information is collected under the assumption that it will prove useful at a later date, something which is not compatible with data protection laws.

The ICO has recently drafted new guidance on data transparency in a health and social care context, which will give practitioners an idea of our expectations. The draft guidance is currently out for consultation<sup>3</sup>, and my team has circulated it to stakeholders in health and social care organisations across Wales. While our guidance applies to the UK as a whole, this will allow us to consider views specific to Wales as we develop the final version.

### **Individuals' control over their data**

It may be useful to the Committee to know that while data protection laws undoubtedly afford citizens greater control over their data, some of the rights provided by the UK GDPR are not absolute. By way of example, the right to have data erased is a qualified right that allows for individuals to *request* their data is deleted. However, the data controller is compelled only to *consider* the request, and may determine that they are lawfully entitled to continue to hold and process it. Requests submitted under UK GDPR for the deletion of health data being processed for legitimate reasons (such as GP or hospital health records) are unlikely to be accepted.

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<sup>3</sup> [ICO consultation on the draft transparency in health and social care guidance | ICO](#)

Similarly, when considering an individual's request under UK GDPR to restrict access to their records to specific clinicians or professionals, organisations will take into account the fact that the record exists to support safe and appropriate provision of care. This will be balanced against the individual's reasons for the restriction being put in place, before an outcome is reached.

The ICO has the power to investigate complaints that information rights have not been upheld, although we do not have the clinical expertise to determine a view on the provision of care; that is a matter for health and social care professionals or other regulatory regimes to determine. However, we support the view that holding details of professionals who have accessed specific records is good practice and can help identify and address issues of inappropriate access. This is something we are aware that exists in Welsh healthcare bodies through the National Intelligent Integrated Audit Solution (NIIAS) system.

In our experience, informing patients as to how they can expect their rights requests to be handled, along with likely expectations, can form an integral and effective component of transparency measures. As stated earlier in this letter, this is likely to help engender trust in how data is being processed, and empower individuals to exercise their rights appropriately and effectively.

### **Offences and breaches of data protection law**

It may be useful for the Committee to be aware that section 170 of the DPA makes it an offence for an individual to access or disclose (or procure access or disclosure of) personal data without the consent of the data controller. In essence this means that clinicians and other staff can only lawfully access medical records when it is necessary to do so in order to perform their functions. There are a number of instances where health staff have been prosecuted for such offences, either by the ICO or by the police<sup>4</sup>.

### **Processing of children's data**

Under data protection law, children are afforded greater measures of protection, and practitioners across Wales who process the data of children and young people need to be aware of this fact. In particular, transparency information must be written in clear language appropriate to the age of the audience and

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<sup>4</sup> [Former NHS secretary found guilty of illegally accessing medical records | ICO](#)

any reliance on consent for data processing must take into account the age of the individual.

Further guidance on the rights of children under data protection laws can be found on our website<sup>5</sup>. I realise that some of the guidance and resources, such as our tools for safeguarding practitioners, may be outwith the scope of the Committee's interests at this stage but share here for awareness nonetheless.

I trust that the Committee finds this letter to be of use in their inquiry into data justice in Wales, and would be happy to provide further evidence should it be required.

Yours sincerely

A handwritten signature in black ink, appearing to read "David Jones". The signature is written in a cursive style with a long, sweeping tail on the final letter.

Regional Manager

ICO Wales

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<sup>5</sup> [Children's information | ICO](#)