

Jane Hutt MS
Minister for Social Justice and Chief Whip

20 July 2023

Dear Jane,

Inquiry into data justice

The Equality and Social Justice Committee recently held a one day inquiry into data justice. Intended as a short, targeted inquiry, our focus has been on the use of personal data in the Welsh NHS, how secure this data is, and how it will be used and shared when electronic prescribing (e-prescribing) is rolled out. Further details, including terms of reference, are available on our [website](#).

The following key themes emerged during our evidence gathering and we draw these to your attention for consideration as the Welsh Government moves forward in this area. A more detailed summary of the evidence gathered is attached as an annex.

Public understanding of health care data

NHS Wales produces, relies on, retains and reports on significant amounts of patient data. However, we heard that public messaging about data needs to be better balanced between data security, risk and concerns and the potential for using data in research and improving patient care.

Please could you outline the effectiveness of programmes of engagement with patients and the public to improve and share understanding of the concerns and potential benefits around the collection and use of health data.

The reasons for data collection

Evidence suggested that while there is a good degree of trust in the NHS and research institutions, patients are more hesitant to share their data with private sector organisations.

The NHS and research institutions such as SAIL and universities can and do play a key role in maximising the collection and use of patient data. However, the recent pandemic has shown the potential value of active work with the commercial sector with appropriate safeguards. Those partnerships can play a significant role in improving patient care as long as safeguards are in place against the harvesting of data for commercial purposes.

The quality and completeness of health data

We heard particular concerns about the potential under-reporting of data related to minority ethnic groups, those who are socially or economically disadvantaged, and women. Such under-representation can result in their needs not being adequately reflected in the development and delivery of services. Further, questions were raised around imbalances in research because of the quality of the available data.

While ethnicity coding standards exist for researchers, these are used inconsistently across the UK. Incomplete data, poor recording and missing data means data cannot be used to its full potential.

You may be aware of the concerns raised recently by the UK Health Data Research Alliance, who have [called for action](#) to improve the coding of ethnicity data and set out a number of draft recommendations to progress this, including:

- the need to record ethnicity data consistently across all four UK nations; and
- the need to roll out standard guidance and/or training for data collectors in NHS and social care settings.

In addition, the UK Government's Race Disparity Unit has recently published [revised standards for ethnicity data](#) which provide guidance on best practice when collecting, analysing and reporting ethnicity data.

The need to ensure all groups are represented effectively in data collection and use is one of the key tenets of data justice. The ability to collect and use large data sets is vital, but should be balanced also with the need to work with smaller or under-reported groups. **We would welcome the Welsh Government's view on ensuring more consistent and complete collection and use of ethnicity data.**

The drivers for data collection

One of the key drivers for certain types of data collection, especially that linked to research, could be availability of resource or funding linked to specific projects or programmes. This clearly has the potential to skew priorities and moreover, to remove the focus from groups under-represented in available data, as discussed above.

There is a need to ensure that data collection and use serves specific priorities. Improved patient care and better sharing of information across care settings and organisational boundaries should be a key driver for both research and data developments, such as e-prescribing. **Please could you set out the Welsh Government's view on increasing work with public bodies to ensure they can access and use the full range of data effectively in planning and developing health and social care services.**

Data complexity

Data can be found in a broad range of systems and formats which can make its integration and use more difficult.

Mr Rhidian Hurlle from Digital Health and Care Wales (DHCW) told us: "the delivery of a health and care record should be available wherever the patient presents", yet data sharing between one body

and another remains a significant challenge for NHS Wales.¹ E-prescribing and the shared medicine record presents an opportunity for developing greater data sharing across care settings but there is still significant progress to be made.

Data security

Data security and effective information governance remains a key priority in an increasingly digital care environment. Safeguards need to develop in parallel with systems, and the wishes and views of patients around the management of, and access to, their health data must be reflected and respected.

Developments in data collection and use

It is clear that the potential of advances in digital and data technology, such as the NHS Wales App, could make for improved patient access to data around services and their own health record. We heard that the recent pandemic has driven change and the development of new tools and approaches. Yet it is important to remain mindful of digital exclusion, not just in terms of access to devices but also access to wi-fi and the subsequent range of digital services and programmes this offers. **Please could you set out Welsh Government plans for giving the patient direct digital access to their patient record.**

Patient engagement

It was widely acknowledged in our evidence that patient engagement and the patient voice was still playing a limited role in the development and management of data and data systems. We heard little evidence of focused efforts to engage with under-represented groups, and we were concerned that DHCW did not appear to have a clear or widespread approach to public engagement in its programmes. **Please could you set out the Welsh Government's view on how patient engagement can be put more strongly at the centre of developing data and data systems.**

IT and workforce development

While not covered in-depth in our inquiry, we are mindful of concerns that have been raised over investment in basic IT and workforce development regarding data skills and literacy, most recently by the Health and Social Care Committee and the Public Accounts and Public Administration Committee in their scrutiny of DHCW.² We note the view set out in their report that having the right skills and capacity within the workforce is key to delivery. **The Welsh Government should consider this matter during its forthcoming budget discussions.**

Next steps

We would welcome your comments in relation to the themes set out above and to our interim findings on data justice more broadly. In particular we would welcome a summary of what actions the Welsh Government is taking to address the issues raised.

¹ Equality and Social Justice Committee, [27 March 2023](#), Record of Proceedings, paragraph 191

² Health and Social Care Committee and Public Accounts and Public Administration Committee, [Scrutiny of Digital Health and Care Wales](#), July 2023

We intend to return to this inquiry in the autumn term, when we will hear from a panel representing the patients' voice, to allow us to consider this issue further.

I am copying this letter to the Minister for Health and Social Services.

Yours sincerely,

A handwritten signature in black ink that reads "Jenny Rathbone". The signature is written in a cursive style with a large initial 'J' and 'R'.

Jenny Rathbone MS

Chair, Equality and Social Justice Committee