

A WISE  
DOCTOR

ONCE WROTE

*Am. I  
found out  
every*

**The data's  
identifiable**

...but you can still use it

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Narratives are detailed



They contain insight that structured data doesn't



They are vital for gaining detailed knowledge about care experience



NLP is getting ever more powerful



**PROBLEM:** our raw data processing is biased towards structured data

## Nuance and Knowledge

# Information Governance ‘Secret’

Narratives are never anonymous

Too much detail

Too hard to remove references to others

Even if you do a fair job you’ve ruined the  
nuance

Unethical

Why do you want to that...?



# Wasted effort

There is a wealth of regulatory support to handle any data that is identifiable

Ultimately the responsibility of the Data Controller to determine anonymity

Excerpts of health records simply are not

Claiming anonymity is not a shortcut around regulation – it wastes everyone's time

Data must still be processed accurately, securely, accountably and usually transparently

# Data must be adequate

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Enough for you to achieve  
research goals



Not so much that you are not  
going to even use it



That's a hard balance to  
strike



Be as clear as you can from  
the outset with data subjects  
and regulators

# “Relaxed Data Sharing Rules”

Opportunity to engage more with patients and the public during COVID

Very clear that people are worried about security of their data

Data Sharing Rules were not relaxed

Duty of Confidence set aside by regulation – the COP/ Notice and international equivalents

We do not have carte blanche – understanding of data driven research importance but with limits



# Dame Fiona Caldicott

## 1941 – 2021

“As we ... think about what data use should look like in a post coronavirus landscape, we must continue to listen to the public. We have already begun to see emerging evidence, which suggests that people are becoming more knowledgeable about the importance of health and care data, and more accepting of its use. We now have an opportunity to build on this growing awareness. And at this time, transparency will be key to providing the reassurance that earns confidence. We must make a concerted effort to engage with the people whose data we hold before making important decisions about it.”

See [Department of Health and Social Care Tribute](#)