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2025-01-22 stats assembly remarks - session on Breakout 7,11:50 to 12:50: Data linkage ROOM 201

Hi, I'm Sam from medconfidential.

When our data gets used, it shouldn't be used in ways we're told it won't be.

I'll talk about that in three ways: **consensual, safe, and transparent**. All the references I skip over can be found at the top of the news page on medconfidential.org as I have 4 minutes.

ONS runs surveys asking people what crimes they've committed, and people choose to answer, and do so honestly. **In a survey ONS makes a promise about answers to respondents. But with data linkage, instead it's weasel words** which might imply you have a choice but lets government then ignore it.

The data being linked is your health records to your tax records, and your education records, and your electricity smart meter, and your clubcard spending. The HDR/Sudlow Review says they want to link everything on everyone, because "research is good". There are real legitimate challenges where better linked data analysis will help, I worked on them for a decade, but I'm not sure that because a researcher says they are good people doing good things, they should be able to fill in a 3 page form and get the data on the worst events in your life without you having any say.

If ONS treated its own data the way it treats linked NHS data, there'd be mutiny in Titchfield. **100% population admin data is much more like a census in mandate and coverage, yet it's treated more recklessly than the surveys.** There's an NHS thing going on at the moment where data copied "only for the pandemic" is going to be sold off to racists because the new government doesn't like the previous government's promises. When data is linked, are promises going to be kept, or are they going to be broken? How will you know?

ONS is using health data on people who have expressed a national data opt out – people who don't want their data used. ONS get data for "statistics" uses, and then reuse it for "research". ONS tells us that they do this because they have public support. So let's take a look.

Firstly, what are they doing? They're currently linking NHS medical histories to tax records to assess whether NHS treatments are contributing to economic growth, and that outcome will be used to delay care on treatments that don't. I'm not sure grandma's new hip contributes as much to the economy as helping finance bro who skied into a tree. In a finite pot of money, in a finite NHS budget, DH/E picks who gets the operating theatre, and it's not grandma… The analyses we choose aren't neutral, and if they're secret you know how that will go..

Transparency is necessary for safety. It's welcome that ONS now publishes a list of projects – they didn't used to because secrecy was the easy default, but things can get

better. Summaries of every project using data should be publicly listed to the standards followed by the NHS. We know how to build safe and transparent systems deserving of public trust, but instead we the race to the bottom in terms of access and accountability in the HDR/Sudlow Review, which also said the primary organisations who should be listened to are Emma's outfit and Cassie's boss. That's neither transparent nor safe.

What do we want?

In summary, **as a human being you have choices around data and those choices should be respected not ignored**. there are legitimate reasons for a pregnant woman to share her heart rate from her smartwatch with her doctors; that's good for care. But you are being notified that if you share data for your health, then others must be able to link it to your entire life, sell it, and you get no choice – it literally is your data or your life.

I'm not sure what public acceptability of that will be, but **HDR/Sudlow ONS argument is government should be able to do whatever they want with your linked health and tax records because people trust ONS with surveys, so my question is this: if that's true, why is the LFS response rate 20%?**