

Fairchild | Panel Discussion Big Data | October 12, 2017

Point of departure is the new WHO surveillance guidelines and the emphasis they place on equity as a foundational ethical consideration.

Important keep in mind not only the potential of digital disease detection (e.g., using cell phone technology to track dengue by household) but also the gap (e.g., the reality that many agencies store their records not in electronic form “in the cloud” but on paper “in the closet”).

Underscored that countries with the highest rates of MDRTB are also the ones that lack the capacity to undertake surveillance (hence the current publication effort looking at the intersection of the TB and surveillance guidance is critical).

The potential for big data also needs to recognize that there is an enormous gap between what the public and private sectors can do in terms of data collection and analysis:

- January 2017, the US President signed a bill allowing internet service providers to sell personal client data for commercial purposes
- This stands in stark contrast to the “patchwork” nature of privacy law in the US, where multiple layers of state and federal privacy laws and regulation make it comparative more difficult to collect, share, and analyze data
- The EU provides one alternative model in risk alike (and hence level of required protection) regardless of whether data is commercially or publicly held

While, then, there has been a remarkable transition in the US over a short period of time from paper to electronic forms of medical data storage, an overarching point is that the distribution of technology is not enough. In the US, for example, despite the efficiencies that this massive data migration offers, we have still seen an actual decline in life expectancy amongst some groups. And, indeed, the gaps on which we need to focus are not between the 1% (who are wealthy) and the 99% (who are left behind), but on the 50% of Americans who now constitute “the poor.” While America is behind compared to other industrialized democracies, this broad and deep pattern of inequity is important to recognize in middle and low income nations.

In other words, big data analytics may, in fact, make it possible to detect and treat TB quickly and efficiently. But if we don’t address the underlying structural inequalities, populations may not die of TB but will still die due to energy insecurity, inadequate education, food insecurity, racism....

So, then, looking at the challenge of Big Data from the perspective of surveillance, I am less concerned with access to care and less concerned with questions of the risks to privacy and ore concerned with social justice and inequality.

Julio Frenck made the point that the origins of the word “evidence” mean information that “makes something visible.”

The question, then, that we have to ask about Big Data is not *How* but *What? What* are we making visible?