Sharing surveillance data:
The value of collaboration in curbing the next pandemic

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Monitoring the spread of infectious diseases through surveillance programmes is fundamental to maintaining good public health and a key component of strong and resilient health systems. Surveillance can determine levels and prevalence of antimicrobial resistance (AMR) helping clinicians identify medicines that are no longer effective. Comprehensive surveillance can only be achieved through collaborative and coordinated data-collection efforts. If cases of drug resistance are identified and data is promptly shared, we will be better equipped to stop the spread of resistance within the community, locally and globally. Here we make the case for pharmaceutical companies to share surveillance data sets publicly, including through the AMR Register.

Disease surveillance is a largely neglected branch of public health, and often only receives significant investments in reaction to existing adverse global health events. However, the current COVID-19 pandemic is reinforcing the argument that comprehensive disease surveillance measures are necessary to protect people, their livelihoods, and the global economy and should not be carried out on an *ad hoc* basis.

Adequate surveillance data on resistant infections could further our understanding of resistance spread globally, guide optimised use of antibiotics, steer antibiotic development and enable implementation of impactful early interventions.

Data on resistant infections are already routinely collected in high- as well as low- and middle-income countries by public health bodies, the pharmaceutical industry, and academic organisations.

However, public and private sectors work in silos, often collecting, storing and analysing their data separately and not communicating with one another. Surveillance data is underused and, as a result, local resistance patterns are not widely available to doctors or policy makers to guide treatment selection, local action or implementation of guidance. Diverse stakeholders need to work collaboratively and in solidarity to coordinate and scale up efforts to address possible future pandemics related to AMR.

Routine surveillance is essential for monitoring and controlling the spread of diseases and has proven to be a critical element of addressing the COVID-19 pandemic. It is also essential for controlling the rise of antimicrobial resistance. But the world struggles to monitor and track the spread of drug resistant infections with data still being patchy – especially in low- and middle-income countries – and lacking full transparency.

Why data from pharmaceutical companies is valuable

Pharmaceutical companies hold the key to some of this critical data. While surveillance is primarily the responsibility of governments, pharmaceutical

companies with surveillance programmes have unique knowledge of the resistance map, particularly where their data covers countries without national surveillance efforts. Their data and insights are valuable puzzle pieces.

Surveillance data can provide insight into where resistance to specific medicines is occurring and can lead to better treatment choices by helping doctors determine which medicines are likely to be ineffective due to resistance. It can lead to more targeted pharmaceutical R&D to develop the most critical new products, and it can support public health authorities in forecasting disease trends and planning medicine purchases to avoid unexpected stockouts and shortages.

Moreover, by using and combining the raw data from companies' surveillance programmes, third-party researchers can explore the potential for further research, beyond the specific questions asked by the companies themselves. Sharing the raw data from these programmes would help inform critical global surveillance efforts. Data could be contributed to the Global Burden of Disease study, published by the Institute of Health Metrics and Evaluation (IHME).

Incentives and initiatives to promote transparency and the wider use of industry data

Wellcome's Drug Resistant Infections Team and the Access to Medicine Foundation are working together to promote ways that researchers and policy-makers can optimize the use of data from industry surveillance programmes, promoting stronger transparency and open access. In 2018, Wellcome launched a pilot online portal, The AMR Register, which published information on global AMR surveillance programmes run by the pharmaceutical industry. The AMR Benchmark incentivises and rewards companies for publicly sharing raw data from their respective surveillance programmes, including with the AMR Register.

Through this platform, Pfizer is the first company to share the raw data from its ATLAS programme, which is active in more than 74 countries. Previously, Pfizer was publicly sharing some of its surveillance data with limited options for analysis in an online database. Now, by sharing its raw data with the AMR Register, Pfizer has demonstrated the value and practicality of making additional surveillance datasets available for in depth analysis by multiple parties, creating the critical momentum to make open pharmaceutical AMR surveillance data a reality.

Obtaining raw data from important surveillance programmes of other companies (such as GSK, Merck & Co., Inc, and Shionogi) would greatly contribute to the global picture of resistance. GSK's SOAR programme spans more than 30 countries. GSK committed publicly to sharing its raw data, in 2018, and again in 2020 at the World Economic Forum in Davos and is preparing the data for release to the AMR Register. However, the company has not yet released it to the AMR Register. Additionally, Merck & Co, Inc's SMART programme operates in 63 countries, and Shionogi runs multiple AMR surveillance programmes, including one that tracks resistance of Gram-negative bacteria in 13 countries. The AMR Register, and the research community utilising its data, is already benefitting from the sharing of Pfizer's data. Additional datasets would allow the research community to combine data from different sources creating a more comprehensive picture of resistance patterns at the local and regional level.

On November 20th, 2020, Wellcome launched a Request for Proposal (RFP) to further develop the AMR Register. Wellcome is committed to fostering greater collaboration and to guaranteeing better industry surveillance data availability and access. This will only be achieved through the development of a sustainable data governance framework for the use of surveillance datasets to better fulfil research and analysis requirements. In turn, the goal is that the revisited platform will offer a dedicated space where the pharmaceutical industry can share global surveillance programmes datasets in fulfilment of their commitment to combat AMR. By working collaboratively, industry can contribute to identifying, monitoring and addressing drug resistant infections, a severe and real threat to modern medicine that must be prioritised before time runs out.