Why the pharmaceutical industry needs NHS data to develop new medicines

Blog post by Janet Valentine

Why NHS Data is important for medical research

To a greater or lesser degree, most countries charge their citizens to access health care. This means researchers can only study health outcomes in these countries, using data from those people who can afford to pay for care.

The NHS is a free at the point of care service available to all. This means NHS data contains medical information on people throughout their lives, regardless of where they live, their ethnicity, or their socioeconomic situation. Because NHS data is inclusive of all UK patients, it is possible to analyse NHS data to get a truly representative picture of the cause and treatment of disease across the entire population.

Carrying out research using NHS data gives scientists a more accurate assessment of the effectiveness and safety of medicines, unmet treatment needs and the best healthcare options for patients living in the UK. In addition, the diversity of the UK population enables these results to be extrapolated to patients in other countries.

It is the representativeness of NHS data that makes it such an important tool for the pharmaceutical industry. It allows companies to develop new and effective medicines and ensure they are safe to use in the NHS, regardless of patients' socioeconomic circumstances.

Maintaining patient anonymity

Before NHS data is used for research, it is anonymised, removing information that identifies a patient, such as name, address and NHS number.

Industry researchers analyse anonymised NHS data to understand risk and progression of a disease, to develop and test new medicines and to comply with conditions set by the medicines regulator once they have licenced a medicine for routine use.

By using anonymised representative NHS population data, industry scientists can be more confident that that their research findings are not biased and will not disadvantage patient groups that are typically under-represented in research.

It is critical that when using NHS data, patient confidentiality is maintained, and that data is used securely for legitimate purposes. This is why access to NHS data for research is only granted to bona fide researchers, including those within pharmaceutical companies, where the research is aimed at improving patient outcomes or for public health benefit.

The ABPI has long stressed the importance of trustworthy use of health data. In partnership with our members, government, charities and patients, we developed our 'Principles for analysis and use of health data,' which clearly outlines what is expected of our members when using NHS data for research.

Public support for use of NHS data for research

Over the past decade, there have been multiple surveys of public attitudes to using NHS data for research.

During this time there has been a global pandemic, where the pharmaceutical industry worked at record pace to develop effective and safe vaccines. Despite this, public support for the pharmaceutical industry's use of NHS data to develop new medicines has remained stable between 60 per cent and 70 per cent.

Today, the spotlight is once again on the use of NHS data for research, with the government's recent pledge of up to £600 million in partnership with the Wellcome Trust, to establish a Health Data Research Service.

For this new venture to succeed for UK patients, the NHS, and to boost economic growth, it will be essential that healthcare professionals, patients, and the public support and trust the reliable operation of this new service.

Examples of how companies use NHS data in research

To help understand why NHS data is crucial for research, developing innovative, safe, and effective medicines, we have created a publicly accessible case study library.

This new ABPI health data case study library contains examples of how the pharmaceutical industry has used NHS data in medical research and the benefits that have emerged as a result. These examples cover different therapeutic areas, datasets and types of research. We will add more examples over time.

We hope the case studies library serves as a valuable resource for our partners and stakeholders to better understand why NHS data is a crucial asset for the UK and how the pharmaceutical industry uses this data to benefit patients both in the UK and globally.