



**Health Data for Research and Analysis – A Dermatology View:
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An analysis, initiated by the government and directed by Dr Ben Goldacre, will investigate how health data for research and analysis can be used effectively and securely. It will balance the forthcoming Data Strategy for Health and Social Care (under the direction of Secretary of State, Matt Hancock) which will set the direction for the use of data in a post-pandemic healthcare system.

Perhaps the best example of successful use of population data to improve population healthcare is deCODE. This was a commercial scientific project set up by a Professor of Neurology at Harvard of Icelandic descent in 1996. The aim was to sequence all the Icelandic population's genome and look for genetic variation which might lead to genetic variation. The aim was to look not only for Mendelian alleles but also variations that might link to common diseases, such as the majority of chronic diseases, cardiovascular disease and cancer. The benefit for the Icelandics was that any medicines generated by the study would be available free to the islands population. The current Icelandic population is 350,000 and was 250,000 in the mid 1990's. This is the equivalent of a small town in the UK. The deCODE company has now been sold to AMGEN, a large American pharmaceutical company.

A related UK project was the 100,000 genomes project. In contrast to deCODE, this was initially a non-commercial study. The project was founded to sequence 100,000 genomes from around 85,000 NHS patients affected by a rare, suspected genetic disease, or malignancy. In all cases, there was a rigorous consent process before samples were taken for genetic analysis. The project's other aim was to create a new genomic medicine service for the NHS, transforming the way people are cared for and bringing advanced diagnosis and personalized treatments to all who need them. It closed in 2018. The UK now has a strong genomics economy, which has led to the UK being able to have a significant contribution to the management of COVID19 infection.

There are potential barriers to optimum data usage. It would be useful for accurate ICD 11 diagnostic codes to be linked to NHS data. This would enable audit, research and proper evaluation and planning of services. It is important to investigate thoroughly the reasons why data are not shared, rather than just make data sharing compulsory. Mandating data sharing could lead to evasion by those who didn't want to share. Informed consent must be paramount in the data gathering process. Communication between different data platforms is important so that they can "talk" to each other and maximise utility of data collected in different ways. Training for those accessing data is ok, but this should be open to clinicians and should not create a new industry or profession of data gatekeepers. It is essential to continue to engage with clinicians so that the data collected are of use to clinicians in service improvement.

Dermatology in the UK has three large data projects facilitated by the British Association of Dermatologists (BAD) covering many of the common skin diseases;

1) BADBIR

This is a pharmacovigilance register for standard systemic and biological therapies in psoriasis. The chief investigator is Prof. Chris Griffiths (University of Manchester). BADBIR stands for the British Association of Dermatologists Biologic and Immunomodulators Register. BADBIR was formed in 2007. It is a British and Irish observational study seeking to assess the long-term safety of biologic treatments for psoriasis. The National Institute for Health and Clinical Excellence (NICE) has recommended that all patients in the UK receiving these therapies for psoriasis should be registered with BADBIR. Once a patient has joined BADBIR, they are followed up via their dermatologist to assess their clinical progression. There are currently over 160 hospital sites across Britain and Ireland taking part in BADBIR by recruiting participants to join the Register. There are over 18,000 registrations in the study, with more than 110,000 follow-ups entered. BADBIR has ethical approval to continue following participants to 31st July 2028. BADBIR receives funds for carrying out pharmacovigilance from pharmaceutical companies, but its views are independent. Although BADBIR has been a great success of British Dermatology, it has been difficult linking BADBIR to other key NHS resources that validate hospitalisation and cancer data for example.

2) A-STAR

This is a pharmacovigilance register for standard systemic agents and biological therapies in atopic dermatitis with an associated biorepository. The chief investigator is Prof. Carsten Flohr (Kings College, London). In 2017, colleagues from 17 UK academic and NHS institutions, as well as patient organisations, were awarded a strategic grant from the British Skin Foundation (charity) to set up the UK-Irish Atopic eczema Systemic Therapy Register (A-STAR). This group will identify the key clinical indicators to observe and study patients with moderate to severe atopic eczema with the aim of providing advanced diagnostics, drug efficacy, reactions and safety among other objectives. It is expected it will sustain its activities from collection of unbiased safety data on behalf of the pharmaceutical industry, similarly to BADBIR.

3) BAD-PHE

The BAD has formed a partnership with the National Cancer Registration and Analysis Service (NCRAS) which is part of Public Health England (PHE) to study the epidemiology of both basal cell carcinoma and squamous cell carcinoma in the UK. Since 2013, automated processing of the majority of basal cell carcinomas and cutaneous squamous cell carcinomas has resulted in improved data collection of skin cancers in England. Additionally, the BAD-PHE partnership, formed in March 2020, collaborates with cancer registries in Scotland,

Wales and Northern Ireland to gather UK-wide statistics and standardize skin cancer reporting. The strength of the partnership stems from its multidisciplinary team of clinical, epidemiology, data and analytical professionals supported by the wider expertise of both organisations.

In conclusion, the lessons from deCODE are clear. It is possible to monetize health data in an anonymous way and improve the public health of the population. The NHS should create similar opportunities in the UK, especially as pharmaceuticals is a large sector of the economy and the role of artificial intelligence in medicine is growing.