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How Equitable Data Sharing is key to realising precision medicine in APAC

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Asia's multi-ethnic population presents challenges and opportunities for precision medicine. Collaborative management and analysis of patient data are helping researchers in the Asia Pacific region to spearhead improvements in disease diagnosis, treatment and prevention. Hence there is a good scope for collaboration that will put Asian haplotypes at the heart of global precision medicine.

Targeting treatments to individuals is the panacea for precision and personalised medicine. It depends on a detailed understanding of the genetic profiles and molecular signatures that can be linked to disease. But to achieve this goal and ensure all patients can benefit from therapeutic innovations and novel prevention measures, researchers and drug hunters must test their hypotheses and findings on diverse populations that include all relevant genetic haplotypes.

Historically, Asian haplotypes have been underrepresented in patient biobanks and datasets used by researchers, mainly in the US and Europe, to develop novel therapies and treatments. Yet, in many parts of the APAC region, comprehensive datasets exist, and new ambitious population level programmes are underway, including the SG100K programme in Singapore and the National Orphan Disease Programme in Japan. These studies involve thousands of people representing the diverse population of the region, including Chinese, Malay, and Indian ethnicities.

It is these population level cohort studies, devised and led by local experts that will help redress the lack of Asian real-world data in global life science research. Such studies should enable researchers to identify the interplay between environmental, lifestyle and genetic factors that increase the risk of heart disease, diabetes, cancer and other chronic diseases prevalent in the APAC region.

To ensure the data can be used to benefit people across the region, leading Asian healthcare institutions are partnering with organisations which can provide the infrastructure to manage this copious and complex genomic data and make it accessible to researchers in a controlled, secure and equitable way.

For example, in Singapore, where efforts are underway to implement a National Precision Medicine programme, the Health for Life in Singapore (HELIOS) study has been established and led by the Lee Kong Chan School of Medicine at Nanyang Technological University. The study, which is part of the wider SG100K project to sequence the genomes of 100,000 Singaporeans, uses BC Platforms' TCE (Trusted Collaboration Environment) with BC/INSIGHT and BC/RQUEST to manage the genotypic and phenotypic data.

This new data infrastructure enables multiple data partners to securely share real-world data. It is paving the way for sustainable collaborations between partners at local and international levels and will accelerate innovations in research and development that transcend geographical and economic boundaries, improving healthcare outcomes for people across the region.

BC Platforms acts as a trusted adviser and has developed TCEs to enable researchers to analyse de-identified data in a tightly regulated and secure manner. With appropriate collaborative agreements in place, the platform provides an environment for different datasets from diverse locations to be combined as one virtual research cohort, with capacity to incorporate federated AI learning and other statistical approaches and facilitating polygenic risk score model validation across multiple haplotypes.

Creating virtual patient cohorts in this way will transform the way rare diseases, such as rare cancers, autoimmune diseases and neurodegenerative conditions, can be studied. Such innovations in data management also mean that researchers can robustly and repeatedly test findings on diverse populations expressing different haplotypes, accelerating the translation of research into clinical practice through rapid generation of translatable, actionable, research insights.

The scope for collaborative research is now almost limitless. With appropriate regulations in place, state-of-the-art data management infrastructure brings together diverse datasets, from low and high-economic regions, country-wide and international cohorts and facilitates equitable data sharing. This trusted data infrastructure provides immediate value by creating a secure and sustainable environment to investigate pathways underlying health and disease in Asian populations, locally and globally. Such collaborations will put Asian haplotypes at the heart of global precision medicine.

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