WHITE PAPER

The necessity of personalised data in precision medicine – A programme by Akrivia Health

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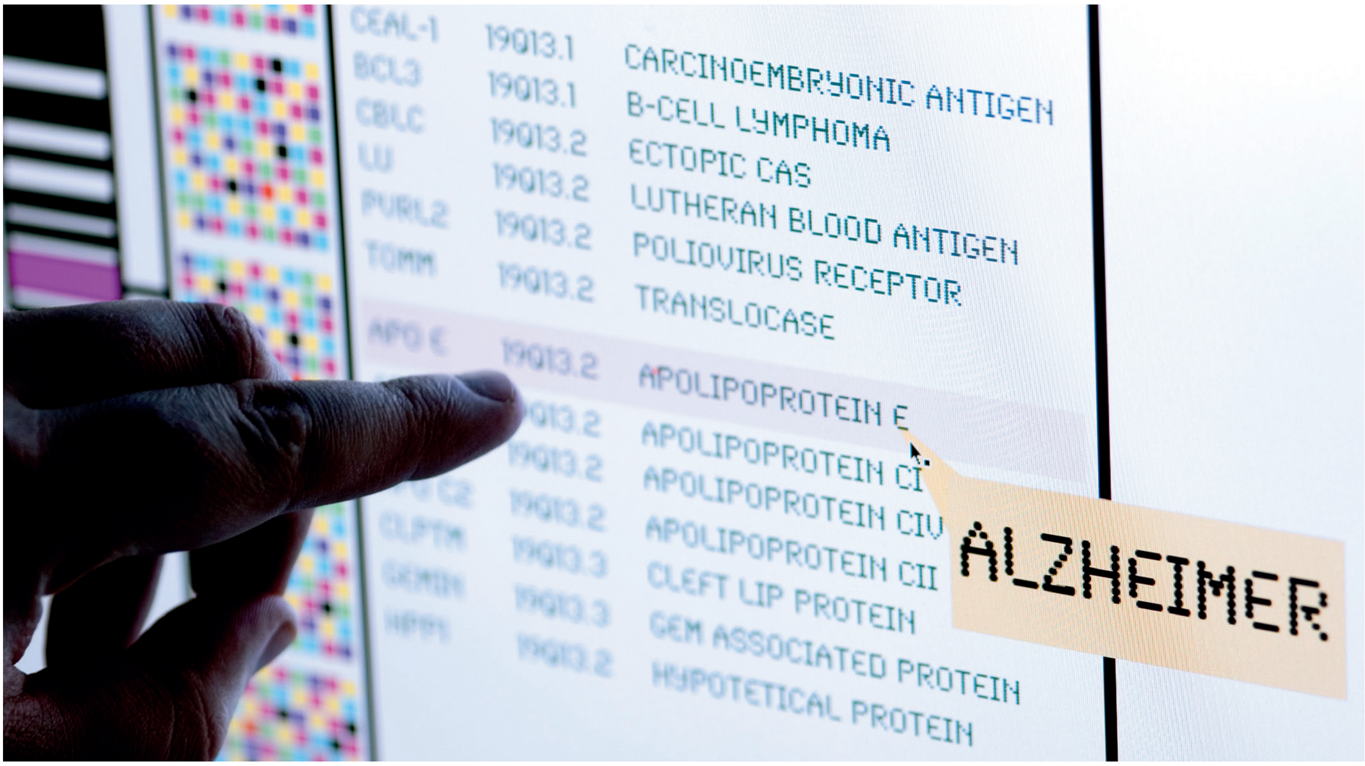

It is probably true to say one of the most terrifying aspects of Alzheimer's Disease (AD) is in its very nature as a disorder; a currently untreatable condition. Such an uncompromising word would, understandably so, lead sufferers and their family to despair upon a diagnosis. "Untreatable", Akrivia Health considers is a misleading term however. It may have no implications when considering the preventability of the disease and certainly it does not lead to it being untreatable in practice.

A most promising advancement in the research of Dementia, in particular AD, can be found in the clinicopathological results concluded from studies conducted on the current health data of those with the disease, that has been made available to researchers. Common symptoms are beginning to be supported by laboratory data such as individual genomics, in particular the presence of the ApoE4 gene, in a reversed cause and effect method of deduction. That is to say, common observed symptoms can now be used to trace back to the cause behind them.

Ultimately, it is the goal of Akrivia Health to provide research projects with the data needed to accelerate such insights. The vast amount of diagnosed sufferers of AD can be seen, in a most optimistic manner, as an advantage when attempting to find a treatment and prevention, not to mention the mis or undiagnosed sufferers showing signs and symptoms of this complex disease. Health data is invaluable when looking into such a heterogenous disease as it provides a standard of information into the typical physiological and environmental background of a patient with Dementia.

In 2019 Akrivia Health was launched from the department of Psychiatry in the University of Oxford. Initially, its purpose lay in innovating the electronic health records across much of the NHS. Our goal was to create a better structured, more unified record of patient data in the UK; something that could be accessed by increasingly modernising research organisations. Previously, patient records in the NHS and private health sector provided little aid due to their disorganised nature. In fact the majority of health data found on their servers was considered "dark", that is to say unstructured and for the most part un-actionable .

A far more organised data set was necessary for research because the previous system was not structured in a way where patients could be accurately compared, creating great difficulty in identifying what could perhaps be common causes of the disease. As of the start of 2022, Akrivia Health is sought to expand its data bank further by implementing additional data to aid in precision medicine approach. This method of treatment is especially

important in treating neurodegenerative diseases as it is tailored to individual patients through their molecular and clinical health records, rather than a generic model, what can be considered a “one size fits all” method of treatment.

This new programme will require the capture of more data, under study conditions, this time the collection of DNA samples from consented participants to map their individual genotypes. An individually tailored mapped genome creates a great advantage to precision medicine as the many thousands of genes and their millions of combinations can be plotted by artificial intelligence and the result of different gene interactions predicted based on symptoms of the participants with the same gene interactions. On a more simplified level, an increased ability for identifying cause and, crucially, predicting the hereditary nature of the expressions in the phenotype these gene interactions may cause (or possibly suppress) in individuals and their children.

Whilst this can be considered incredibly exciting by innovative researchers, it can only be natural for the majority of the public to be feeling rather excluded from how their data is processed. The idea of a data base containing millions of psychiatric records, such as past treatment, and now a proposed bank of individual genomics being accessible must be expected to lead to questions over data security.

In reality, no personal data is made available to researchers by Akrivia health, or indeed any other law abiding UK data organisation. The process of deidentification and anonymisation ensures that any identifiable information from health records is removed completely. The use of artificial intelligence to improve this data security is becoming increasingly prevalent in an increasingly digitised health system. GDPR legislation is followed completely to allow for transparency in data usage and authorisation for each user is required before these anonymised data are accessed in the secure UK Cloud environment in which they is held.

Every effort is made to ensure these increasingly useful data are protected to a full extent. There is no need for personal data in research, instead an anonymous bank of data points representing a huge range of mental health issues can serve just as much purpose in the research of such neurodegenerative diseases. Still, public inquisitiveness is encouraged to a great extent as transparency in data usage can only serve to benefit us all. Through increased understanding of what can be achieved by such a collaboration of health records and precision psychiatry, it is hoped data collection will be viewed with optimism as researchers seek to prevent and treat such diseases as AD.

1. de la Torre JC. Alzheimer’s disease is incurable but preventable. J Alzheimers Dis. 2010;20(3):861-70. doi: 10.3233/JAD-2010-091579. PMID: 20182017.
2. Elahi, F., Miller, B. A clinicopathological approach to the diagnosis of dementia. Nat Rev Neurol 13, 457–476 (2017). https://doi.org/10.1038/nrneurol.2017.96
3. Sienski G, Narayan P, Bonner JM, Kory N, Boland S, Arczewska AA, Ralvenius WT, Akay L, Lockshin E, He L, Milo B, Graziosi A, Baru V, Lewis CA, Kellis M, Sabatini DM, Tsai LH, Lindquist S. APOE4 disrupts intracellular lipid homeostasis in human iPSC-derived glia. Sci Transl Med. 2021 Mar 3;13(583):eaaz4564. doi: 10.1126/scitranslmed.aaz4564. PMID: 33658354; PMCID: PMC8218593.
4. Maju S.V., Gnana Prakasi O.S. (2022) Utilization of Dark Data from Electronic Health Records for the Early Detection of Alzheimer’s Disease. In: Shetty D. P., Shetty S. (eds) Recent Advances in Artificial Intelligence and Data Engineering. Advances in Intelligent Systems and Computing, vol 1386. Springer, Singapore. https://doi.org/10.1007/978-981-16-3342-3_16
5. National Research Council (US) Committee on A Framework for Developing a New Taxonomy of Disease. Toward Precision Medicine: Building a Knowledge Network for Biomedical Research and a New Taxonomy of Disease. Washington (DC): National Academies Press (US); 2011. PMID: 22536618.
6. Schwartzentruber, J., Cooper, S., Liu, J.Z. et al. Genome-wide meta-analysis, fine-mapping and integrative prioritization implicate new Alzheimer’s disease risk genes. Nat Genet 53, 392–402 (2021). https://doi.org/10.1038/s41588-020-00776-w
7. Mendes.O. (2020). custom NPL approaches to data anonymization. towards data science. https://towardsdatascience.com/nlp-approaches-to-data-anonymization-1fb5bde6b929. Doi (12/21).

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