

DNAdigest

- a non-profit organization to promote and enable open-access sharing of genomics data

The genomics revolution is upon us: the techniques for researching and characterising genomics diseases is available to both researchers (next generation DNA sequencing) and the general public (in form of personal testing like 23andme), so we should soon be able to diagnose any genetic disease by sequencing a patients DNA. This is the glorified goal of research into all genetic diseases, including hereditary diseases and cancer.

However, while data output is flooding research centres around the world, and genomics results published in high-esteemed journals, the sharing of the data that enables this research is embarassingly limited.

The data ownership, the legal consent of the patients involved, the privacy of the patients involved and the mere volume and complexity of these datasets are a major hindrance to sharing of personal genetics data. As a result, each research unit is currently maintaining their own 'silo' of potentially valuable sequence and patient data.

Needless to say, there may be several big genetic discoveries "out there" already sequenced, but not discovered, because noone has had the means to bring together the matching pieces of the puzzle.

The technological means to solve this problem are already existing and available, but no solution has been proposed until now, because demands a non-profit enterprise to sufficiently engage all stakeholders including researchers and patients and address their concerns while maintaining the goal: the advancement of genomics research.

I will present the underlying idea and strategic plan for how DNAdigest will enable researchers to publish their genomics data in an online open-access fashion without compromising patient consent or data privacy.