Plan Overview

A Data Management Plan created using DMPonline

Title: STRIVE: Studying The Retina In m.3243A>G disease to predict Visual and systemic outcomE

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Project abstract:

Inherited retinal diseases (IRDs) are an area of rapidly advancing therapeutic development, yet many promising treatments have failed in early clinical trials because existing outcome measures cannot detect meaningful change in slowly progressive, variable conditions. Mitochondrial disorders such as m.3243A>G related disease are an important subgroup of IRDs and provide broader insight, as mitochondrial dysfunction is increasingly recognised as a unifying pathological mechanism across IRDs. The retina offers a uniquely accessible system for detecting subtle neuronal changes relevant to both mitochondrial and non-mitochondrial disease. Building on pilot adaptive optics (AO) findings showing early photoreceptor disruption that conventional tests miss, this proposal will integrate high-resolution imaging, electrophysiology and psychophysical measures to define early structural and functional retinal change with far greater precision than current classifications allow. Longitudinal follow-up and parallel neurological assessment will determine how these retinal features relate to visual outcomes and systemic progression. These insights will inform a final stage evaluating AO-based cellular functional endpoints and the photostress electroretinogram (ERG) as novel, highly sensitive surrogate markers that capture residual photoreceptor function and may reflect underlying mitochondrial health. Together, this proposal aims to deliver robust, patient-relevant biomarkers that improve prognostic counselling and address a major barrier to therapeutic translation across mitochondrial and inherited retinal disease.

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STRIVE: Studying The Retina In m.3243A>G disease to predict Visual and systemic outcomE

Data and software outputs

The data and software outputs your research will generate and/or re-use

The main aim of the research proposal is to identify and validate novel retinal markers as surrogate endpoints that reflect visual level. As a result the main data outputs consist of these markers and include:

1. Adaptive optics processing data. The data that is acquired and processed to generate image datasets comprise of large .fits and .yaml files. These files are extremeley large and will be stored during the study on an encrypted external hard drive and archived/backed up via the secure file store server at Newcastle University, Research Data Warehouse.
2. Adaptive optics structural datasets. The final data set, used for analysis, consist of large image files comprising multiple (~7-15 per participant, per visit) .tif files of approximately 5,000 KB. Therefore the study is estimated to generate up to 8 GB (up to 105 visits, 15 images per visit; 1575x5000KB) of these type of datafiles.
3. Adaptive optics functional datasets. A small number of functional adaptive optics datasets will be generated from 10 participants at a single visit. These datasets will generate similar data files including videos and this is estimated to comprise a total of 10 MB of data.
4. Electrophysiological data. The raw data generated from electrophsiology will be stored (pseudonymised) on a secure database. The data will be shared as .TXT/.csv files or as figures. A secure archive of the data will exist on shared drives and external hard drives. The file size will be negligible.
5. Clinical imaging. Clinical imaging data will be generated and stored on the clinical database in an pseudononymised format (using participant/study ID as convention, identifiable information stored separately). Some pseudononymised data will be stored on shared drives used for the study.
6. Other study data. Other study data includes simple quantitative metrics such as visual level and demographic data which will be stored securely with all study data.

The metadata and documentation that will accompany the outputs

Relevant data to study outputs will be shared anonymised in research figures and supplementary materials where necessary.

When you intend to share your data and software

All arising publications will be made available in open access formats and will contain links to data locations where necessary. I will acknowledge the funding source in all publications and presentations.

My approach to research outputs management will be dynamic. I will review my output management plan on a yearly basis throughout the research lifecycle.

Where your data and software will be made available

All software developed as part of the study for data processing and analysis will be managed and shared via GitHub repositories.

How your data and software will be accessible to others

To enable long-term accessibility and validation, data will be stored in formats that are open and in common use (e.g., TXT, CSV, TIF, DICOM).

Whether limits to data and software sharing are required

All collected personal data will be handled in accordance with the Data Protection Act (1998), the Caldicott Principles and the Newcastle University and Newcastle upon Tyne Hospitals data management policies. Data will be anonymised as early in the study process as possible and study identifiers will be stored separately in a secure place. Typically, data will be collected using a paper-free method directly onto encrypted computers/laptops. No data will be permanently retained on these computers; at the end of each data capture, data will be securely transferred onto either encrypted external hard drive or secure server (research data warehouse). Any data collected in digital free formats, for example participant consent forms, will be stored in secure location, accessible only to members of study team.

How datasets and software will be preserved

Data will be archived via Newcastle Universities file store service, Research Data Warehouse.

Research materials

What materials your research will produce and how these will be made available

The proposal may generate analysis tools specifically for adaptive optics image analysis. These tools will be accessible via GitHub repositories.

Resources required

You should consider what resources you may need to deliver your plan and outline where dedicated resources are required.

For data storage hard drives and storage on file sharing platform Data Warehouse will be required with a minimum of 5TB of storage.

Intellectual property

What IP your research will generate

Previous IP related to adaptive optics system has been included in a patent application and is managed by its inventors. Future IP generated from the fellowship could include datasets, analysis tools, software and protocols.

How IP will be protected

Any IP generated from the fellowship will be managed by continued working with host and partner organisation and the Business Development manager at Newcastle University to ensure any tools developed and utilised are maintained and accessible post-award.

How IP will be used to achieve health benefits

Outputs and tools generated will be open-access and shared with the research community at the earliest opportunity to promote its use and increase benefit.

Provide the name and contact details for the person in your organisation (e.g. Technology Transfer Officer or Business Development executive) who can act as a point of contact for Wellcome in connection with the protection and commercialisation of this IP

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