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SOIN – *MI Data Lab*: Personalized Ophthalmology Through Collaborative Data Collection and Dynamic Patient Consent

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Abstract. The *Swiss Ophthalmic Image Network* (SOIN) is part of the *Swiss Personalized Health Network* (SPHN). SOIN contains a collaborative, clinical research environment, *MI Data Lab*, which allows privacy-preserving, data-driven, research. Personalized care of chronic ocular disease, based on Machine Learning (ML) and medical imaging, can dramatically improve quality of life and reduce the burden on health and social care systems. *MI Data Lab* allows research partners to consolidate their data in a space where doctors and data scientists cooperate to design novel ML algorithms, on curated datasets. To date, we have created several algorithms to detect ocular biomarkers automatically, and applied such tools to 100k+ retinal images. *MI Data Lab* enables the development of predictive models, the extraction novel traits to be explored in terms of -omic associations, treatment outcome, and priors for disease progression.

Keywords. Personalized medicine, research platform, dynamic patient consent, ophthalmology, SOIN, MI Data Lab, scientific IT services, sensitive data

1. Introduction

Machine Learning (ML) algorithms hold the potential to revolutionize personalized care of chronic ocular diseases. Research in ophthalmology is often hindered by proprietary formats, lack of dynamic patient consent, and difficulty of extracting complementary variables from patient records. These factors significantly hinder the creation of adequate training datasets for ML. The aim of the SOIN project is to address these issues by providing a collaborative space where data from consenting patients is seamlessly aggregated into study-specific datasets.

2. Methods

The *Swiss Ophthalmic Image Network* (SOIN) is part of the *Swiss Personalized Health Network* (SPHN). *MI Data Lab* (Medical Imaging Data Lab) is a collaborative, clinical research environment created during the SOIN project. *MI Data Lab* was built within BioMedIT, a secure infrastructure provided by the SPHN [1]. BioMedIT offers technical

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support for the onboarding of new users and the customization of user-specific spaces. Access to *MI Data Lab* is cloud-based, with double authentication, resolving accessibility and interoperability issues.

MI Data Lab, is a closed space, with no internet connectivity, where data import/export are technically and judrically restricted (in line with governance principles for data reuse). A unidirectional migration of medical data, images, and consent status has been established between the Jules-Gonin hospital's IT infrastructure and *MI Data Lab*. Data are transformed into open formats during the transfer process. A data dictionary is supplied for additional data fields, such as derived patient phenotypes. The data required are specified during project submission, and they are unpacked in a project-specific workspace: this way, basic data engineering tasks and common software needs are taken care of. Data access and user account management are performed centrally, per project. The iterative process of enriching available tools, software packages, and environments, continues to be the focus of the SOIN project.

3. Results

The proposed paradigm eliminates the need for a data transfer agreement, shortening the time from project conception to development, from years to weeks. To date, *MI Data Lab* has been used to extract ocular biomarkers from 100k+ retinal images, demonstrating its effectiveness.

4. Discussion

Data remain consultable by the clinician thanks to an embedded viewing software. The next objective of the SOIN project is to allow manual annotation tasks to be queued, and subsequently made available for review.

5. Conclusion

MI Data Lab facilitates rapid access to sensitive patient data to approved researchers, in a format and environment adapted to ML development needs. MI Data Lab aims to accelerate the development of predictive models and decision support systems, improving the quality/cost ratio of ophthalmic care and making important gains in personalized medicine achievable in ophthalmology.

References

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