NOVARTIS

Modality partnership

Project Name: Quality Improvement Project focusing on review of Inherited Retinal Diseases (IRD) Patients' electronic health records in Primary Care - Collaborative Working

Project Summary:

Piloting a nationally scalable, technology-driven approach to identifying "hard-to-reach" Inherited Retinal Diseases (IRD) patients in a primary care setting who may be appropriate for genetic testing, to unlock treatment options.

1. Deploy a case-finding algorithm on primary care Electronic Health Record to identify patients with an IRD diagnosis who have not received testing.
2. Review flagged IRD cases and refer for follow up if appropriate

Follow up with patient, secondary care Ophthalmologist, and General Practitioner (GP) to measure impact including patient agreement to referral, appropriateness of patients referred for testing, and increase in population eligibility for treatment or potential future clinical trials.

Planned Milestones:

Milestone 1: EHR Access & Processing

Milestone 2: Pilot Experience Survey Data Collection

Milestone 3: Pilot Outcome Report

Expected Benefits:

Anticipated Benefits for Patients:

- This project aims to support patients to access more information about their IRD diagnosis, this in turn will support patients to make informed decisions about their condition
- An IRD diagnosis and access to dedicated time with health care professionals to discuss their IRD diagnosis, will mean patients will benefit from improved awareness and clarification of molecular cause of their visual impairment
- Having an IRD diagnosis has potential for improved future treatment and/or management options for patients entered into further clinical studies
- Improved potential for eligible patients to access NICE approved medicines

Anticipated Benefits for Modality Partnership:

- By engaging with this Project Modality Partnership will have the opportunity to offer proactive care of patients with Inherited Retinal Disease
- The Project offers the chance for Modality Partnership to lead a pilot linked to Rare Disease Action Plan 20223 developed by the Department of Health and Social Care, and England Genetic Testing agenda4; with the potential to publish and share of outcomes with peers. For the avoidance of doubt, nothing in this Agreement shall be understood as an obligation to publish, and any such publication shall depend on

both Parties' agreeing such publication following the assessment of the outcome of this Project.

Anticipated Benefits for Novartis:

- Working collaboratively on this Project will support improved partnership alignment with Modality Partnership
- This Project supports Novartis' vision that no patient should have to wait for an extraordinary life; by engaging in this Project, Novartis has the potential enhance reputation nationally and internationally.
- The Project has the potential to increase identification of patients eligible for treatment with NICE-approved therapy, including that of Novartis.

Start Date & Duration: Start Date: November 2022 Duration: 8 months

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