Harnessing Generalizable Real World Ophthalmic Big Data: A Descriptive Analysis of the Bodhya Eye Consortium Model for Collaborative Research

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Abstract

Background: Recent advances in genomics and anthropology have confirmed that most Indian groups descend from a mixture of two genetically divergent populations: Ancestral North Indians (ANI) related to Central Asians, Middle Easterners, Caucasians, and Europeans; and Ancestral South Indians (ASI) not closely related to groups outside the Indian subcontinent. Studies of the north Indian populations are more generalizable to these aforementioned populations and thereby potentially have immense global health implications.

Objective: This conglomeration of genomic heterogeneity is unique in the world to north India.

Methods: We describe the development and successful implementation of a formalized consortium in north India with infrastructure incorporating standardized approach to patient data collection, clinical and research governance and checks and balances.

Results: The volume of patients seen means that this data is not only big but also relatively rapidly acquired.

Conclusions: Collaborative research from north Indian high-volume eyecare organizations provides an opportunity to harness this potentially invaluable generalizable data.

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Title: Harnessing Generalizable Real World Ophthalmic Big Data: A Descriptive Analysis of the Bodhya Eye Consortium Model for Collaborative Research

Abstract:

Background: Globally eyecare organizations and personnel are increasingly trying to bridge the gap between population health and medical practice. Recent advances in genomics and anthropology have confirmed that most Indian groups descend from a mixture of two genetically divergent populations: Ancestral North Indians (ANI) related to Central Asians, Middle Easterners, Caucasians, and Europeans; and Ancestral South Indians (ASI) not closely related to groups outside the Indian subcontinent. Studies of the north Indian populations are more generalizable to these aforementioned populations and thereby potentially have immense global health implications.

Objective: The Bodhya Eye Consortium is a collaboration between eight high-volume non-profit eyecare organizations, from across north India. The aim of the consortium was to harness real-world data in a consistent, quality assured manner for collaborative research. This paper describes the formation of the consortium as a proposed model for controlled collaborative research among leading eyecare organizations of north India.

Methods: We describe the development and successful implementation of a consortium through a formalized road map consisting of: Planning and Assessment, Setting up and Exploratory Task Force, Defining Speciality Areas, Setting Up Objectives/Prioritising, and, Defining Strengths, Weaknesses, Opportunities and Threats. Key amongst this was the data audit conducted to standardize the data collection process across the participating organisations.

Results: Currently, nine organisations constitute the consortium, and the governance structure has been setup to represent the inputs of all members through the Governing Council. The scientific standards for the research being published through the consortium is set and monitored by the Scientific Committee, and the Conflict Resolution Committee handles any unresolvable disputes, if any. The working groups structured across the different eyecare specialities collaborate to conduct research and are coordinated through virtual interactions. The foundation of this research is the organisation-wide data audit where most organisations were found to be compliant with accurate and standardized data collection and reporting, and those missing more than 10% of the information provided action plans to remedy the same. This led to the use of data collection proformas within the consortium and has resulted in the publication of high quality manuscripts with merits such as low dropout rates.

Conclusion: Collaborative research from the Bodhya Eye Consortium: a group of mainly north Indian high-volume eyecare organizations provides an opportunity to contribute to scientific knowledge in various domains of eyecare as well as harness the established heterogeneity of anthropological and genomic origins allowing the findings in this population to be generalizable, to an extent, to European, middle Eastern and European American populations, giving them access to potentially invaluable generalizable data. The consortium has major global health implications and possibilities for collaboration. The model provided in this descriptive paper may be used by other healthcare organizations to develop similar collaborations for research and knowledge sharing.

Keywords: Anthropological and Genomic Heterogenity; Big Data; Consortium; Collaborative Research**;** Generalizability; Global Health Impact; North India

Introduction

Globally eyecare organizations and personnel are increasingly trying to bridge the gap between population health and medical practice. Recently, an emphasis has been placed on alliances to expand capacity [1], leading to an emergence of public-private partnerships and co-operation between governmental policy makers and high-volume non-profit eyecare organizations [2].

Crucial to developing generalizable knowledge for public health initiatives from any data, is the population being studied. In India, most non-profit eyecare organizations conducting clinical and epidemiological research and providing baselines for almost every ocular affliction [3-6], are concentrated in the south of the country. While this data is invaluable, is it generalizable to other populations outside India? A look at the world of anthropology and genomics shows that recent advances have confirmed what many had already suspected: most Indian groups descend from a mixture of two genetically divergent populations: Ancestral North Indians related to Central Asians, Middle Easterners, Caucasians, and Europeans; and Ancestral South Indians not closely related to groups outside the Indian subcontinent [7]. Contrary to the homogenous south Indian population, north Indian populations are more heterogenous and similar to Middle Easterners, Central Asians, and Europeans [7], and thus consequently to Euro-Americans. Therefore, studies of the north Indian populations are more generalizable to these aforementioned populations and thereby potentially have immense global health implications. This conglomeration of genomic heterogeneity is unique in the world to north India. Developing a network of institutions across north India for collaborative research would seem on the face of it, an ideal opportunity to harness this fortuitous fluke of anthropological and genomic serendipity, to acquire real world big ocular data [8]. Real-world data refer to observational data as opposed to data procured from a randomized controlled trial. Bian et al showed via a systematic scoping review of the literature that data quality with real world data is not consistent in the literature due to its complex and heterogeneous nature [9].

The Bodhya Eye Consortium is a collaboration between eight high-volume non-profit eyecare organizations, from across north India. This paper describes the formation of the Bodhya Eye Consortium as a proposed model for controlled collaborative research among these leading eyecare organizations of north India. The aim of the consortium was to harness real-world data in a consistent, quality assured manner.

Methodology

We used a road map consisting of several components:

Planning and Assessment

The idea for the consortium originated from a global eye genetics consortium where a few organisations such as ours were also participants. Thus, the organizations approached for the Bodhya Eye Consortium were those that had similar structures and were already interacting with each other at various common forums such as the genetics consortium. These organizations have been in these settings for a period of at least 10 years before joining the consortium. Ten high patient volume organizations from north India were invited to form the consortium, based on the location of the main eye hospital and catchment areas. Initial discussions, conducted on digital platforms, consisted of joint weekly virtual meetings for twelve months.

Setting Up An Exploratory Task Force

These discussions were followed by an exploratory task force establishing shared goals, defining commitment necessary to achieve them and acquiring commitment of leadership at the institutions. There followed an in-person meeting at a mutually convenient eye hospital based in Delhi where the consortium’s scope and structure were established, and the legal status of a consortium discussed- forming a clear shared clinical and research governance structure for future projects and funding applications.

Defining Specialty Areas

Within ophthalmology the specialty areas are cataract, cornea, retina, pediatric, glaucoma, oculoplastics, public health and ocular microbiology. Working groups were formed based on these specialties. Each group consists of specialty related representatives from each member organization.

Setting Objectives/ Prioritizing

The objectives defined in the initial discussions were building capacity for research and sharing knowledge. A consensus led focus was to conduct high quality research culminating in publications of scientific papers in top-ranking ophthalmological journals. A list of these was determined by looking at both the h-index and median h-index of each Medline cited ophthalmology journal, as well as the published journal impact factors. Further objectives were to organize funding for research, as well as, to ascertain robustness of data collected and shared across the consortium organizations, through a data audit.

The data audit was conducted for all participating hospitals, with an aim to ascertain whether patient information was entered in the face sheet (first page) of the patient file, and whether it was done accurately. The audit process followed established protocols and was conducted by trained auditors at each centre through a standardized proforma. 20 files from each of the ten organisations were chosen through a predefined methodology to ensure randomization. Each day, a number was randomized ,and the patient accessing services at that number from the hospital, had their file chosen, for five working days. This resulted in five patient files per week, over four weeks.

Basic patient information such as the unique identifier, name, age, gender, contact number, address and date of examination were noted. The presence of primary and secondary diagnosis, ICD coding, procedure or surgery performed, complications, and consent for procedure were also noted. The variables and their coding have been displayed in Table 1. Proportional analysis was performed in the form of percentages.

Variable	Coding Based on Presence on Facesheet

Name	Yes	No			
Age	Yes	No			
Gender	Yes	No			
Contact Number	Yes	No			
Address	Yes	No			
Date of Examination	Yes	No			
Primary and Secondary Diagnosis on Facesheet	0: None entered	1: Primary diagnosis incomplete or missing for one eye and important diagnosis not entered	2: Primary diagnosis incomplete or missing for one eye but important diagnosis entered	3: Primary diagnosis complete but speciality absent (where applicable)	4: Primary and speciality diagnosis complete
ICD Coding	0: None entered	1: Incomplete (part of diagnosis missed)	2: Complete but inaccurate	3: Complete and accurate	
Procedure/Surgery	0: None entered	1: Entered but incomplete	2: Complete but without date	3: Complete with date	
Complications	0: Not entered	1: Entered	2: Not applicable		
Consent for Procedures	0: Absent	1: Present	2: Not applicable		

Table 1: Variables and their coding for the data robustness analysis [Original].

Defining Strengths, Weaknesses, Opportunities and Threats (SWOT)

A SWOT analysis of the Bodhya Eye Consortium, and its’ working, was conducted.

Results

Planning and Assessment

During the initial tele-discussions, two organizations dropped out, having expressed their inability for a sustained contribution. However, about four years after intitally bowing out, one of these two organisations became a part of the consortium again, having established their catchment area and being able to provide sustained input. In recent years, more organisations from across India, not just north India have been included, which differ from existing organisations in terms of research capacity, geography, or experience in the community. This is another factor that ensures that the consortium's research have external validity to populations outside of just north India.

Setting Up An Exploratory Task Force

The governance structure of the BEC was formed (Figure 1). Within each level of governance, all the organizations are represented equally and thus, the roles are similar across all organisations. The Governing Council consists of the Heads of Institutions of Bodhya Eye Consortium member organizations. The Scientific Committee, sets research standards through guidelines for ethics and authorship in conjunction with the Governing Council and consists of two appropriately trained members from each organization, nominated by the Head of each Institution, and having a keen interest and experience in research. It also has members from varying backgrounds – clinical from different sub-specialties, public health and basic sciences including genetics. This helps in keeping the research topics relevant and innovative. The Scientific Committee is administrated by the Lead Coordinator (non-voting member). A Bodhya Eye Consortium Project Manager tracks timelines of all projects and ensures continued progress, reporting directly to the Governing Council. The Scientific Committee and Governing Council play important roles in maintaining the standard and quality of research and being the key decision-making and regulatory body of the BEC, respectively.

Therefore, their role also entails ensuring that everything is above board in terms of all legal requirements. As members of both these committees are also in senior positions within their own organisations it part of their day-to-day working to be above board on these matters.

To manage any potential conflicts arising from the sharing of intellectual property and data across multiple organizations and assign credit where it is due, especially with respect to authorship, a conflict management committee was established, reporting to the Governing Council. The committee is headed by an external member of the consortium, i.e, a member not a part of any of the collaborating organisations within the consortium. This committee primarily exists to arbitrate any disputes arising within subgroups that cannot be handled through conversation, such as authorship concerns. The presence and structure of Institutional Review Boards and Ethics Committees was also confirmed across all organizations.

Defining Specialty Areas

The specialty focused working groups are the virtual fora where members discuss, develop and conduct research. The decision-making for research topic selection takes place at the working group level, which consist of specialists in the field.

Typically, one member from an organisation will pitch a research topic to the group, with a small write up which is then circulated across the subgroup members, who go through the same and discuss any modifications, as well as their centres’ ability or inability to participate in the same. Once the centres participating in that particular study are finalised, they make a proforma for data collection and also initiate IRB approval proceedings at their respective centres prior to initiation of data collection.

Overall standardisation and quality of research topics within the consortium is assured by the Scientific Committee through detailed reviews of the study proposal. The study is led by the member or centre pitching the research proposal and once the proposal is finalised and the lead centre has received IRB approval for the same, the study lead submits the proposal to the scientific committee for review. Once the scientific committee provides feedback, the study lead makes alterations to their proposal based on the same and resubmits to the Scientific Committee for review. Upon receipt of a go ahead from the scientific committee, the data collection process begins.

This process ensures that each subgroup is able to conduct more than one study at the same time, and also allows leeway to different centres to decide their own contributions, while allowing for different members to lead their own studies and see them through. The establishment of research processes, authorship guidelines, by the SC also fortifies this process. The scientific committee also reviews the final manuscript of each study prior to submission. They look into the scientific relevance of the manuscript, the value added by multi-centric involvement, and how that has been presented in the manuscript.

These working groups are are led by conveners selected from within each working group, who rotate every three months and ensure that research guidelines, and task deadlines are followed. Administrative support for the working groups is provided by coordinators, one from each center, who keep meeting minutes, track emerging tasks, coordinate with other consortium centers and stakeholders. Quarterly updates by conveners to all the consortium members regarding progress in their subgroup, encourages cross-germination of ideas.

Virtual monthly interactions foster cooperation, collaboration and mutual respect, for all participants with real time discussion and debate. They also lead to knowledge exchange and build capacity within member organisations. This is shown directly from the establishment of virtual grand rounds, and research workshops. Virtual grand rounds are a monthly knowledge sharing platform, open to all clinical personnel from member organizations, conducted by each specialty area by rotation. Research workshops are conducted to engender a research ethos by training all staff about the importance of research, forming research questions, conducting literature reviews, interpreting statistical analyses, and reading journal articles. These workshops are open to all the clinical and research staff of the consortium hospitals; encouraging discussion both in-person, and virtually. They are held at member organisations by rotation. One example of a very impactful knowledge sharing workshop, was the microbiology training, which helped each site meet the basic microbiology requirements. Two to three paramedical personnel from each partner institution attended the microbiology department of one of the founding members of the consortium over a period of six days each. Theoretical materials and starter kits containing stains and slides were also distributed during this training of trainers, to initiate basic microbiology services for improving keratitis diagnosis at their hospitals, and establish a network for upcoming research projects.

Setting Objectives/ Prioritizing

One of the foremost activities to ascertain robustness of data was to conduct a file audit with an intention to standardize routine data collection processes across the member organizations, prior to formal initiation of research and data sharing within the consortium. A total of 200 randomly selected files were audited across all ten participating organisations at the time.

All 200 files (100%) reported the patient’s name, age, gender, contact number, address, and date of examination. 130 of 200 files (65%) reported the complete diagnosis, both primary and specialty, while 25% (50 of 200) reported only the primary diagnosis: the specialty diagnosis was applicable, available in the detailed clinical records yet missing from the diagnosis cell. Only two (4%), one

(2%) and seven (14%) files from 200 had incomplete diagnosis with the important portion entered, had incomplete diagnosis with important portion missing, and had none entered, respectively. 81% (162 of 200) files had complete and accurate ICD coding. 5% (10 of 200) and 4% (8 of 200) files had complete but inaccurate coding, and incomplete coding, respectively. 11% (22 of 200) files did not have ICD coding. 79% (158 of 200) files completely reported the procedure or surgery undergone by the patient, with date. One file each (2%) had the procedure or surgery written without the date, and was incomplete, respectively. 19% (38 of 200) files did not have the procedure or surgery entered. 92% (184 of 200) files had reported the patients' consent to undergo the procedure or surgery, while the remaining 8% (16 of 200) files did not.

All the organisations participating in the Bodhya Eye Consortium collect and store data using electronic medical records, therefore, fields which were missing more than 10% data were highlighted to remedy practices for clinical data-based studies. Organizations identified their respective deficiencies, formed action plans to rectify the same, and implemented them. Organisations joining the consortium in the future underwent the same data audit process.

This activity then led to the use of proformas to aid recording of reproducible and accessible data within working groups. An example of this would be for pediatrics, where not only was data on a patient's vision important, the method through which it was acquisitioned was as well. Proformas were also used to collect information from patient notes and a feasibility form was circulated prior to studies being proposed to establish the nature of clinical and research operations at each center. Based on this, each center decided on their ability and capacity to participate in each study proposed through the consortium subgroups. Thus, not all centres participate in all studies. This allowed us to plan, execute and publish our first study [10], which had participation from three of the consortium centers. Some variations are natural in clinical practice, but we make sure that all planned research has uniform diagnostic and treatment practices amongst the centres participating in that particular research. At present, data heterogeneity is addressed at the start of the research endevour and generally leads to exclusion of the centre not able to meet the required standards.

Focusing on the objective to publish a high-quality manuscript, the first study, describing the clinical features, visual acuity, and causes of ocular morbidity in 532 children (0-18 years) from north India who had microphthalmos, anophthalmos, and coloboma, conducted under the aegis of the consortium has been published by a major international journal [10]. The data that needed to excluded because of quality was less than 2%. Since then the collaborative efforts have led to the successful completion of various research projects based on retrospective and prospectively collected data: a further eight peer-reviewed studies have been published or accepted by international and national journals [11-16]. At present the consortium's research effectiveness is measured through its ability to publish such high-quality research.

Define Strengths, Weaknesses, Opportunities and Threats (SWOT)

SWOT analysis has been detailed in Table 2.

Strengths	Weaknesses	Opportunities	Threats
• Abundance of talented providers and scientists within member hospitals. • High-volume clinics allowing access to big data. • Determination to establish a strong pedigree of research and clinical excellence. • Extraction of quality retrospective data.	• Time as a limiting factor in terms of planning and conducting organized research- stresses that come with working in regular eyecare service delivery organizations. • Lack of a central monetary source. • Lack of a data sharing agreement	• Funding for research and administration.	• Dependance on social media platforms and security of conducting regular communications and sharing medical data.

Table 2: Strengths, Weaknesses, Opportunities and Threats of the Bodhya Eye Consortium [Original].

Discussion

The BEC was formed by establishing a formal collaboration between pre-existing, high volume, clinical eye centers in north India. Literature on the formation of such a collaborative process is limited [17], especially in eyecare. The Bodhya Eye Consortium was founded using a standard approach to develop an organization and determining needs such as: standardization of data collection systems [18], establishing research protocols and guidelines, training the correct personnel and utilizing cutting edge tools, techniques and technology to advance functioning and knowledge. The value of such a consortium lies in its varied geographic location and robust inter-institutional collaboration.

Being a diverse country, inhabited by, and representing populations of varying demographics, India provides a rich pool for genetic analysis with the potential to deliver significant impact across the world [8]. The unique geographical location of the Bodhya Eye Consortium makes studies with globally generalizable (except Africa) data possible [8], as do the large patient numbers for whom high quality big data has been collected through this collaboration of non-profit eyecare organizations. This plays a huge role in advocacy, and has the potential to influence the priorities of the government in terms of allocation of funds for research and disease control, to eye care in general and to some conditions in particular.

This collaboration has been made possible by utilizing digital platforms, which not only streamlined communication, but also prepared the Bodhya Eye Consortium to continue functioning despite the Covid-19 pandemic, and subsequent lockdown [19]. Collaborative multi-centric research is propelled by a desire to improve data to help our patients [20], and this is driven by the constant zeal and engagement of clinical researchers interested in translational work.

Grand Rounds and workshops have allowed an improvement of skill and knowledge levels and developed a better understanding of research methodology. Once the consortium’s bank account is established, the pooled funds will provide us the ability to advertise these on our website and open them up to the larger public, based on their demand as well. This progressive approach has already led to working with organizations such as the Global Eye Genetics Consortium [21], providing hitherto rarely accessible resources such as guest speakers and subject experts from across the world- opening new thought pathways and developing networks.

The scientific committee is also working to develop advanced policies for authorship, data sharing and research processes. Having more in-person meetings and collaborative sessions would also improve interdisciplinary collaboration within the member organizations of the consortium. Member organisations already have scientists, genetic and public health specialists and microbiologists as a part of their representation to subgroups, over and above clinicians, and thus new inter-disciplinary studies are being explored through the consortium, where these personnel bring different perspectives to the table.

To ensure that all personnel are proficient in research methodologies and data management, the scientific committee implements regular workshops to enhance these skills and is planning a series of online continuous workshops and activities for the same. Discussions are also underway to make it mandatory for principal investigators to have undergone training and received certification for the same from handpicked institutions, prior to their study proposal being greenlit by the scientific committee.

As a foundational activity, the data audit has been especially beneficial to control quality and accuracy of data during data collection and thus overcome drawbacks persisting in even retrospective studies [22-23]. Once the consortium opens a joint bank account and starts sharing finances, a travelling manager will be hired to travel across organisations, assuring standardization in data collection practices, quality, and storage, as well as, consent procedures. This will help us enhance the consortium's data collection methods to ensure better standardization and more consistent quality across all member organizations [24]. At present the analysis for the consortium studies are being performed by the biostatistician of one of the participating centres who is allocating around 20% of their time the consortium studies, even those not led directly by the center employing the biostatistician. Similar to the travelling manager, in the long-run we will hire a biostatistician devoted entirely to the Bodhya Eye Consortium.

Upon acceptance of the first publication under the aegis of the Bodhya Eye Consortium [10], the editors stressed that the high quality multicentric data was a key strength of the paper, as were the large number of patients examined and included in the study in a short time. Furthermore, the use of proforma driven data recorded during consultations meant that although this was a retrospective study, the low (2%) patient exclusion rates, made the research valuable in the field, subverting the need for techniques to overcome data “missingness”[25]. Currently, there are almost thirty more studies underway, at various stages of the writing and submission process, with six already published, and two more accepted [11-16]. While at present the consortium is in a nascent stage and the impact of its research is being measured primarily thorugh publications, in the medium to long term, as we grow more impactful in terms of health policy and behaviour, we will expand our considerations to not only include impact factors but also other relevant factors. Further, as we develop a mechanism to setup a common pool of resources, we would be able to attempt publication in higher impact factor open access journals as most of them have a stipulated publication fees. We would then be in a position to track the impact factors, and citation counts as quality indicators for journal reach, prestige and impact. At present, all members currently in the BEC have participated in an audit for standardization, scaling up will definitely also bring more variables into play.

Although the initial working has been kicked off through retrospective “data only” studies, alongwith a limited number of prospective studies, future work involving expansive prospective studies and biological samples will increase the cost of research as groundwork is needed for the same in terms of protocols and monitoring activities. While it is encouraged to initiate vast prospective studies and collect biological samples, the consortium needs an expansive and reliable framework through which public health and clinical studies can be streamlined, before larger studies, where biological tissues are collected, can be considered.

As the consortium research intensifies, strategies can be implemented to overcome the time constraints faced by researchers and clinicians involved in the consortium. These can range from incentivization of participation in research by allocating dedicated time to senior faculty for research, to provision of administrative support so that the clinicians’ time is only used for research activities. Additionally, at present the consortium’s engagement with the community is limited to the research work that has been performed such as a study to understand the Awareness, Knowledge and Challenges faced by beneficiaries and non-beneficiaries of Ayushman Bharat- Pradhan Mantri Jan Arogya Yojana, with has been accepted for publication by a renowned peer-reviewed journal. However, as we conduct more such studies which actively engage with the local communities, such as need assessments and qualitative studies, it will provide us evidence through which we can put in more systems to strengthen the impact and relevance of our work and therefore more such studies are being rolled out within the BEC. An example of this would be in the Glaucoma subgroup where we are looking at the awareness of glaucoma and another one in the public health subgroup where we are attempting to understand the level of awareness about eye health in rural women. As we conduct more such studies, we will also plan to use different platforms to disseminate our findings and using the evidence for advocacy.

Further, in current times, with many social media platforms constantly changing their privacy and encryption policies, sharing even anonymized medical data is a grave concern, however communications are constantly monitored and patient data is never discussed over social media. Despite that, in light of changing social media privacy policies and the new Digital Personal Data Protection Act, 2023 [23], a more robust and secure data sharing platform is the need of the hour. The new act allows legitimate use of medical data wherein a patient enrols themselves voluntarily [26]. However, as research is exempt from legitimate use by the act, updating patient consent forms to include data sharing for collaborative consortium research across the organisations part of the consortium becomes imperative to allow reprieve. In the medium to long run, the BEC can harness the need for a secure data sharing and communication platform, and with the help of relevant professionals develop digital infrastructure customized to its needs. A platform dedicated to medical and health research enabling encrypted communication, with provisions to safeguard privacy and follow all legal statutes for sharing medical data is the aspiration. One such platform is currently being tested by a member organisation at the individual level and based on their experience will be brought into use for the consortium. These resources are important to maintain validity and quality of the data on which research is based, as well as deliver higher impact through prospective studies.

The first step to securing sustainable funding for ongoing and future research projects would be establishing a legal data sharing agreement and then opening a joint bank account to share financial responsibilities. This activity has already been initiated and would enable the consortium to apply for joint national and international research grants. Some funders already associated with these organizations for service delivery would also be approached. The programmatic sustainability of the consortium is currently maintained through regular meetings of the subgroups, and other bodies of the consortium, as well as quarterly meetings, and the established monitoring and motivating mechanisms. The financial sustainability will be important in the medium to long term when the consortium opens a joint bank account and established a Finance Committee. Thus, developing appropriate financial mechanisms such as processes for common fund contributions, fund raising for grants, and disbursement of these grants will be a priority. Funding would also be helped by the publication of a descriptive methodology paper, positioning the consortium in scientific fora.

At present, the Heads of the Institutions are working to reach and sign a conclusive legal and financial agreement. Since the Indian Ministry of Law and Justice has introduced an Act to govern and regulate healthcare data [26], it becomes necessary to hasten this processes in accordance with the same. We keep updating our practices as per the latest data protection act and its modifications. Some of the organizations are already arranging regular good clinical practice training for all the researchers and we plan to roll out the same for all the organizations once we have the necessary resources. Till the time a uniform data sharing agreement can be adopted, for each research endeavor only anonymized data is being collected through proformas to facilitate ease of working at the subgroup level, and each institution takes separate approvals from their respective Institutional Review Boards and Ethics Committee-a time consuming process from beginning to end [27]. Further, the study lead also has to apply for, and get, Scientific Committee approval which focuses on the relevance of the proposal as a multicentric study and the positioning of the Bodhya Eye Consortium within it. To streamline this process, we are working to get Institutional Review Board credentials for Scientific Committee members as representatives of each member organisation, and also include external members from the United Kingdom and/or the United States. This will enable principal investigators of consortium studies to get uniform approval at the central level, over while also receiving detailed feedback, before applying at the individual organisation level.

In the short to long term, good financial practice and well-structured transparent systems, along with significant publications such as the one already secured, could attract grants for global research as well enable the consortium to create a monetary fund to finance the activity of the consortium and establish encrypted data sharing structures. Thenon the consortium can also focus on furthering its reach and impact in global health, beyond the current genomic and anthropological focus, given that amongst its collaborators are a group of diverse members: basic scientists, clinicians, public health researchers, epidemiologists, etc. Consortium-wide collaborations with existing individual collaborative organisations at the International Centre for Eye Health, London School of Hygiene and Tropical Medicine, the University of Wisconsin–Madison, the University of Iowa, and the University of Pittsburgh, can also be planned, and executed. These are the administrative objectives for the consortium.

The consortium also has some future scientific objectives which align with the global health research agenda [28-29]. For example, in line with the focus established by the World Health Organisation and the International Agency for the Prevention of Blindness: effective cataract surgical coverage, refractive error, and myopia. Collaborative studies are already ongoing on all of these in various sub-groups. In the long term the endeavour is to move towards advocacy and policy influence through high-quality, high-volume research.

Conclusion

Our consortium provides a unique opportunity to members enabling them to contribute to scientific knowledge in various domains of eyecare. Unique to the population of north India is the established heterogeneity of anthropological and genomic origins allowing the findings in this population to be generalizable, to an extent, to European, middle Eastern and European American populations as well. The consortium has major global health implications and the model provided in this descriptive paper may be used by other healthcare organizations to develop similar collaborations for research and knowledge sharing.

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Authors' Contributions:

IS: conceptualization, formal analysis, methodology, validation, visualisation, writing-original draft, writing- review & editing; SS: conceptualization, formal analysis, methodology, supervision, validation, visualisation, writing- review & editing; UM: conceptualization, methodology, project administration, supervision, validation, visualisation, writing- review & editing; EJ: conceptualization, project administration; MB: conceptualization, project administration; DA: conceptualization, project administration; AK: conceptualization, project administration; VM: conceptualization, project administration; AM: conceptualization, project administration; VG: conceptualization, project administration; SK: conceptualization, project administration; KKN: conceptualization, methodology, supervision, validation, visualisation, writing- review & editing

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Figure Legends

Figure 1: Governance Structure of the Bodhya Eye Consortium (BEC).

Supplementary Files

Figures

Governance Structure of the Bodhya Eye Consortium (BEC) [Original].