Meeting pack

National eye research collaborative forum

Initial meeting

28 April 2021

This paper has been developed to provide attendees with background information to the forum.

It has been informed by data collected through the pre-forum survey, and at various points identifies some **questions that forum attendees are encouraged to consider as preparation for the forum discussions.**

It is important to note that research priorities identified in the recent Lancet Global Health Commission report on Global Eye Health have been used as the initial basis for identifying priorities.

While these have a service development focus, it is envisaged that the eventual list of priorities that will be developed through this forum and subsequent engagement will include **a balance of both discovery and translational priorities.**

The forum will be hosted by Vision 2020 Australia, and will be facilitated by Ms Ivana Gillard.

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Agenda

		Indicative timing
1.	**Welcome, purpose of forum, housekeeping, introduction of facilitator**	1:30 – 1:35
2.	**A national eye research collaborative – the journey thus far** Professors Peter McCluskey and Bill Morgan	1:35 – 1:45
3.	**The international experience – the impacts of collaboration in the UK** Professor Keith Martin	1:45 – 1:55
4.	**A case for change – the lived experience perspective** Mr John Simpson	1:55 – 2:05
5.	**Principles to guide collaboration** Professor Lisa Keay	2:05 – 2:15
6.	**Questions and comments**	2:15 – 2:40
	BREAK	**2:40 – 2:45**
DEVELOPING CROSS-SECTOR PRIORITIES – SMALL GROUP WORK		
7.	**Overview of purpose of session** Ivana Gillard	2:45 – 2:50
8.	**Setting the scene: The Lancet Global Eye Health Commission Research priorities** Hugh Taylor	2:50 – 3:00
9.	**Small group discussion 1**	3:00 – 3:20
10.	**Small group discussion 2**	3:20 – 3:35
	BREAK	**3:35 – 3:50**
11.	**Voting on priorities**	3:50 – 4:00
12.	**Reviewing initial results – facilitated group discussion** Ivana Gillard	4:00 – 4:25
13.	**Wrap up and next steps** Judith Abbott	4:25 – 4:30
	CLOSE	**4:30**

Instructions for videoconferencing:

1. To join the research forum, please click this link https://www.eventbrite.com.au/x/national-online-forum-developing-cross-sector-priorities-for-eye-research-tickets-143663899591

Introduction and context

Over the years, various parts of the eye health and vision sector have highlighted the challenges of securing sufficient funding to support research activities.

In other sectors, a collaborative approach to identifying and advocating for research priorities has been successful and similar experiences have been reported internationally.

Vision 2020 Australia has agreed to co-ordinate a process to support such an approach in Australia, if feasible.

As a first step, it has coordinated a national online forum to facilitate a cross sector discussion around how such an approach might be progressed and what priorities might be for cross sector advocacy.

This is an initial opportunity for a diverse range of individuals with an interest in the area to start connecting around the shared goal of increasing investment in eye research. The discussion and priorities identified through the forum will help shape how such a collaboration might be taken forward in what will, if supported, be a process spanning some months to develop a cross sector approach.

Purpose of forum

To discuss and agree an initial list of potential eye health and vision research priorities that could be developed as the basis for advocacy to secure increased funding for eye and vision research, enhance outcomes for the Australian community and enhance Australia's reputation as an international leader and innovator.

Background

In the United Kingdom, a collaborative, cross sector approach to agreeing to priorities for research and advocating for funding has proven successful in securing resources to enhance eye health and vision research.

In response to requests from its members, Vision 2020 Australia has agreed to explore the potential establishment of a national eye research collaborative in Australia to achieve similar goals. This would be a diverse, inclusive, multidisciplinary collaborative that would:

- Identify cross sector priorities for eye health and vision research.
- Support development of a compelling, succinct and evidence-based case for enhanced and sustained investment in eye health and vision research and associated cross sector advocacy at a national level
- Proactively identify current and emerging risks and opportunities for Australian eye health and vision research.
- Provide input to research consultation processes such as the review of MRFF strategic priorities to strengthen the position and visibility of ophthalmic research.

To help shape thinking and provide a starting point for discussion at the forum, all forum registrants were asked to complete a short, pre-forum survey. In late April, a total of 25 survey responses had been received and the information therein is summarised in this background paper.

The forum will provide an opportunity for all participants to discuss and suggest additions and/or potentially amendments to the initial lists of principles and priorities discussed on subsequent pages.

Guiding principles

A set of guiding principles for such a collaborative would be helpful in promoting a common understanding of, and approach to, its work.

As part of this, participants were asked to rank a set of principles from most to least important. Suggested priorities to guide national collaboration on eye research are listed below in the order survey respondents ranked them (from highest to lowest ranked).

- **Informed by consumers and carers**: the perspectives and expertise of consumers and carers is valued, including the perspectives of Aboriginal and Torres Strait Islander Peoples, and their participation will be integral to all facets of the collaborative's work
- **Inclusive**: the collaborative aims to bring together all organisations involved in eye health and vision research across multiple disciplines, both within the eye sector and beyond
- **Respectful and open to new ideas**: participants will be open to, and respectful of, all partners input, fostering a culture of partnership and collective endeavour
- **Transparent**: processes for setting priorities and assessing potential proposals will be open and clear to all participants, with clear processes for managing interests and differences of opinion
- **Strategic:** decisions will be shaped by strategic insights regarding government priorities, the operating environment and other critical factors to maximise potential for success

The below principles were also identified by respondents as important -

Principle	Description
Equity	Equitable: an equal voice for non-medical and non-white male voices.
Addressing barriers to eye health	We also suggest it is an important principle that research will help address community need or known barriers to eye health
Aboriginal and Torres Strait Islander leadership and engagement	Suggest a separate principle pertaining to research for Aboriginal and/or Torres Strait Islander Peoples, such as, 'Aboriginal and Torres Strait Islander leadership and engagement.
	Any research relating to Aboriginal and Torres Strait Islander eye health must be co-designed; informed and determined by engagement with Aboriginal and/or Torres Strait Islander Peoples and communities.
	The principle transparent also needs to include a commitment to feedback to Aboriginal and Torres Strait Islander stakeholders.
	The principle 'Strategic' should include a reference to being iterative, it is not enough to consult as a one off, the consultation process must revisit the individuals and organisations consulted to ensure that the information captured is accurate and aligns to the aspirations of the stakeholders involved.

Pre-work for forum: There will be an opportunity at the forum for attendees to ask questions and identify any other principles they think should be added to this list. **Are there are other principles you feel it is essential to include?**

Developing Eye Health & Vision Research Priorities

The purpose of the national research forum is to commence discussion regarding potential eye health and vision research priorities in Australia where a cross-sector approach might be adopted.

Beginning a process to identify cross sector priorities

To commence the process, we asked individuals who registered for the forum to tell us what they see as top priorities for investment in eye-related research in Australia.

As the Lancet Global Health Commission had recently identified 16 research priorities for the eye sector into the future, these (along with some specific Aboriginal and Torres Strait Islander priorities identified via other processes) were used as the starting point for that process with scope for respondents to add additional priorities as desired.

Of all the priorities identified, three have not been included in subsequent listings as they are not research topics per se:

- the priority with the widest support from survey respondents was "strengthen leadership and public health expertise across all levels of eye care and ensure that national leadership can influence policy and resource allocation. Additionally, strengthen regional and national professional bodies for eye health practitioners". This is what the current collaborative process is trying to work towards.

- the priority "ensure financing exists for eye health in national budgets" was supported by 70% of survey respondents. This is already being progressed through the work of Vision 2020 Australia and is not a research topic as such.

- the priority around encouraging governments to adopt integrated, people centred eye care which, while supported, is not a research topic.

Ranked priorities from the initial survey

The table below includes a summary of the remaining priorities, how highly they were ranked by the collective respondents, and also some commentary made by survey respondents.

Research priority	Description	Level of support
Research to develop **screening and early detection strategies for eye conditions**	Develop and implement evidenced-based, effective, sustainable, and context-relevant screening and early detection strategies for eye conditions	82%
Research to support **community led models for Aboriginal and Torres Strait Islander Peoples**	Develop and implement Aboriginal Community Controlled Health Organisation led models of eye care so that opportunities for community leadership are maximised.	76%
Research to support **development of services for disadvantaged/hard to reach groups**	Develop and implement services that prioritise, and by design, reach marginalised or vulnerable groups (women, poor communities, Indigenous people, ethnic minorities, people with disabilities, people in residential care, prisoners, and refugee camps) and people living in rural communities with quality affordable eye services. *Note: it was suggested by one respondent that this be narrowed to specifically focus on Aboriginal and Torres Strait Islander Peoples, and that specific consideration also be given to rural and remote settings. Use of the language of co-design in relation to this was also emphasised.	70%

Research priority	Description	Level of support
Research to support **increased uptake of eye care services & treatment**	Develop and implement responsive programmes to increase the access to and use of eye health services and treatment—eg, reduce barriers to accessing services and increase demand through greater awareness of need and confidence in health-care provision. *Note: specific suggestions were made regarding potential areas of focus in this area, for example - increasing access to public ophthalmology services outside metropolitan and regional centres, particularly for Aboriginal and Torres Strait Islander Peoples - piloting innovative models of care to address known access problems, such as access to IVIs	70%
Research to support training **for Aboriginal Community Controlled Health Organisation staff**	Develop and support eye health training for Aboriginal Community Controlled Health Organisation staff and a national network leading to sustainable local eye health expertise	67%
Research to support strategies that **address cost barriers**	Develop and implement strategies that reduce out-of-pocket costs for those requiring eye care who are unable to afford full-cost services – e.g. subsidy, tiered pricing, or insurance.	57%
Research to develop strategies for integrating **eye health services between the primary, secondary, and tertiary level to improve referral pathways**	Develop and implement evidence-based strategies for the effective integration of eye health services between the primary, secondary, and tertiary level to improve referral pathways, ensuring recognition of those who need secondary care and a timely, reliable, accessible, and affordable care mechanism.	57%
Research to develop a **one-stop service for people with diabetes**	Develop and implement one-stop services for people with diabetes by integrating diabetic retinopathy screening services with general diabetes care and develop robust systems to ensure ongoing follow-up and referral for assessment and treatment.	52%
Research to develop pathway **approaches for managing glaucoma**	Develop and implement effective, accessible, and inexpensive pathway approaches for screening, diagnosing, monitoring, and managing glaucoma	52%
Research into strategies to **integrate eye care with other medical services and at the primary care level**	Develop and implement evidence-based strategies for the effective integration of eye care at the primary care level and with other medical services (e.g. child health, diabetes or other NCD services), ensuring that services are widely accessible, affordable, of high quality, and meet the primary eye care needs of the population	48%
Research to develop and integrate **school eye health programmes in education systems**	Develop and implement sustainable school eye health programmes, including screening and management for refractive error or amblyopia, which are well integrated within education services.	48%
Research into approaches that will strengthen **information systems**	Strengthen the information system for eye health within health facilities, integrating them into national systems	44%

In addition to the Lancet Global Health Commission priorities, survey respondents identified a range of other priorities with the importance of support for discovery and translational research to

develop the next generation of treatments for blinding eye disease emphasised. Additional priorities identified were:

- Development of therapies to restore vision in previously untreatable conditions
- Development and testing of therapies that improve quality of life in ageing individuals with eye disease
- Targeting of therapies to those most at risk of blindness using genomics and other predictors of individual risk (personalised medicine)
- Ocular surface, as this was considered to be an area of global strength.
- Funding to support clinical trials, noting that these were essential to achieving a range of the priorities identified by the Lancet Global Commission. It was noted that Australia had advantages compared to other jurisdictions in this space, with the example of animal models cited.
- Support development of service user groups and resources, to facilitate the engagement of community members and consumers regarding research ideas and the logistics of completing research involving those groups

Through the forum and follow on actions, the goal is to develop a broader list that incorporates a balance of both discovery and translational research priorities.

Eventually this work will need to lead to a relatively small number of priorities that could form part of an eye research agenda and advocacy strategy. A collaborative process will be run to support an inclusive and strategic refining priorities to agree that list then build the case for investment, with the aim of launching this in late 2021.

A starting list for discussion

A consolidated list of the priorities outlined in the previous section is provided below in alphabetical order. This will form a starting point for discussion at the forum.

Addressing barriers to service access for Aboriginal and Torres Strait Islander Peoples*
Client and community engagement in research development and trials
Community led eyecare for Aboriginal and Torres Strait Islander Peoples*
Development and testing of therapies that improve quality of life in ageing individuals with eye disease
Development of therapies to restore vision in previously untreatable eye disease
Enhance quality, uptake and productivity of eye care
Ocular surface conditions
Pathway approaches for managing glaucoma
School eye health programmes into education systems
Screening and early detection strategies for eye conditions
Service development - disadvantaged/hard to reach groups
Strategies to integrate eye care and health into broader health care, particularly NCDs, across primary, secondary and tertiary care
Support for more clinical trials
Targeting of therapies to those most at risk of blindness using genomics and other predictors of individual risk (personalised medicine)

*Participants are asked to note that, through the Indigenous Health Research Fund, there is already a funding source for Indigenous-led Aboriginal and Torres Strait Islander eye health and vision research.

Pre-work for forum: A significant portion of the forum will provide the opportunity for small, mixed group discussion regarding priorities.
Please review the list above, and think about **what additional priorities for research funding are critical to add to the list**?