VISION 2020 THE RIGHT TO SIGHT AUSTRALIA

National Primary Health Care Data Asset

Vision 2020 Australia Submission in response the Australian Institute of Health and Welfare draft Data Development Plan

June 2019

National body working in partnership to prevent avoidable blindness and improve vision care

Contact details

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2. Who are you providing a submission on behalf of?

Organisation

3. If submitting on behalf of an organisation, which one?

Vision 2020 Australia, the peak body for the eye health and vision sector, with around 50 member organisations that are involved in local and global eye care, research, health promotion, low vision support, vision rehabilitation, professional assistance and community support.

4. Do you consent to the publication of your organisational name?

Yes

5. Which stakeholder group best describes your affiliation?

Policy maker

Introduction

1. What do you see as the key areas of opportunity in developing the National Primary Health Care Data Asset?

Vision 2020 Australia members believe this data asset offers a unique opportunity to develop a comprehensive, 'whole of system' evidence base that is essential to understanding of the broader system of care, how people move through that system and where there are opportunities to improve quality and outcomes through targeted prevention, early intervention and treatment in eye health.

Critical areas for focus include building a strong evidence base regarding:

- patient pathways through the broad health and social care,[1] and the outcomes delivered through these different referral pathways.
- the outcomes of services provided (including clinical/treatment outcomes, patient reported experiences of care, cost and functional impacts of care/delays in access)
- workforce, technology and other related elements that are critical to delivery of timely, effective care and support.

Box 1 (overleaf) provides additional details regarding these.

[1] Including different referral patterns, the time taken between key points in those pathways and identification of how people move between different parts of the broader system.

The proposed staged development of this asset also offers the opportunity to test and explore a systems approach in the first stage of development and use this to inform the development and roll out of stage two.

While the current proposal is that all non-medical workforces be brought into stage two of the project, Vision 2020 Australia proposes that consideration be given to bring forward inclusion of optometry and other relevant eye health and vision data into stage 1 of the project, and use the eye health and vision sector as a 'test case'.

This would provide the opportunity for early exploration of how best to design and develop data collections that span multiple occupational groupings (including GPs, medical specialists, optometrists, orthoptists and others involved in, multiple settings (hospital, other public settings, private and NGOs), and the full spectrum from prevention through diagnosis, treatment and low vision/rehabilitation support.

The eye health and vision care is uniquely positioned to be a 'test sector' for this purpose, and sees significant strategic value to the broader project in doing some early exploratory work for a defined subsector within the broader system. We would welcome the opportunity to work with the AIHW to bring together a wide range of members from across the different occupational groups, service delivery settings, and research bodies with expertise within the eye health and vision sector to support this.

Box 1: What could the data collection deliver?

With a focus on a whole of systems approach, the National Primary Health Care Data Asset, Data Development project offers the opportunity to address some of the key challenges encountered in current approaches to service development, delivery and innovation in eye health and vision care. Some of the key opportunities identified by Vision 2020 Australia members are identified below:

A more accurate picture of the patient journey

Currently available data provides little or no information regarding the overall patient journey: while for example there are existing data about waiting times for key surgeries, there is limited or no information available regarding:

- how long it takes for a patient to move through the system from initial contact and diagnosis to treatment and follow up care and support

- distance travelled

- the quality and effectiveness of care (from both clinical and patient experience perspectives) over the entire patient journey, including primary care

- who is receiving services, who doesn't receive services, and why.

Data that can drive quality improvement

The integrated, 'whole of system' concept for the project offers a unique opportunity to deepen the understanding of service safety and quality alongside outcomes. Enhancing understanding in this area, including a more comprehensive understanding of performance against those outcomes that are important to people receiving services, could significantly enhance continuous quality improvement efforts.

Expanded opportunities for early intervention & prevention

For a range of ocular conditions, early identification and treatment can reduce or slow associated vision loss. Similarly, for people who develop severe vision loss, early access to rehabilitation services and support can reduce the functional impacts of their vision loss. Strengthening data collection to better understand functional impacts of vision changes and maximise opportunities for early intervention is strategically critical, particularly given the increased prevalence of vision loss and blindness as people age.

Stronger understanding of the interplay between effective services and workforce

Vision 2020 Australia members have highlighted that often, workforce factors have a critical impact on the mix, timeliness and quality of services provided but current data collections typically separate service and workforce factors. In eye health, both primary and tertiary data coexist (for optometry and ophthalmology services, respectively. This makes eye care a unique sector, with optometry the only non-medical professional group with a long history of MBS funded primary care service delivery) within the MBS data collection. Development of this data resource offers the opportunity to bring key collections together, allowing for more integrated planning and prioritisation of effort.

2. What are your top primary health care data needs?

Data regarding primary health delivery of eye health and vision care, and the interface between primary care and eye health and vision care (delivered by ophthalmologists, optometrists, orthoptist and specialist blindness/rehabilitation providers), have been identified as key priorities for Vision 2020 Australia members.

In particular, data that provides additional information regarding access to, mix and outcomes of eye and vision care is a priority, to deepen understanding around:

- what services are being provided to whom, by whom and in what setting over what timeframes
- barriers to accessing eye and vision care, what these are and who they affect
- barriers to developing integrated care models
- the impact of early intervention and preventive interventions (and the functional and other impacts of delays in access)

Data regarding workforce availability alongside service and population data was also identified as a priority, to support more integrated service and workforce planning.

3. Please rank in order of importance the following topics from the Data Development Plan

(1 being the most important and 6 the least).

1. Data sources
2. Reporting requirements
3. Data governance
4. Data flow models
5. Data element selection
6. Data indicators

4. From your perspective what are the top three key barriers and their enablers in developing the National Primary Health Care Data Asset?

Barrier: The diversity of data collection systems, with varying levels of sophistication and technical interface. While the eye health and vision care sector has a relatively small number of systems compared to some other areas of health care, eye health care professionals collect patient information in a number of different ways, from paper-based patient records to a range of electronic health records/practice management systems. This impacts a range of factors including the accuracy of data; the complexity of collection/extraction/reporting; comparability of data sources.

Enabler: The establishment of the NPHCDA must include resourcing to enable quality, consistent data collection from a range of systems, ideally through an approach that incentivises systemic

change to simplify future data collection and comparability. MBS data is a mechanism to overcome the range of data collection mechanisms within practice.

Barrier: Engaging some data holders may be difficult, especially if they don't view themselves as primary health care providers.

Enabler: Identifying potential risks (some of which will be sector specific) and working collaboratively with the various stakeholders to address these will be important. Peak bodies like Vision 2020 Australia can assist with this kind of engagement.

5. In order of priority rank the following uses of the National Primary Health Care Data Asset (1 being the top priority and 7 the lowest priority).

1. Help identify gaps in the provision of primary health care services
2. Support quality improvement
3. Enable better population health planning
4. Provide the best evidence to be able to reduce hospitalisations and emergency department attendance
5. Facilitate increased efficiencies in care delivery through comparison of patient outcomes and services across geographic and socioeconomic gradients
6. Improve patient outcomes and experiences
7. Shape primary health care programs and policies

Data sources

1. Which is your preferred model of data flow from general practice to the Data Asset?

Other: From primary health care provider to data asset.

Comments: To ensure data flows quickly and reports are timely, Vision 2020 Australia members recommend straightforward data flow, involving as few intervention points as possible – directly from the primary health care provider to the data asset. This should include MBS data.

2. What are the implications, opportunities and challenges for the proposed general practice data flow models (Figure 3.2)?

No comment.

3. What potential data flow models could capture other primary health care data sources: allied health, community, dental?

Both optometry and ophthalmology bill Medicare for much of their service provision, offering a simplified data flow directly from MBS. Optometry is unique amongst allied health professions in this arrangement.

4. Are there additional sources of primary health care data you would like to see included?

Point in time surveys

The AIHW and the eye health and vision care sector rely on the National Eye Health Survey 2016 (NEHS 2016) for population based data on the prevalence of eye disease, blindness and low vision.

Vision 2020 Australia is currently advocating for a second National Eye Health Survey to be funded for 2020, to build on the benchmark created by NEHS 2016 and provide data that will support a number of projects, including the NPHCDA.

A point in time survey of this type can capture data that other collection mechanisms miss, for example, a point in time survey can reveal who is not accessing primary eye health and vision care services and why, as well as identifying barriers some experience when trying to see an eye health professional.

Point in time surveys can also be used to deepen understanding of why some people who need care do not receive it, or what influences their treatment journeys and clinical outcomes. This could, for example, include collecting data:

- regarding why some patients do not proceed with referral and/or a care plan,
- and/or better understanding time lapses in accessing/progressing through care.

This data could then be used to identify supports to keep people in the system and get the treatment they need, thereby minimising risk of suboptimal outcomes such as avoidable vision loss.

Vision 2020 Australia members also expressed support for snapshot surveys or random samples of geographically diverse segments to provide essential information about the primary health care experience.

5. How satisfied are you with the decision making matrix for assessment of new data sources?

Satisfied

6. Do you have any additional comments or suggestions regarding data sources

No comment.

Data governance

1. How satisfied are you with the proposed data governance arrangements?

Satisfied

2. Do you have any additional comments or suggestions regarding data governance?

Governance mechanisms that support the NPHCDA must encourage participation, be inclusive and collaborative, and ensure people with experience receiving health care services and people with disability are supported to participate.

Additionally, eye health professionals involved in primary health care should be involved in governance structures as experts in the data that will be collected.

Dennis Trewin, in a paper released by The Academy of Social Sciences in Australia, describes the "trusted access model". Examples of expansion could include:

Safe people

- establishing the bona fides of the researcher, taking account of the researchers previous history in accessing data if available,
- provision of a training module (which may be on-line),
- entering into a legally binding agreement that sets out responsibilities for both partners, and
- an emphasis on communication rather than policing.

Safe projects, to be defined through the development of a set criteria for pre-approved purposes. For example, if it is to report against certain approved key performance indicators, measure success or for use in for certain pre-determined purposes.[2]

Data requirements

1. How much do you agree with the proposed list of core data elements suggested in Table 5.1?

No comment.

2. How much do you agree with the potential indicators for general practice outlined in Table 5.3?

No comment.

3. Please list any primary health care data gaps not identified in the Data Development Plan.

See comments above.

4. Do you have any additional comments or suggestions regarding data requirements?

No comment.

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[2] Trewin, D., Academy Papers 4/2016 "Trusted Access Model" The Academy of Social Sciences in Australia, Canberra 2016

Summary

1. From your perspective, what else should the AIHW be considering in the development of the Data Asset?

Capacity of the eye health and vision care sector

Across the eye health sector, there are a wide range of professions, research organisations, service providers and others who are experienced in working with data and genuinely engaged and committed to evidence based system improvements.

With around 50 of these organisations represented through the peak body (Vision 2020 Australia), there is also strong capacity for a coordinated cross sector approach.

As previously mentioned, eye care is also uniquely positioned to be a 'test case' for this project in its first stage, as a combination of general practitioners, optometrists, and ophthalmologists all provide MBS funded eye care alongside provision of specialist eye care services by ophthalmologists, optometrists and orthoptists in public and private settings.

The unique opportunity presented by the long standing involvement of optometry in Medicare alongside ophthalmology and other medical providers means there is extensive, longitudinal data available and while there are a range of electronic health records/practice management systems used across the eye care professions, the total number of electronic record systems is relatively small compared to many other professions which may pose practical advantages.

Functional impacts data

An additional source of primary health care data from nurses and support workers in aged care should be included – this will likely include some functional impact elements – and also data about the reason for the patient encounter, which might highlight if the patient is experiencing functional issues, for example, impact of vision loss at home.

2. What do you see as the biggest risks in developing a National Data Asset and how would you mitigate them?

The potential scope of the collection could prove challenging as for many parts of health care, the complexity in terms of number of providers, range of systems, complexity in settings, lack of longitudinal data or other data limitations and mix of care and other factors will make it extremely difficult to achieve the kind of broader system view and understanding of outcomes that this asset could support.

Doing an initial test in the early stages of the project's implementation with a subsector like eye health and vision care, which has a history of working collaboratively, strong interest in supporting the project, a unique mix of data (including substantial longitudinal data in MBS that includes both medical and allied health provision) and a genuine commitment to enhancing patient outcomes, would allow some of the complexities of developing such a data project to be explored and mitigated in broader roll out.

3. Do you have any final advice or comments for the AIHW?

No comment.