Themes arising out of patients’ views (Phase 1)

Factors which make it challenging to access LVR services in a timely manner

- Financial challenges: owing to change, uncertainty, and mobility, hiring new care skills
- Organizational challenges: limited services available by region, health service regulations, slow referral, long waiting times
- Access challenges: difficulty seeing people, mention activity

When to refer to LVR services

- Early: at time of diagnosis, when vision change is significant or when vision is sufficient to learn adaptation

- When vision is affected

- When earlier: in case of diagnosis, if the service can get started and the case is identified early, it would have been much better to have it at that time

- When diagnosis is necessary

How timing for referral for low vision services may be improved

- Provide information about: progress of vision loss, low vision technologies, current developments, educate school kids.
- Provide support: outreach to hospital patients, access to support groups, organise support and understanding of vision impairment, follow up to referrals.
- Early referral

- As soon as possible, diagnosis is made, it is ready to get some help
- I feel scared because it’s about to do something to me

Stakeholders’ Combined Action plan to achieve timelier referral to low vision services

- Shared Goals: adopt best and good practices with respect to early and adequate information provision and referral

- Common discussion with patients to get feedback on needs

- Educate trainee clinicians about LVR services

- Involve a second person (family and friends) with consent to be present at the consultation to share and get help information about the vision condition and LVR services

- Eye care professional bodies to cooperate and communicate better through umbrella organisations to achieve best practice

- Education of the general public about LVR services

Who should carry out changes?

- All eye care provider and all service provider should work together to carry out desired changes

- When changes should be carried out?

- As soon as possible, “I definitely refer to this report once it’s released. Yes, we need it and we need it now”

What resources are needed to carry out the changes?

- Government funding

- Who should be communicated with?

- Eye care and professional organisations; optometrists, ophthalmologists, primary care, GPs. And the other key organisations, Muscular Dystrophy Foundation, Guide Dogs. All these rehabilitation specialists, they’re the ones who need to know the plan

Continuous information about LVR services

- Stakeholders agreed on the need to give people with irreversible vision loss should not be a hard fact of life of “inert” blindness. Instead, rather that people with irreversible vision loss should be approached factually

- Information must be given in a way that gives hope to the person and makes it clear that something is done to help them even in the face of worst-case scenario

- “On diagnosis of vision impairment, information on what happens if disease progression is not further oiled or done in early stage.”

- “Yes, you need to use the term blindness.” “Stigma doesn’t think applies to them.”

- “They need them to do that to have all the information and, learn it and start to use it, so that they can provide it to the patient as necessary. That many patients are more appealed and see better.”

Discussion: The literature was searched for examples of best-practice models (described below)

Community-based screening

- Hospital co-location

- Eye clinic liaison officer (ELO)

- Patient-centric team care plan

Themes arising out of stakeholders’ views (Phase 2)

- Medical referral refers to the process of directing or redirecting a patient to an appropriate specialist or agency for definitive treatment. It is an integral part of a patient’s management system. It requires an effective, timely procedure as well as a low cost loop system for referral completion, correspondence and patient feedback (Jarve et al., 2011). Lack of referrals to LVR services has been earlier reported to be a major barrier to accessing LVR services (Cupples et al., 2012). Timing referral is critical as it promotes optimal intervention and care in the management of medical cases. Studies show that delays in referral to LVR services are introduced very late, when the eye care practitioner has exhausted all other treatment options (Overbury, 2011) and conclude that “nothing more can be done.” (Pollard et al., 2003; Overbury et al., 2011). At this stage vision loss is so advanced that it may be difficult to benefit from compensatory techniques and assistive technologies (Wittch et al., 2013).

- In a previous study, we found general practitioners (GPs, medical doctors) and optometrists referred mainly to ophthalmology for treatment, with little direct referral to low vision services or patient support services (Jameus et al., 2014). Suggesting that direct referral by primary care health professionals to low vision services and support services may be one way to increase the timeliness of referrals.

- This study is phase 2 of a larger study. The aim of the present study is to understand stakeholders’ perspectives on the timing of referral to LVR, considering patient preferences (Phase 1, presented at the AAD meeting in 2018), and to develop an action plan based on patient preferences to improve timing of referral to LVR services.

Method:

- Participants and Recruitment: Inclusion criteria: stakeholders in the eye care or LVR industry and/or must hold a current or previous role as either LVR provider, management of vision impairment, referer to LVR services or involved in the administrative formulation and implementation of policies in the eye care industry. Letters of invitation were sent to major LVR services, professional organisations within the eye care and related medical industries (optometry, ophthalmology, orthoptists, orientation and mobility, GPs). Snowball recruitment methods were used.

- Study Design: Qualitative focus group study of 1-2 hours duration. Participants were invited with patient views regarding timelier referral to low vision services. There was one main facilitator and two assistant facilitators, a GP and an optometrist. Study participants were provided with patients’ views, asked to reflect and respond, then develop an action plan. Interviews were audio-recorded. The audio recordings were professionally transcribed then analysed using thematic analysis. Each research finding was critically evaluated, the focus group data (using NVivo software to aid in the coding process), then the four researchers met as a group and discussed and compared findings. This was to ensure themes were not missed or duplicated. The action plans for each focus group were combined to include all suggested actions.

- RESULTS: 21 people expressed interest, 17 took part (six males and 11 females). Four were unable to attend for the following reasons: illness, inclement weather and unforeseen engagements. Three focus groups were formed. Participants identified as: Optometrists who practice low vision in private practice, multidisciplinary LVR service and researchers; a health professional and a university and occupational therapists; orientation and mobility specialists at LVR service provider; policy and advocacy manager of an eye care professional body; orthoptist; low vision service coordinator at a LVR service; educators and counsellors at patient support services; colleagues in the LVR industry; and senior optometrist who refers to LVR services.

Stakeholders agreed that information regarding LVR services should be delivered early but that it also needed to be delivered repeatedly, at multiple timepoints, by multiple practitioners, in a staged fashion, and be tailored to the individual patient as much as possible. Many expressed a wish for more guidance, education, and practice guidelines on how to best to act in such a situation to often be at the start of their vision impairment diagnosis.

The ECLD and patient-centric team care models address many of the patient and clinician concerns, however both models may need to be funded for eye care practitioners to embrace the models. Electronic practice software that triggers information provision/referral may be an easily implemented strategy. Education of the general community to raise health literacy with respect to vision disorders and LVR was considered a good strategy by both patients and stakeholders, as it may facilitate LVR service seeking behaviours. Schemes such as the National Disability Insurance Scheme Australia, which employs planners to distribute funding, cover only permanent disability and necessary care, which may not address quality of life concerns during the early stages of vision impairment diagnosis.