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## SUMMARY

### OBJECTIVES

- Globally, the number of cases of moderate and severe vision impairment and blindness are increasing. Ensuring quality-of-life (QoL) tools like the EuroQoL Five-Dimension questionnaire (EQ-5D) adequately capture the impacts of sight loss, including the multi-faceted and substantial psychological effects, is essential when evaluating health technologies that target sight loss.
- The objective of this research was to evaluate whether the EQ-5D adequately captures the psychological impact of sight loss and to assess its sensitivity compared to vision-specific instruments.

### METHODS

- Evidence was synthesized via a targeted literature review to identify peer-reviewed studies examining EQ-5D performance in visually impaired populations, including analyses of the tool's psychometric behaviour, limitations, and comparisons with vision-specific patient reported outcome measures (PROMs).
- Key outcomes and conclusions related to the overall sensitivity and responsiveness of the EQ-5D in capturing the impacts of sight loss, including the psychological effects, were extracted and analysed.

### FINDINGS

- Most studies found that the EQ-5D is inadequate in its ability to capture the QoL impacts of sight loss.
- None of the reviewed studies methodologically evaluated the effectiveness of EQ-5D at capturing the psychological impacts of sight loss.
- The psychological effects of sight loss were only captured by the anxiety/depression domain within the EQ-5D; failing to characterise the multifaceted mental health and emotional challenges related to sight loss.
- The HUI-3 instrument was commonly reported as the best generic measure of QoL in patients with sight loss, likely due to its incorporation of a vision domain.
- Versions of the EQ-5D with a vision-based bolt-on (e.g., EQ-5D + V) generally exhibited greater sensitivity and responsiveness at detecting QoL differences between patients with and without sight loss and at varying severity levels.

### RECOMMENDATIONS

- Given upcoming National Institute for Health and Care Excellence (NICE) changes where EQ-5D-5L will be the recommended tool for capturing QoL estimates in future health technology assessments (HTAs), additional research is needed on the ability of the EQ-5D-5L to capture the impacts of sight loss, including the psychological effects.
- When evaluating vision-related interventions in HTA submissions or general cost-effectiveness analyses, alternative measures that better capture QoL in patients with sight loss should be explored (e.g., HUI-3, EQ-5D + V).
- Further research is needed to develop a QoL tool that adequately captures the psychological impacts of sight loss.

## BACKGROUND & AIMS

- Globally, the number of cases of moderate and severe vision impairment and blindness are increasing, largely due to aging populations with longer life expectancies<sup>1</sup>. In those aged ≥50 years, the primary cause of blindness is cataracts followed by glaucoma<sup>1</sup>, while in children and young adults, rare eye diseases are a leading cause of visual impairment and blindness<sup>2</sup>.
- Given the progressive and often irreversible nature of vision loss, the effects on a patients' social and mental well-being can be significant, including higher rates of depression<sup>3</sup>, increased risks of social isolation and exclusion<sup>4</sup>, lower self-esteem<sup>5</sup>, and reduced participation in education and employment<sup>3</sup>. Therefore, capturing the psychological impact of sight loss when evaluating the QoL benefits of vision impairment interventions is crucial.
- The EQ-5D is a standardised tool used to measure generalised QoL and generate utilities by asking questions across 5 domains: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each dimension has 3 or 5 levels depending on the version used (EQ-5D-3L vs. EQ-5D-5L).
- The EQ-5D is recommended for use in HTAs by many agencies including NICE due to its brevity and simplicity, allowing for economic comparisons using the same tool across interventions and disease areas. However, the EQ-5D is also commonly criticised for being insensitive or failing to capture important aspects of QoL<sup>21</sup>.
- Other tools to elicit QoL values exist, including condition-specific instruments (e.g., NEI-VFQ-25) or generic instruments with a vision dimension (e.g., HUI-3); however, they can generate different QoL results. Therefore, the choice of instrument can significantly impact whether an intervention is considered cost-effective.
- Given the increasing relevance of evaluating health technologies related to vision conditions, it is important to analyse whether the current, most used QoL instrument, EQ-5D, effectively captures the burden of visual impairment in patients including the psychological impacts of sight loss.
- This study aims to evaluate whether the EQ-5D adequately captures the psychological impacts of sight loss and to assess its sensitivity compared to vision-specific instruments.

## METHODS

- A targeted literature review was conducted to identify peer-reviewed studies examining EQ-5D performance in visually impaired populations, including analyses of the psychometric behaviour of the EQ-5D, limitations, and comparisons with vision-specific PROMs.
- The Medline database was searched to retrieve relevant, peer-reviewed publications published between 2005 and 2026. Key sources included large cross-sectional datasets, systematic reviews, and instrument-level evaluations.
- Key evidence relating to the sensitivity and responsiveness of the EQ-5D in capturing the QoL effects of vision impairment was extracted and conclusions from the studies were synthesized.

**Table 1. Instruments used in studies exploring the QoL of patients with sight loss**

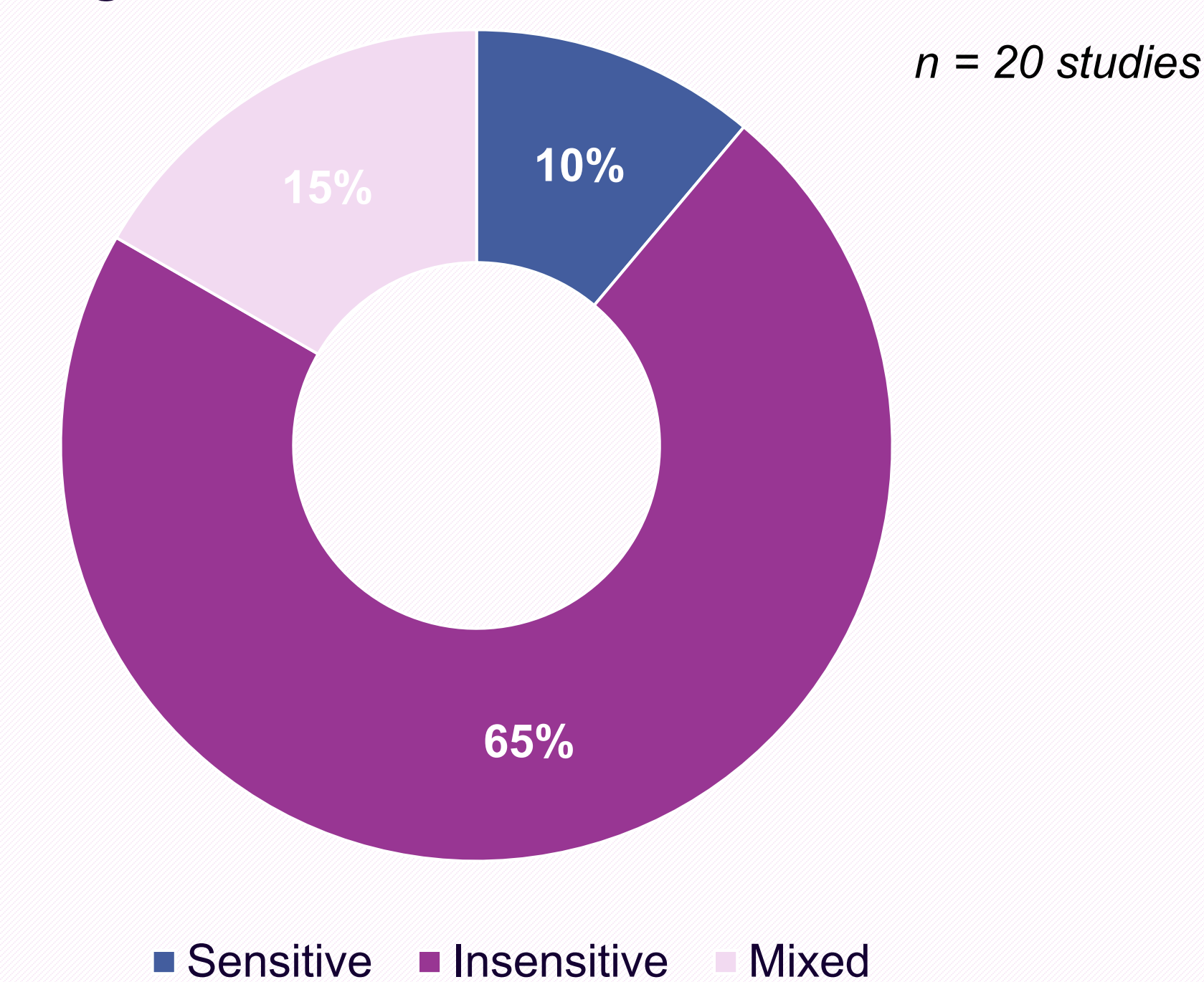
Instrument	Measure type	Psychological domains	Sensitivity to Sight Loss
EQ-5D (n=20)	Generic	Anxiety/depression	Low – poor detection of vision-related impact
SF-36/SF-12/SF-6D (n=7)	Generic	Social functioning, mental health, role emotion	Low - poor detection of vision-related impact
HUI-3 (n=5)	Generic with vision domain	Emotion	Moderate – incorporates vision-specific dimension
EQ-5D + V (vision bolt-on) (n=5)	Generic with vision domain	Anxiety/depression	Moderate – incorporates vision-specific dimension
AI (Activity Inventory) (n=3)	Vision-specific	None	High – designed to evaluate low vision rehabilitation
VF-14 (Visual Function Index 14) (n=3)	Vision-specific	None	High – measures QoL in patients undergoing cataract surgery (validated for age-related macular degeneration)
NEI-VFQ-25 (n=2)	Vision-specific	Mental health, social functioning, dependency	High – strong correlation with vision function

**Note:** The following instruments were excluded since only 1 study discussed their use: IVI (Impact of Vision Impairment), VisQoL, WHOQoL, LHS (London Handicap Scale), LVQoL, IADL (Instrumental Activities of Daily Living), GDS (Geriatric Depression Scale), PROMIS-29, PROMIS Global Health, Satisfaction with Life scale. Some studies reported TTO values separate to EQ-5D values; however, given use of TTO in generating EQ-5D utilities, a summary related to TTO-specific instrument is excluded from this table.

## RESULTS

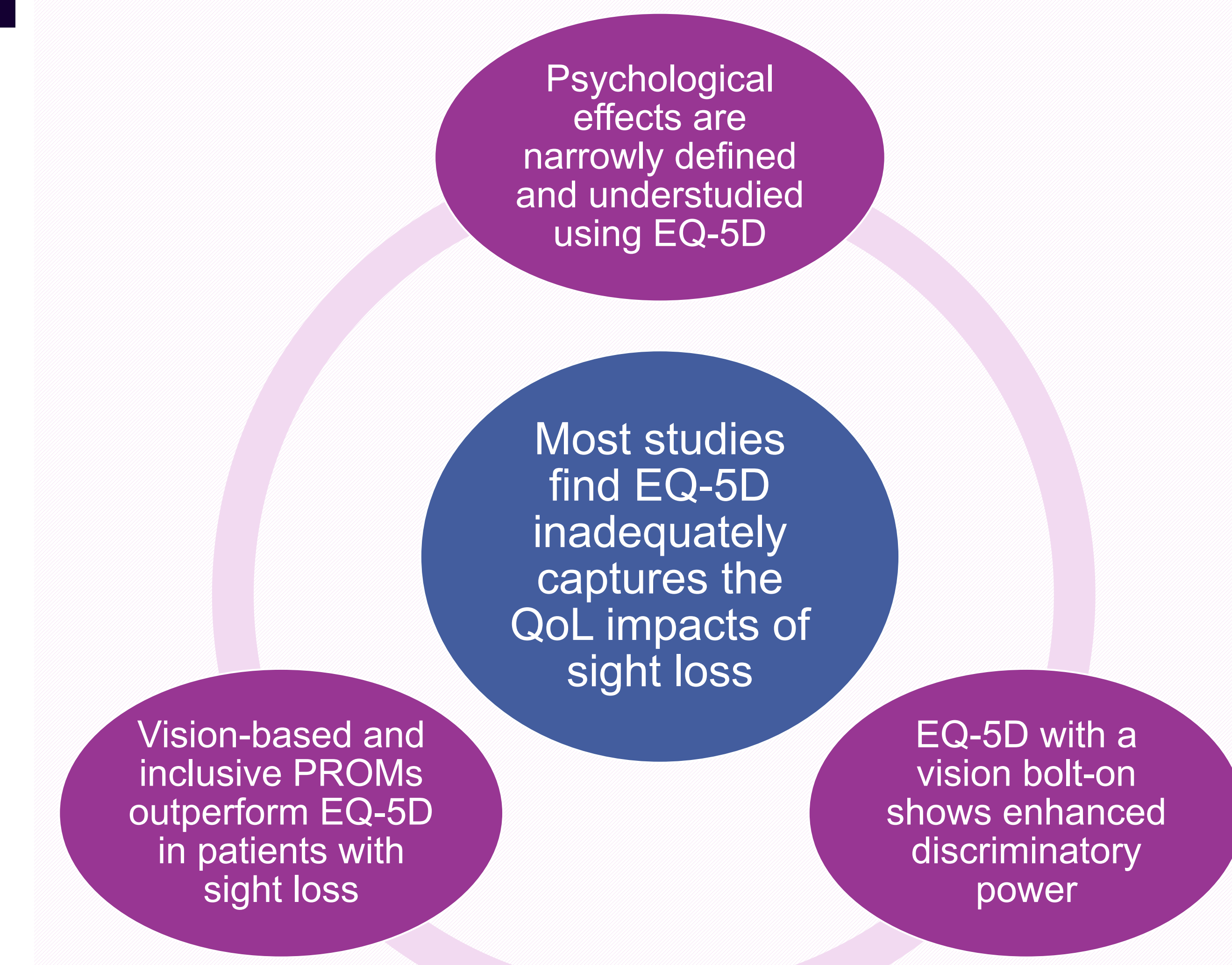
- Twenty publications, consisting of 14 cross-sectional studies, 4 systematic literature reviews, and 2 modelling studies, were included in the review. Of these studies, 4 appraised EQ-5D exclusively, 11 considered EQ-5D as well as other generic or vision-specific PROMs, and 5 evaluated EQ-5D plus a vision-specific bolt-on to EQ-5D.
- Sixteen (80%) of the studies discussed EQ-5D-3L, while 4 (20%) of the studies used EQ-5D-5L.
- The vision loss aetiologies considered in the studies were heterogeneous including diabetic retinopathy, glaucoma, or macular degeneration, however the majority (10/20; 50%) of studies considered populations with generalised or unspecified visual impairments or vision loss.
- Across the publications evaluated, only 2 (10%) studies<sup>6,7</sup> concluded that the EQ-5D was sensitive to visual impairments, while 13 (65%)<sup>8-20</sup> found that the EQ-5D was insensitive to sight loss either generally or in comparison to other disease-specific PROMs. Three (15%) studies found the EQ-5D was effective at capturing QoL effects in only certain conditions<sup>21,22</sup> or in severe visual impairment<sup>23</sup>. Two studies<sup>24,25</sup> did not make an explicit assessment (Figure 1).

**Figure 1. Study assessments on the sensitivity of the EQ-5D to patients with sight loss**



- While 1 study<sup>23</sup> commented on uncertainties related to the mental dimensions of QoL instruments in patients with sight loss, no studies methodologically evaluated the ability of EQ-5D to capture the psychological impacts of sight loss beyond the anxiety/depression domain.
- Across the studies that compared EQ-5D to other general or vision-specific PROMs (Table 1), 90% (10/11) considered EQ-5D to perform worse than the comparative tool.
- HUI-3 was most commonly reported<sup>9,13,19,21,22</sup> as the best generalised tool for measuring QoL in patients with sight loss, likely due to its incorporation of a vision-specific domain.
- Among the studies that considered a vision bolt-on to the EQ-5D, 100% (5/5) saw significant improvements in its discriminatory power.
- The conclusions from the studies reviewed are summarised in Figure 2.

**Figure 2. Conclusions based on the reviewed evidence**



## CONCLUSIONS

- While the evidence is mixed and varies by condition, most studies found that EQ-5D was insensitive to sight loss and does not adequately capture the related quality of life impacts.
- The EQ-5D can sometimes detect differences between people with and without visual impairment but consistently performs poorly in distinguishing severity levels of sight loss.
- Using only one domain (anxiety/depression), the psychological effects of sight loss are narrowly defined by EQ-5D and do not capture the breadth of psychological consequences reported by patients.
- The ability of the EQ-5D-5L specifically to capture the QoL impacts of sight remains a critical area of research given upcoming updates to NICE recommendations for utility measurements.
- Vision-specific PROMs or generic tools with a vision domain (e.g. HUI-3) outperformed EQ-5D in patients with sight loss.
- Bolt-on studies (e.g. EQ-5D-V) suggested that adding a vision dimension to EQ-5D significantly improves the discriminatory power of EQ-5D to detect differences in HRQoL among patient with visual disorders.

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