

The state of patient-reported outcome measures for pediatric patients with inherited retinal disease

Kavin Selvan^{1,2,3}, Maria F. Abalem^{4,5}, Gabrielle D. Lacy⁴, Ajoy Vincent^{1,2,3}, Elise Héon^{1,2,3,*}

¹*Genetics and Genome Biology (GGB) Program, The Hospital for Sick Children Research Institute, Toronto, Ontario, Canada.*

²*Department of Ophthalmology and Vision Sciences, The Hospital for Sick Children, University of Toronto, Toronto, Ontario, Canada.*

³*Institute of Medical Science, Temerty Faculty of Medicine, University of Toronto, Toronto, Ontario, Canada.*

⁴*Department of Ophthalmology and Visual Sciences, University of Michigan Medical School, Ann Arbor, Michigan, USA.*

⁵*Department of Ophthalmology and Otolaryngology, University of Sao Paulo Medical School, Sao Paulo, Sao Paulo, Brazil.*

Kavin Selvan: kavin.selvan@mail.utoronto.ca; orcid# 0000-0002-2051-9577

Maria Fernanda Abalem: mabalemd@med.umich.edu

Gabrielle D. Lacy: gabdlacy@med.umich.edu

Ajoy Vincent: ajoy.vincent@sickkids.ca

Elise Héon: elise.heon@sickkids.ca

**Corresponding author:* Dr. Elise Héon; orcid# 0000-0003-4143-9311

Email: elise.heon@sickkids.ca; Phone: 416-813-6525

SUPPLEMENTARY MATERIAL

Table S1. Search strategy by database

Ovid MEDLINE: Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE® Daily and Ovid MEDLINE®

1. exp "Eye Diseases"/
2. Ophthalmology/
3. exp "Vision, Ocular"/
4. (inherited retinal disease or inherited retinal dystrophy or hereditary retinal disease or hereditary retinal dystrophy or macula* or fovea* or retina* or retinitis pigmentosa or leber congenital amaurosis or stargardt disease or choroideremia or cone-rod dystrophy or rod dystrophy or usher syndrome or Bietti crystalline dystrophy or Batten disease or Bardet-Biedl syndrome or Alport syndrome or early onset retinal dystrophy or Cone dystrophy or Achromatopsia or Congenital stationary night blindness or Best disease or "Pattern dystrophy" or "Sorsby fundus dystrophy" or Doyme honeycomb retinal dystrophy or X-linked retinoschisis).ti,ab.
5. 1 or 2 or 3 or 4
6. "Quality of Life"/
7. "Activities of Daily Living"/
8. "health status indicator"/ or "chronic disease indicator"/ or "disease activity score"/ or "organ dysfunction score"/ or "severity of illness index"/
9. (Vision-related or vision-specific or "quality of life" or qol or hrqol or "reported outcome" or "lived experience" or well-being or "well being" or visual function* or "functional vision" or symptom).ti,ab.
10. 6 or 7 or 8 or 9
11. exp "Surveys and Questionnaires"/
12. exp "Health Survey"/
13. exp Psychometrics/
14. (Measure* or scale or index or instrument or assessment tool).ti,ab.
15. 11 or 12 or 13 or 14
16. (Child* or adolesc* or teen* or paediatric or pediatric or youth).ti,ab.
17. (young people or young person).ti,ab.
18. 16 or 17
19. (Vision-related or vision-specific or quality of life or qol or hrqol or "reported outcome" or "lived experience" or well-being or "well being" or "visual function*" or "functional vision" or symptom* or "visual ability" or "health status" or impact of or psychosocial or psycho-social or "visual analogue scale" or "pain severity").ti,ab.
20. 5 and 10 and 15 and 18 and 19
21. limit 20 to (abstracts and humans and ("preschool child (2 to 5 years)" or "child (6 to 12 years)" or

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- "adolescent (13 to 18 years)")
 22. limit 21 to (comment or letter or "review")
 23. 21 not 22
 24. limit 23 to yr="2013 - 2021"
 25. 25. limit 24 to english language

Embase Classic+Embase (Ovid)

1. exp "Eye Diseases"/
 2. Ophthalmology/
 3. exp Vision/
 4. (macula* or fovea* or retina* or "retinitis pigmentosa" or "leber congenital amaurosis" or "stargardt disease" or choroideremia or "cone-rod dystrophy" or "rod dystrophy" or "usher syndrome" or "Bietti crystalline dystrophy" or "Batten disease" or "Bardet-Biedl syndrome" or "Alport syndrome" or "early onset retinal dystrophy" or "Cone dystrophy" or Achromatopsia or "Congenital stationary night blindness" or "Best disease" or "Pattern dystrophy" or "Sorsby fundus dystrophy" or "Doyme honeycomb retinal dystrophy" or "X-linked retinoschisis").ti,ab.
 5. 1 or 2 or 3 or 4
 6. "Quality of Life"/
 7. "daily life activity"/
 8. "health status indicator"/ or "chronic disease indicator"/ or "disease activity score"/ or "organ dysfunction score"/ or "severity of illness index"/
 9. (Vision-related or vision-specific or "quality of life" or qol or hrqol or "reported outcome" or "lived experience" or well-being or "well being" or visual function* or "functional vision" or symptom).ti,ab.
 10. 6 or 7 or 8 or 9
 11. exp Questionnaires/
 12. exp "Health Surveys"/
 13. exp Psychometrics/
 14. (Measure* or scale or index or instrument or assessment tool).ti,ab.
 15. 11 or 12 or 13 or 14
 16. (Child* or adolesc* or teen* or paediatric or pediatric or youth).ti,ab.
 17. (young people or young person).ti,ab.
 18. 16 or 17
 19. (Vision-related or vision-specific or quality of life or qol or hrqol or "reported outcome" or "lived experience" or well-being or "well being" or "visual function*" or "functional vision" or symptom* or "visual ability" or "health status" or impact of or psychosocial or psycho-social or "visual analogue scale" or "pain severity").ti,ab.
 20. 5 and 10 and 15 and 18 and 19
 21. limit 20 to (abstracts and human and (preschool child <1 to 6 years> or school child <7 to 12 years> or adolescent <13 to 17 years>))
 22. limit 21 to (book or book series or letter or "review")
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23. 21 not 22

24. limit 23 to yr="2013 - 2021"

25. 25. limit 24 to english language
