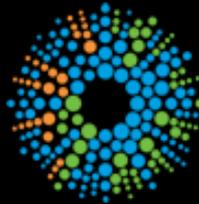




Understanding the Burden of Illness: Cultivating Best Practices in Patient Evidence Engagement, Analysis, Reporting

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The FOUNDATION
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Disclosure

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CHALLENGE 1: A NEW PARADIGM

- Treating patient perspectives as legitimate evidence is part of a relatively new paradigm
- As such, high-quality research on patient perspectives is limited
- Result: No strong consensus on research methodology or best practices
- CADTH's recent HQA of MIGS (section: "Patient Preferences and Experience Review") found that out of 67 relevant studies, 15 met the inclusion criteria, and after critical appraisal only one was deemed "credible," three "trustworthy," and three "transferable."

Table 1

Characteristics of the traditional medical model and patient-centered medicine

Traditional medical model	Patient-centered medicine
Provider-centered model	Patient-centered model
Founded on the principles of beneficence and authoritarianism	Founded on the principle of autonomy
Disease-oriented care	Patient-oriented care
Focuses on outcomes of importance for physicians and regulators	Focuses on outcomes of importance for patients
The patient's perspective is usually ignored	The patient's preferences, objectives and values are taken into account during decision making and delivery of healthcare
Compliance with the physician's decisions	The patient and physician share decision making
Improve outcomes for the average patient	Improve outcomes for the individual patient
Population-oriented research	Patient-oriented research

“Patient-centered medicine and patient-oriented research: improving health outcomes for individual patients” (*BMC Medical Informatics and Decision Making*. 2013. 13: 6.)
 José A Sacristán

CHALLENGE 2: POTENTIAL BIASES

“Six ‘biases’ against patients and carers in evidence-based medicine” (*BMC Med.* 2015. 13: 200.)

Corresponding author: Rosamund Snow

1. Limited patient input into research design
1. Patient experience undervalued in the hierarchy of evidence
1. Conflation of patient consulting with use of decision tools
1. Underestimation of power imbalances
1. Overemphasis on clinical consultation
1. Unbalanced focus on patients who seek and obtain care

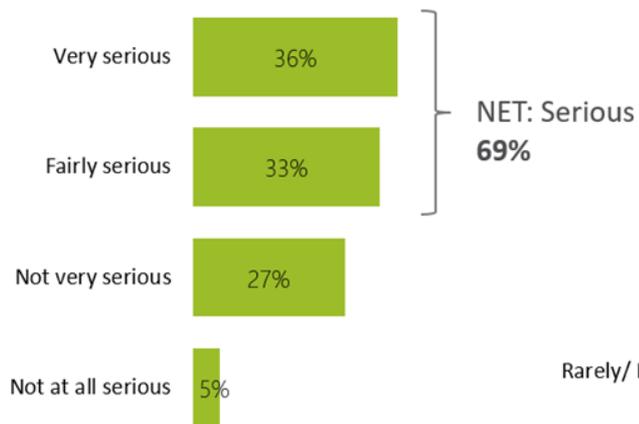
CASE STUDY 1: DIABETIC MACULAR EDEMA PATIENT STUDY

- Research conducted in 2017
- Engagement mechanism was a 10-minute online survey
- Survey was completed by 64 Canadians, each screened to ensure they either a) self-confirm having DME, or b) self-confirm a diabetes diagnosis and a history of injections

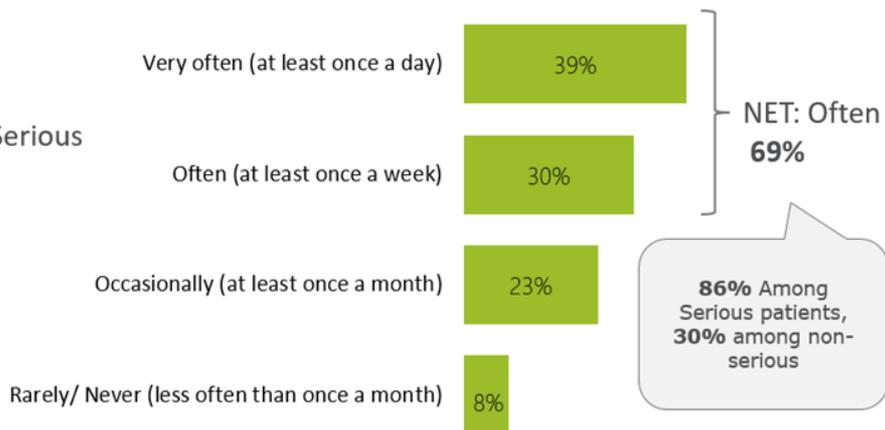
SERIOUSNESS OF DME

Seven out of ten patients consider their DME to be serious. The same number of patients think about their DME often (at least once a week)- particularly among those who consider their DME to be serious.

Seriousness of DME

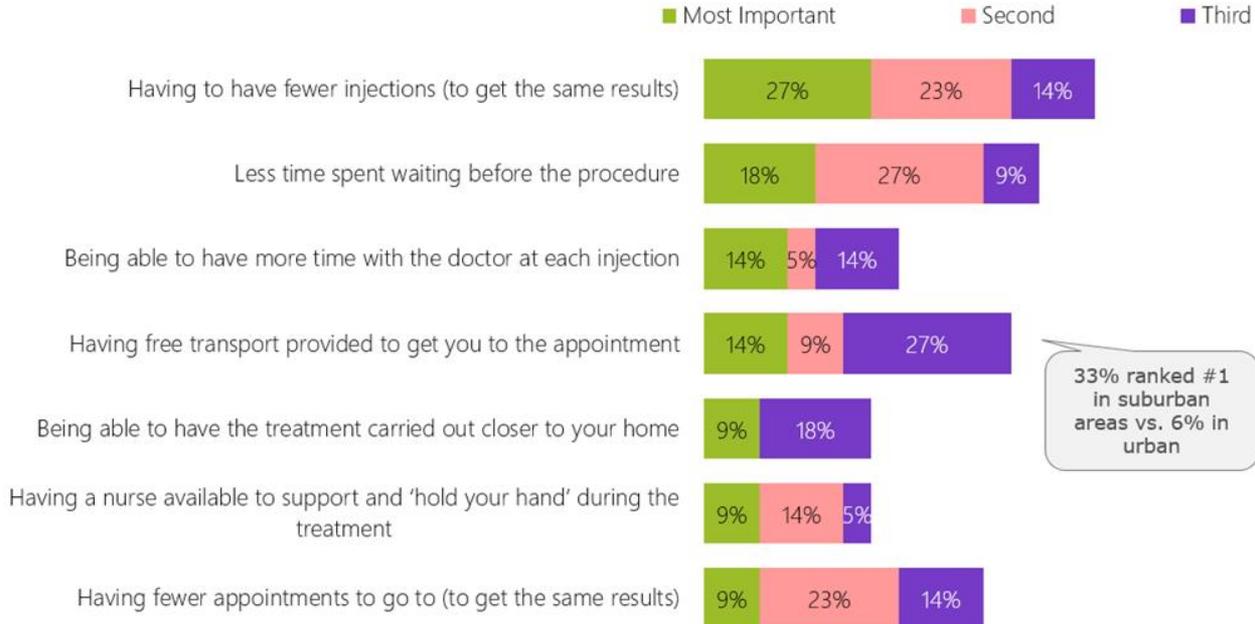


How Often Thinking of DME



IMPROVING THE INJECTION EXPERIENCE

Decreasing injection frequency is the most important factor in improving patient experience. Decreased wait time, and paid transportation are slightly less important, though would help to improve patient experience.



REPORTING THE DME EXPERIENCE:

CADTH Patient Input Submission: Ozurdex (dexamethasone)

Sample:

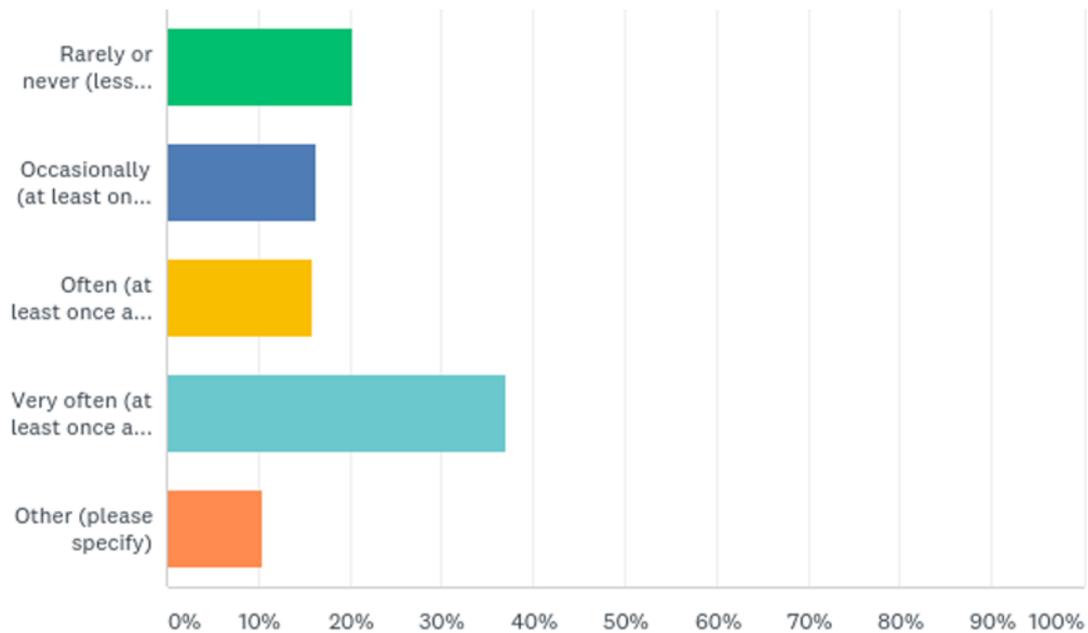
- What stands out clearly in the collected survey data is that DME has a significant impact on the daily lives of those living with the disease, with nearly half of the surveyed patients reporting that their lives are affected in some way by the condition, often in the form of a high impact on their ability to participate in work and school activities. Patients also reported that their DME impacts them nearly as much as other chronic and costly conditions such as COPD, cancer, and depression.

CASE STUDY 2: **GLAUCOMA PATIENT STUDY**

- Research conducted in 2018
- Engagement mechanism was a 10-minute online survey
- Survey was completed by 213 Canadians, each of whom reported being diagnosed with glaucoma

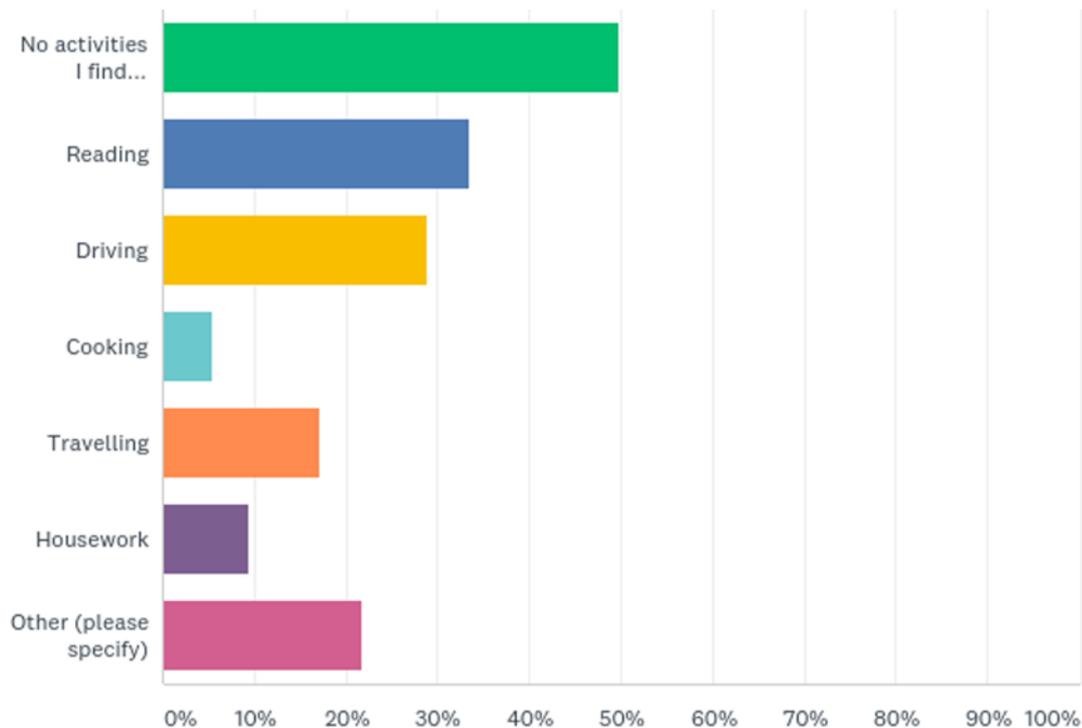
Q10: How often do you think about your glaucoma?

Answered: 221 Skipped: 27



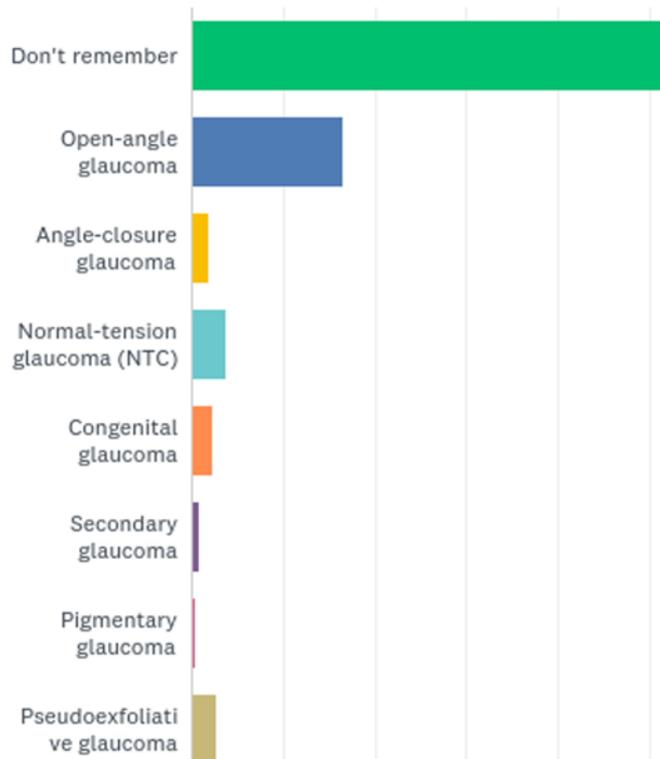
Q8: Are there activities that you find particularly difficult or can no longer do? Please select all that apply.

Answered: 221 Skipped: 27



Q29: Do you remember what type of glaucoma you were originally diagnosed with?

Answered: 213 Skipped: 35



Research Methods: Engagement, Analysis, Reporting

REPORTING THE GLAUCOMA EXPERIENCE:

Feedback on CADTH's "Optimal Use of Minimally Invasive Glaucoma Surgery: A Health Technology Assessment"

Sample:

- A general lack of detailed information in the CADTH draft on the daily challenges associated with living with glaucoma heightens the sense of a gap in our understanding of glaucoma's burden on patients. Responding to the question "What are the daily challenges you face living with glaucoma?" our survey respondents selected a wide range of challenges, with many selecting multiple. These included "no daily challenges" (40%), "difficulty reading" (40%), "frequent visits to the eye doctor" (37%), "not able to drive" (26%), "depression" (15%), "difficulty cooking" (11%), and "general mobility" (10%). Many of those who selected "other" (29%) provided insights that illustrate how complex their daily challenges are, including "Need enlarged monitor with computer," "have hard time seeing if dishes I was are clean, vacuuming, wash floors - close-up work," "problems with depth perception, tripping," "Difficulty walking through busy public areas, people bumping into you," "Regular Medication + Interventions," and "Anxiety."