


## Development of an Empowering Language Assessment Tool for Type 1 Diabetes

Gwen Geiger Wolfe, MPH, MLS\*<sup>a</sup>, Sally Bowler-Hill, MA, MSIS, PMP<sup>b</sup>, Lisa M. Acuff, MPH, MSIS, AHIP<sup>b</sup>

<sup>a</sup>Science and Engineering Librarian, KU Libraries, University of Kansas, Lawrence, Kansas, <https://www.orcid.org/0000-0002-3309-2488>, [gwen.geigerwolfe@ku.edu](mailto:gwen.geigerwolfe@ku.edu),

<sup>b</sup>Manager, Administrative Operations, Health Sciences Library and Informatics Center, University of New Mexico, Albuquerque, New Mexico, <https://www.orcid.org/0000-0002-8371-0408>, [sbowler-hill@salud.unm.edu](mailto:sbowler-hill@salud.unm.edu),

<sup>b</sup>Education and Research Librarian, Health Sciences Library and Informatics Center, University of New Mexico, Albuquerque, New Mexico, <https://www.orcid.org/0000-0001-8427-4073>, [LAcuff@salud.unm.edu](mailto:LAcuff@salud.unm.edu),

**Cite as:** Geiger Wolfe G, Bowler-Hill S, Acuff LM. Development of an Empowering Language Assessment Tool for Type 1 Diabetes. *Hypothesis*. 2024;36(1). doi:10.18060/27668



CC BY-NC 4.0 DEED

Attribution-NonCommercial 4.0 International

Geiger Wolfe, Bowler-Hill, Acuff. All works in *Hypothesis* are licensed under a [CC BY-NC 4.0 DEED Attribution-NonCommercial 4.0 International](https://creativecommons.org/licenses/by-nc/4.0/). Authors own copyright of their articles appearing in *Hypothesis*. Readers may copy articles without permission of the copyright owner(s), as long as the author(s) are acknowledged in the copy, and the copy is used for educational, not-for-profit purposes. For any other use of articles, please contact the copyright owner(s).

## Abstract

**Introduction:** This brief report describes the early development of an Empowering Language Assessment Tool (T1D-ELAT) for patient education materials (PEMs) designed for people with type 1 diabetes (T1D), consisting of a checklist to assess the frequency of disempowering language.

**Methods:** The authors followed professional society guidelines to develop a checklist to quantify the use of disempowering words and phrases. We determined inclusion and exclusion criteria and grouped checklist terms into functional categories. We also collected descriptive characteristics about each PEM, such as publication date, authorship, and country of origin, and created a codebook defining these terms and descriptive characteristics.

**Results:** The authors tested the checklist in two rounds and added nine term variations as a result. We removed the imperative can/can't/cannot during testing because it was not consistently used as an imperative.

**Discussion:** Pilot testing the checklist informed revisions to the checklist and study protocol. Future phases of this research project will also explore the context in which disempowering terms are used in these materials.

## Introduction

This brief report describes the development of an Empowering Language Assessment Tool (T1D-ELAT) for patient education materials (PEMs) designed for people with type 1 diabetes (T1D) and their caregivers. The tool consists of a checklist to document the frequency of disempowering language usage in PEMs authored by academic, clinical, government, and health-related organizations. Disempowering language in diabetes care and education includes the use of stigmatizing, blaming, and condition-first words and phrases, such as “diabetic,” “good/bad control,” or “must.” The authors anticipate future usage of the T1D-ELAT in academic and clinical settings or by any professional evaluating PEMs for community dissemination. Background information for this research is available on the Open Science Framework<sup>1</sup> and in the *Journal of Consumer Health on the Internet*<sup>2</sup>.

## Methods

Professional society guidelines on the use of language in diabetes care and education informed the development of the checklist<sup>3</sup>. The guidelines list disempowering words and phrases with empowering alternatives. The checklist includes disempowering language relevant to written PEMs and excludes terminology specific to clinical communications. The T1D-ELAT assesses disempowering language because empowering alternatives are many and various. Empowering alternatives for the word “control” used as a noun, for example “good control,” include “an A1C less than 7%” or “glucose values within target,” which focus on factual terms that are neutral<sup>3</sup>.

The authors grouped T1D-ELAT words and phrases into functional categories: *control* (verb or adjective), *control* (noun), *diabetic* (adjective or noun), imperatives, *prevent*, and *test* (verb

or noun); and excluded medical terms, such as *diabetic ketoacidosis*. **Table 1** provides a complete list of T1D-ELAT terms. In addition to disempowering language, the checklist collects descriptive characteristics, including country of origin, authorship, audience, and publication date. The authors subsequently excluded the audience characteristic because the terminology in PEMs for people with T1D was similar for adults, parents, and children. Finally, we created a codebook to define the disempowering terms and descriptive characteristics and guide the application of the tool.

Table 1. T1D-ELAT Disempowering Words and Phrases by Category

Category	Disempowering Words and Phrases
Control as Verb or Adjective	Controlled / Uncontrolled Well controlled / Poorly controlled Control your / Control the/ Controlling your
Control as Noun	Glycemic control / Glucose control / Blood sugar control Poor control / Bad control Good control / Tight control
Diabetic as Adjective or Noun	Diabetic person / Diabetes patients Diabetic / Nondiabetic (*exclude diabetic ketoacidosis)
Imperatives	Should / Shouldn't/Should not Have to / Need to Must / Must not
Prevent	Prevent / Prevention / Preventing/ Preventable
Test as Verb	Test blood glucose / Test blood sugar / Test your blood sugar / Blood sugar tested
Test as Noun	Blood test Test strips

## Results

The authors pilot tested the checklist in two rounds: informally with PEMs about type 2 diabetes and formally with eleven PEMs about T1D. We added nine variations during formal testing: *control your*, *controlling*, *blood sugar control*, *preventing*, *preventable*, *test blood sugar*, *test your blood sugar*, *blood sugar tested*, and *blood test*. We removed the terms *can*, *can't*, and *cannot* during testing because they occurred in multiple contexts, often not as imperatives. The authors presented results from the formal pilot study at the Empirical Librarians Conference in March 2023<sup>4</sup>.

## Outcomes

The authors did not count instances of disempowering words in organizational names like the Centers for Disease Control and Prevention during pilot testing; however, we included them in the revised checklist because they potentially impact people's perceptions and experiences. After pilot testing, the authors used the revised checklist to assess a sample of twenty-nine publicly available PEMs, and we are currently engaged in descriptive analyses.

The changing nature of language, such as the shift from condition-first to person-first language in diabetes care and education, is one limitation of the T1D-ELAT. In future phases of this research, the authors plan to explore the context in which PEMs use disempowering language. In summary, the T1D-ELAT offers a tool for assessing the real-world use of disempowering language in PEMs about T1D.

## Author Contributions

Gwen Geiger Wolfe: Conceptualization, Investigation, Methodology, Writing – original draft, and Writing – review

Sally Bowler-Hill: Conceptualization, Investigation, Methodology, Writing – original draft, and Writing – review

Lisa M. Acuff: Conceptualization, Investigation, Methodology, Writing – original draft, and Writing – review

## References

1. Acuff L, Geiger Wolfe G, Bowler-Hill S. Disempowering language in online patient education materials for people with type 1 diabetes: A summative content analysis. Open Science Framework. 2023. Available from: <https://osf.io/wqh35>
2. Acuff L, Geiger Wolfe G, Bowler-Hill S. The language of type 1 diabetes: Why it matters in online patient education. *J Consum Health Internet*. 2023, Mar 07. Cited 2023 Oct 20; 27(1):86-97. doi:[10.1080/15398285.2023.2167424](https://doi.org/10.1080/15398285.2023.2167424)
3. Dickinson JK, Guzman SJ, Maryniuk MD, O'Brian CA, Kadohiro JK, Jackson RA, et al. The use of language in diabetes care and education [Internet]. *Diabetes Care*. 2017 Dec 1. Cited 2022 Aug 26; 40(12):1790–9. doi:[10.2337/dci17-0041](https://doi.org/10.2337/dci17-0041)
4. Eaker C, Sergiadis A. Empirical Librarians Conference. Open Science Framework. 2023. Available from: <https://osf.io/7hjte>