Developing Person-Centered Metadata: A Case Study of The Behaviours in Dementia Toolkit

Nick Ubels*, Lisabelle Tan**, Lauren Albrecht*** and Angel Long****

* *** **** Canadian Coalition for Seniors' Mental Health (CCSMH),
6-20 Crown Steel Drive, Markham, ON, L3R 9X9Canada
**University of British Columbia School of Information, 1961 East Mall, Vancouver, BC V6T 1Y3
*nubels@ccsmh.ca , **lisabelle_tan@nlb.gov.sg, ***lauren.albrecht@ualberta.ca, **** along@osgoode.yorku.ca

Nick Ubels (he/him) is a health promotion coordinator with the Canadian Coalition for Seniors Mental Health (CCSMH). He holds a Master of Library and Information Studies degree from the University of British Columbia. Before coming to CCSMH, he worked in various settings, including journalism, public education, public libraries, and academic libraries. His areas of professional interest include community engagement, instruction, and knowledge mobilization for social good.

Lisabelle Tan (she/her) is an early-career library and information studies professional based in Singapore, where she lives, works, and writes. She completed a professional experience with the Canadian Coalition of Seniors' Mental Health as part of her Master's in Library and Information Studies degree at the University of British Columbia. She is currently an Arts and General Reference librarian at the National Library of Singapore. Outside of work, she dabbles in photography, putters with poetry, and volunteers with a mental health collective for people with lived experiences, with a focus on sustained recovery and resilience.

Lauren Albrecht holds a PhD in Educational Psychology. For the last 15 years she has focused on developing, implementing, and evaluating knowledge mobilization approaches to bridge the research-practice gap in health services. Lauren is particularly interested in foregrounding equity-deserving groups and intersectional perspectives in both knowledge mobilization and research activities.

Angel Long (she/her) is a library technician working as a Law Library Clerk at Osgoode Hall Law School's law library. She has worked as a technical services librarian at the Ministry of the Attorney General's law library in Ontario, and as a library technician at CCSMH. Angel received a Bachelor of Social Work from Toronto Metropolitan University and a Library and Information Technician (LIT) diploma from Seneca College. She hopes to combine her experiences and learnings to promote inclusivity in her work.

Ubels, Nick, Lisabelle Tan, Lauren Albrecht, and Angel Long. 2024. "Developing Person-Centered Metadata: A Case Study of The Behaviours in Dementia Toolkit". *Knowledge Organization* 51, no. 7: 478-494. 36 references. DOI:10.5771/0943-7444-2024-7-478.

Abstract: Terminology used in dementia care is fiercely contested. Advocates, health care providers, and researchers often have divergent perspectives on how aspects of dementia can and should be described. We created the Behaviours in Dementia Toolkit – a free, online library of resources available at behavioursindementia.ca – to equip health care providers and care partners with important health information to better understand and compassionately respond to changes in mood and/or behaviour that often accompany dementia. To centre the personhood of those living with dementia within our online library, we created an emergent metadata schema to support the information needs of our diverse audiences, which included people with lived experience of dementia, care partners, and multidisciplinary health care providers (e.g., allied health, nurses, and doctors, care aides, etc.). This was an iterative process that utilized a combination of methods including a usability study, card sort activity, environmental scan, internal metadata brainstorming exercise, working group discussions, consultations with various stakeholders, and real-world application of the metadata description process. Our approach leveraged interdisciplinary expertise from the library and information studies, knowledge mobilization, dementia health care, and user experience fields, in addition to the lived experiences of people with dementia and their care partners. This interdisciplinary expertise was formative in shaping the dimensions of metadata development and to ultimately create and apply clear, accurate, inclusive, and intuitive terminology for diverse end-users. Creating a robust schema meant negotiating an unresolvable tension between labelling behaviour changes to enhance the navigability of the collection and avoiding pathologizing these behaviours and perpetuating stigma. Our approach was to reframe symptoms of behaviours in dementia (also called behaviours and psychological symptoms of dementia or BPSD in the clinical world) to focus on observable changes in mood or behaviour. This created space to move away from a focus on care partners' or health care providers' reactions to or discomfort with specific behaviours; it also allowed us to step away from interpreting normal human behaviours and emotions as deviant. By contextualizing the changes of mood and behaviour for the person living with dementia, we can affirm their holistic personhood and resist reducing them to a set of symptoms. This approach confers dignity, agency, and hope to people living with behaviours in dementia. This case study describes the process and outcomes of navigating the complexity of creating, refining, and implementing person-centered terminology in the context of the Behaviours in Dementia Toolkit. We illustrate how we grappled with the scope, nature, meanings, and assumptions of terminology about moods, behaviours, and symptoms associated with behaviours in dementia, and the decisions we undertook that guided us to our eventual launch version of the website. We also delve into the inner workings of our online library that are interwoven throughout the seamless and intuitive design of our end-users' experience of the Toolkit website. Through this, we demonstrate that our design and end-to-end development of the Toolkit are anchored in the practice of person-centered approaches at their core, and that these values are embedded with thoughtfulness and careful consideration. As a result of our findings, we suggest the exploration and further theoretical development of the concept of person-centered warrant. We also share how lessons learned from moving beyond stigmatizing terminology to humanizing, person-centered terminology may be adapted to future projects in other contexts across the library and information, health care, and knowledge mobilization fields, and beyond.

Received: 22 March 2024; Revised: 11 July 2024; Accepted: 19 July 2024.

Keywords: person-centered terminology; Behaviours in Dementia Toolkit; controlled vocabulary.

1.0 Introduction

An estimated 55 million people worldwide are living with dementia, a degenerative brain disorder caused by several diseases that impact memory, thinking, mood, and behaviour (World Health Organization 2023). While cognitive changes are commonly viewed as the defining feature of dementia, its onset and progression are often accompanied by changes in mood or behaviour that may be distressing and contribute to a reduced quality of life for people living with dementia and those involved in their care (Canadian Coalition for Seniors' Mental Health 2024; Cerejeira et al. 2012). Knowledge of person-centered prevention and intervention strategies can effectively improve the well-being of people living with dementia; however, reliable information resources can be difficult to find (Isik et. al 2018; Jagoda et. al 2023; Peterson et. al 2016). In response, the Canadian Coalition for Seniors' Mental Health (CCSMH), a pan-Canadian charitable organization, created the Behaviours in Dementia Toolkit (behavioursindementia.ca), an online platform containing a library of more than 300 curated resources to equip formal and informal care partners to better understand and compassionately respond to changes in mood or behaviour that often accompany dementia.

To develop the Behaviours in Dementia Toolkit, CCSMH followed a human-centered design process which prioritizes meeting the preferences and needs of intended users (van Velson et al 2022; Taylor et al. 2011). Moreover, human-centered design can be conceptualized as a flexible, "integrative" practice drawing on interdisciplinary expertise and collaboration for this purpose (Guy 2017). This project primarily addressed two key user groups involved in the care of someone living with dementia: formal care partners which are professional health care providers and informal care partners, which are typically unpaid family members and friends. While people living with dementia were not identified as direct users of the Behaviours in Dementia Toolkit, we intended this library to provide support for them and ultimately improve their well-being. Affirming their dignity, autonomy, and personhood was a core value of this project that guided design decisions, especially our choice of words and phrases to describe both the characteristics of dementia and those living with this condition.

As a source of authority in developing classification systems, warrant is invoked to justify decisions about terms, their relationships, and their order (Bullard 2017, 78). We relied heavily on user warrant, or a "bottom-up approach that prioritizes the language, expertise, and concerns of the immediate user" to construct our metadata schema, with a secondary reliance on literary warrant, in which concepts and terms are derived from the items being classified themselves (81). The value proposition of this library was to provide a highly curated selection of resources; we therefore expected a relatively small collection and sought to ensure that our classification scheme would yield a satisfactory number of results for each term. In this way, literary warrant can also improve the usability of the system. These warrants provided the greatest alignment with a human-centered design process; yet significant disagreements between user groups and within the literature required careful negotiation and principled compromise centering the personhood of people living with dementia.

Terminology used in dementia care is fiercely contested, which made devising effective and inclusive descriptive metadata for the Behaviours in Dementia Toolkit a significant challenge. Advocates, health care providers, and researchers often have divergent perspectives on how aspects of dementia can and should be described (Gilmore-Bykovskyi 2020). The power and influence of word choice on how people with dementia are viewed and treated are widely recognized (Wolverson et al. 2021; Burley et al. 2021). Clinical terminology for specific behaviour and mood changes is often perceived to be medicalizing and stigmatizing (Adekoya and Guse 2019). Deficit-based language can exacerbate suffering from "living under the shadow of negative imaginaries" (van Wijngaarden et al. 2017). The potential impact of such terminology choices is amplified when they are then structurally embedded in the controlled vocabulary of a library catalog. Online public access catalogs (OPACs) assume subject authority and act as powerful communication intermediaries that can either enhance or inhibit users' access to the items they reference (Wells 2021). Those responsible for the creation of such classification systems and the naming of the information referenced therein have significant power to frame, represent, and even construct knowledge in ways that often reinforce existing social norms unless they are critically interrogated (Olson 2002). This is particularly apparent when it comes to the mis- and under-representation of marginalized groups and topics, such as people living with dementia (Olson 2002). Major existing tools (such as the Medical Subject Headings and Library of Congress Subject Headings) do not align with the values of many communities and were likewise ill-suited for describing items selected for inclusion in the Behaviours in Dementia Toolkit (Wells 2021). Advocates recommend using person-centered language as a way to recognize the full humanity of people living with dementia and avoid exacerbating stigma and discrimination (Alzheimer Society of Canada 2017; Flipping Stigma Action Group n.d.). Person-centered language typically rejects the use of labels to describe people, but naming and labelling information is necessary for a functional, accessible library system. Negotiating these unresolvable, multi-directional tensions between conflicting user group preferences; and between the principles of person-centered language and the functional requirements of a library system animated the development of an emergent in-house metadata schema for the Behaviours in Dementia Toolkit.

This case study describes our iterative, human-centered design process to develop, refine, and implement person-centered metadata for the Behaviours in Dementia Toolkit. We step through two critical and complex facets, purpose and symptom, to illustrate how we grappled with the scope, nature, meanings, and assumptions of terminology about moods and behaviours associated with dementia. Through this, we demonstrate that our design and end-to-end development of the Behaviours in Dementia Toolkit are anchored in the practice of user-centered approaches and that these values are embedded with thoughtfulness and careful consideration. Lastly, we also share how lessons learned from moving beyond stigmatizing terminology to humanizing, person-centered terminology may be adapted to future projects in other contexts across the library and information, health care, and knowledge mobilization fields, and beyond.

2.0 Foundations

At the outset of this project, the interdisciplinary Behaviours in Dementia Toolkit working group established shared values to guide website development. These included 1) promoting quality information resources, 2) supporting efficiency in clinical practice and within health systems, 3) encouraging resourcefulness, and 4) leading supportively. We refined our intended primary user groups as formal and informal care partners in Canada and affirmed that the information needs of each group should be equally addressed by the library. Formal care partners include physicians, nurses, psychologists, personal care workers, and other health care and social service providers who work with people living with dementia. Informal care partners include spouses and partners, other family members, friends, neighbours, community members and others who are typically not paid for their support of someone living with dementia. A tertiary, yet significant user group was proxy information seekers such as librarians and social service providers (El Sherif et al. 2022; Ubels and Albrecht 2024). Formal care partner perspectives were well-represented in our interdisciplinary working group, but we recognized a gap in the perspectives of informal care partners and older adults. To address this, we conducted a separate literature review assessing the health information needs of older adults (Ubels and Albrecht 2024). This work, alongside the direct consultations described in each phase of metadata development below, contributed to the extensive use of user warrant in the development of collection metadata. Finally, we established collection scope and curation criteria (see Table 1). This enabled us to begin a thorough environmental scan to identify more than 1400 candidate items to consider including in the library collection. This scan had a secondary purpose of enabling us to more easily establish literary warrant using sample items in the development of our metadata schema (Barité 2018). Our overarching design process, including integrating the input of health care, knowledge mobilization, user experience, and library and information studies professionals, is described in a separate publication (Albrecht et. al submitted).

Based on our emerging understanding of formal and informal care partner information needs, and the common features of candidate items, we used affinity mapping to determine a series of fields and facets to include in our descriptive metadata schema that would support findability (see Table 2).

Our goal was to select controlled terms for each facet that would be perceived by users as accurate, table clear, and inclusive (see Figure 1). The controlled terms for each facet were tested and refined using similar methods as those described in this paper, but we highlight symptoms, the most complex and challenging facet, to illustrate our process and findings.

3.0 Initial metadata construction

Having devised an initial set of facets and fields, we began constructing controlled vocabularies. Equity perspective terms were developed based on a rapid scan of terminology preferred by groups whose identities were being described and direct, one-on-one consultations with service providers from these communities. We began developing a series of purpose categories based on anticipated user goals for use of the information found in each item in the collection. Given our organizational ties to formal care providers, we started with a series of purpose terms oriented to a typical clinical progression for addressing symptoms: Recognize, Assess, Understand, Manage, and Treat.

For the symptoms facet, source material included an internal working list of behavioural and psychological symptoms of dementia (BPSD) provided by the clinical co-leads of CCSMH's BPSD guideline development group, and representative sample items sourced from an external environmental scan of 1,408 knowledge resources pertaining to behaviours in dementia. The internal working list of symptoms and external scan of knowledge resources drew on two distinctive types of warrant: user warrant and literary warrant, respectively.

Criteria	Remarks
1. Relevance	Must have practical relevance when supporting someone experiencing changes in mood or behaviour related to dementia.
2. Credibility	Must reflect evidence-informed approaches.
3. Accessibility	Must be freely available online and follow best practices for universal accessibility.
4. Inclusivity	Must reflect diversity of perspectives and reflect inclusive approach. Items that contain discrimination or harmful language will be excluded.
5. Canadian origin	Priority given to resources created in Canada.

Table 1. Summary of Behaviours in Dementia Toolkit Selection Criteria

Facet	Description
Purpose	Categories of items based on user goals.
Symptoms	Observable behaviour or mood symptoms.
Format	The medium and/or genre of the item.
Equity perspectives	Identifies when items are created by and for a particular equity-deserving group.
Intended audience	The user group(s) the item was created for.
Origin	Whether the item was created in Canada or internationally.
Setting	Whether the item is relevant to a particular care setting.
Type of Dementia	Whether the item is relevant to a particular form of dementia.
Accessibility features	Itemizes accessibility features available (i.e. closed captioning)

Field	Description
Title	Short, descriptive title for item.
Description	Clear language summary of item.
Created by	Corporate or individual author(s)
Date	Year item was published
Length	Length in pages or time as applicable.

Table 2. Facet and field development for the Behaviours in Dementia Toolkit

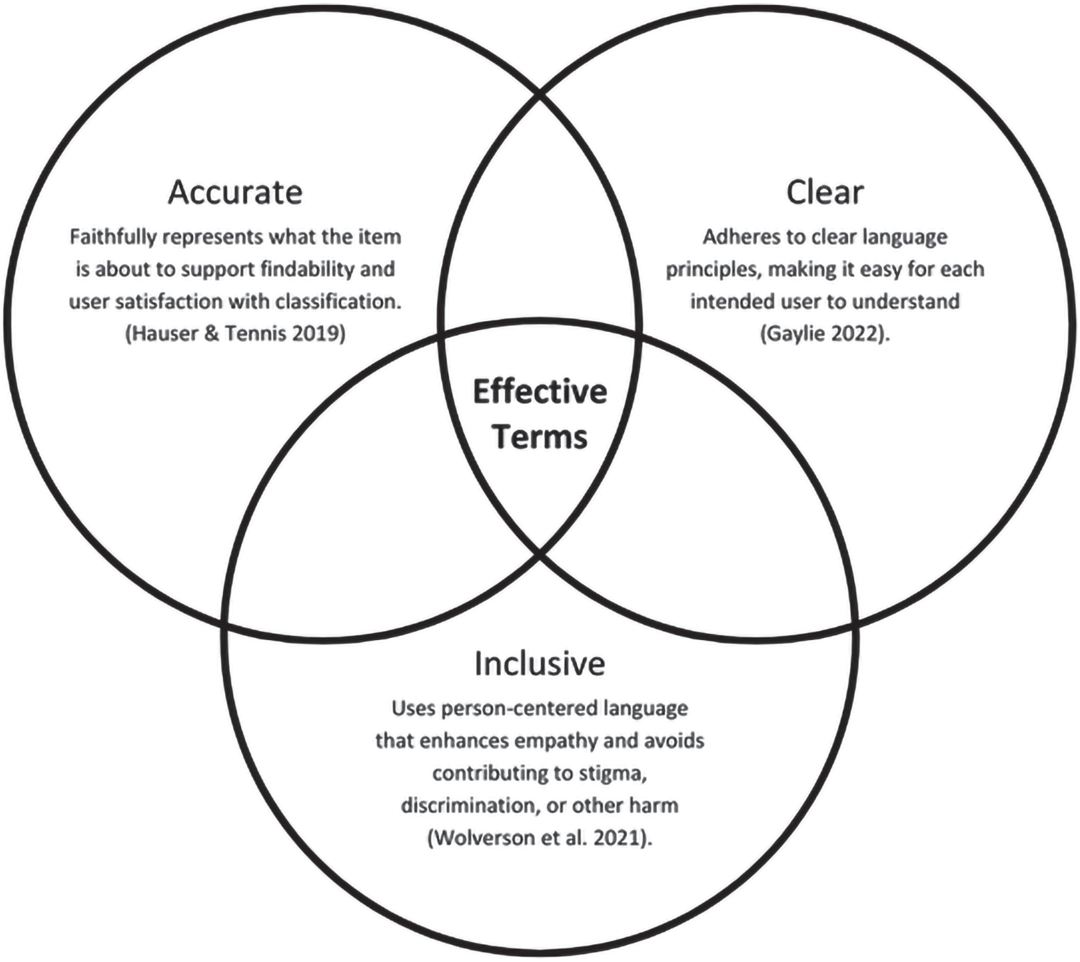


Figure 1. Selection Criteria for Effective Terminology

We began the analysis by extracting all the symptom terms from each source, then combining them into a master list, differentiated by source and organized in alphabetical order. Using a collaborative visualization whiteboarding tool (Miro), we placed the 10 symptom terms from the internal working list in a column on the left, and the 15 symptom terms from the external scan in a column on the right. Across the two sources, there were exactly 6 common symptom terms. Associated or similar symptom terms were clustered together in the same row (i.e., Agitation, Restlessness, Screaming; Nighttime Behaviour, Sleep Disturbances). Symptom terms that were not commonly encountered (e.g. Hoarding, Shadowing), were placed at the end of the right-hand column. Table 3 demonstrates how we grouped similar terms to achieve greater conceptual clarity.

Following the comparative analysis, we drafted a preliminary thesaurus, comprising the 10 symptom terms from the internal working list, Use For (UF) terms, and remarks (see Table 4). Concepts derived from user warrant by way of the initial list of BPSD symptoms were prioritized in this phase while we considered how best to classify items that were about other symptoms. We developed a non-exhaustive list of UF terms to point prospective users towards preferred terminology using the library's search engine. In remarks, we highlight potential limitations or concerns related to each term.

Developed largely by geriatric psychiatrists and tailored to formal care partners, the initial list of BPSD symptoms primarily reflected the expertise of one distinct group of users. Their professional expertise was a valuable foundation, but it still had limitations as it could not comprehensively represent the variety of formal care partners such as nurses, social workers, etc. The list itself was debated among the guideline development group members at the time, meaning symptom definitions lacked precision and consistency. Within the dementia care community, the term and framework of BPSD itself are also contested. Critics argue that it reduces people living with dementia to a set of clinical symptoms and deviant behaviour, instead of acknowledging their personhood (Macauley 2018). Another key criticism is that the term BPSD often implies that changes in mood or behaviour are an inevitable consequence of the condition, ra-

Internal Working List (User Warrant)	**External Scan of Knowledge Resources (Literary Warrant)**	**Associated Terms**
Aggression*	Aggression*	Aggressive behaviour Acting out Assault
Agitation*	Agitation*	Agitated behaviour Getting worked up Increased irritability Increased frustration Distressed Restlessness
Anxiety*	Anxiety*	Anxious behaviour Nervousness Prone to panic Restlessness
Apathy	N/A	Indifference Disinterest Losing interest in activities they used to enjoy No interest in activities Lacking emotion
N/A	Cursing and Swearing	
Depression*	Depression*	Depressed behaviour Feelings of hopelessness Feelings of dejection Feelings of worthlessness Inexplicable crying Distressed
Eating Disturbances	N/A	Change in eating habits Loss of appetite
N/A	Hoarding	Collecting excessive items to the point of extreme clutter
Inappropriate Sexual Behaviour	N/A	Sexual misbehaviour
N/A	Pacing and Repetitive Motor Activity	
Nighttime Behaviour	Sleep Disturbances	Inability to fall asleep Inability to stay asleep Disrupted sleep Nightmares
	Sundowning	
Psychosis*	Psychosis (Delusions and Hallucinations)*	Confused thinking Disordered thinking Auditory hallucinations Visual hallucinations Sensory hallucinations Out of touch with reality
N/A	Repetitive Vocalization	
N/A	Restlessness	
N/A	Screaming	
N/A	Shadowing (Following the carer closely)	
Wandering*	Wandering*	Roaming Getting lost even in familiar places

Table 3. Initial Lists of Symptom Concepts by Source and Associated Terms (as of May-Aug 2023)
*Common symptoms/terms across the two sources

S/N	Symptom/Term	Use For (UF)	Remarks
1	Aggression	Aggressive Anger Angry	Potential overlap with Agitation, if Agitation is a precursor to Aggression.
2	Agitation	Agitated	Potential overlap with Aggression, if Aggression is a result of escalated Agitation.
3	Anxiety	Anxious Jitters Jittery Nervous	Anxiety can refer to an emotion, a state of mind, or a mental health condition. According to the DSM-5, the key features of generalized anxiety disorder are persistent and excessive anxiety and worry that the individual finds difficult to control (American Psychological Association, 2013). The ubiquity and common understanding of this term made it a strong candidate term.
4	Apathy	Apathetic Indifference Indifferent	Apathy refers to an absence of feeling or emotion, while Indifference refers to a lack of concern or sympathy for others in a given context.
5	Depression	Depressed Despondent Melancholic Morose Sad Sadness	Sadness is an emotion that individuals experience, while depression is a mental health condition. According to the DSM-5, the key features of depressive disorders include the presence of sad, empty, or irritable moods and behaviours that significantly affect capacity to function (American Psychological Association, 2013). As an emotion, sadness is distinct from the clinical diagnosis of a depressive disorder. The use of the term can risk pathologizing behaviours in dementia, which may perpetuate stigma.
6	Eating Disturbances	Change in Eating Habits Loss of Appetite	The term “Disturbances” has a negative connotation. It is also a fairly complex word that does not adhere to plain language conventions. The use of this term may also pathologize behaviours in dementia.
7	Inappropriate Sexual Behaviour	Sexual Misbehaviour	Inappropriate Sexual Behaviour is a term that is preferable to its variant, “Sexual Misbehaviour” as the latter has a more significantly negative connotation. “Misbehaviour” suggests deviance from social norms when the individual may not have the intention to harm. However, “Inappropriate” may still be seen as contributing to stigma.
8	Nighttime Behaviour	Inability to Fall Asleep Inability to Stay Asleep Insomnia Sleep Disruption Sleep Disturbances Sundowning	Nighttime Behaviour is vague and may encompass both changes in sleep patterns and sundowning: a phenomenon associated with increased confusion and restlessness in people living with dementia during the late afternoon and evening.
9	Psychosis	Confused Thinking Delusions Hallucinations □ Auditory Hallucinations □ Visual Hallucinations	Psychosis is a less common mental health condition which can lead to the individual experiencing thoughts, beliefs, and perceptions that are not grounded in reality (American Psychological Association 2013). Psychosis is an often-misunderstood condition that is unfamiliar and frightening to the general public, the person experiencing psychosis, and their care partners. The use of this term is not recommended as it pathologizes behaviours in dementia and further perpetuates stigma.
10	Wandering	Getting Lost Inability to Find Way Roaming	Wandering is a term that may be vague but is preferable compared to its other variant terms which are either too clunky (“Inability to Find Way”) or even vaguer (“Roaming”). “Getting Lost” also comes across as curt.

Table 4. Preliminary Thesaurus of Symptom Terms in Alphabetical Order

ther than an expression of an unmet need or behaviour that might be modifiable with more awareness of a person living with dementia's life, wants, needs and environmental, social, cultural, and personal contexts. We also recognize that using the term BPSD as a starting point has other drawbacks. As both containing and consisting of medical jargon, it may pose a barrier for informal care partners and inadvertently signal the library is designed with only professionals in mind (Allen et al. 2023). In fact, members of an older adult focus group tasked with helping name the library website rejected the use of the term or its acronym in its title or tagline entirely. At this stage, we had yet to adequately factor in the concerns of informal care partners and the perspectives of people living with dementia to fulfill our objective of supporting their well-being. While terms gathered from existing literature may better represent the variety of professional perspectives on dementia care, they are inconsistent and may include non-preferred terminology. Drawing literary warrant into conversation with our initial list of symptoms provided an opportunity to test whether these terms could sufficiently represent the breadth of subjects we anticipated including in our collection.

In the Remarks column of Table 4, we identified concerns about how accurate, clear, and inclusive each of the 10 terms were. While some of the terms such as "Anxiety" and "Apathy" were assessed as reasonably accurate, clear, and inclusive, there were terms that were more problematic in their connotation, expression, and form. "Depression" and "Psychosis" are two symptoms of dementia that are also mental health conditions on their own. While "Depression" is popularly understood as a clinical form of sadness, "Psychosis" is an often-misunderstood condition which can mislead people to assume untrue and negative stereotypes of individuals assumed to be experiencing a psychotic episode. Awareness and knowledge of psychosis among the public is limited and subject to the influence of distorted stereotypes and irresponsible media reports. For instance, "Psychotic" and "Psychopathic" are discrete and distinct concepts but are often conflated together as a derogatory term that refers to a dangerous individual. Cultural or spiritual interpretations of the medical symptoms of psychosis may also make this framing exclusionary (American Psychological Association 2013). For example, some Indigenous communities understand hallucinations within dementia to be visions bestowed as an important gift from the Creator (Jacklin and Walker 2020). The use of the term "psychosis" is not recommended as it pathologizes behaviours and symptoms of dementia and further perpetuates stigma and could be reframed more inclusively. Yet identifying a suitable alternative that could adequately encompass this range of behaviours proved challenging.

4.0 Integrating diverse user perspectives

In the second iteration of our controlled vocabulary development, we sought input from a broader range of sources that were grounded in international perspectives on dementia language guidelines and included a diverse array of users. We anticipated these activities would help get us closer to our desired outcome of accurate, clear, and inclusive terms that both centre the personhood of people living with dementia and enhance the usability of the Behaviours in Dementia Toolkit for both cohorts of intended users.

Our purpose categories underwent significant development at this stage as we sought to integrate the perspectives of older adults and care partners. We added categories based on their anticipated information goals (see Table 5) and engaged a group of seven public health workers and care partners in a card sort exercise using 10 sample collection items to investigate category agreement and clarity. Participants generally felt the categories balanced specificity with sufficient breadth. While they offered some differing term suggestions, the concepts broadly resonated with users.

Expanding the scope of our information sources empowered us to include more possibilities of what accurate, clear, and inclusive terminology might look like across transcontinental and transcultural contexts. We cross-referenced dementia language guidelines from international sources to clarify and justify our decisions, while still situating ourselves in a Canadian context (Dementia Singapore 2020; Behavioural Supports Ontario 2018; Flipping Stigma Action Group n.d.; Alzheimer Society of Canada 2018; Dementia Australia 2024). In the context of dementia care, the terms "responsive behaviours" or "personal expressions" are often preferred frameworks that interpret a person's words and actions are a form of meaningful communication, often of unmet needs. Two examples of frequently used terms within these framings to signify what BPSD terms "aggression" are "unsafe behaviours" and "personal expressions of risk."

During this phase we continued to regularly meet with our expert working group. We also met one-on-one with a variety of formal and informal care partners to receive their input on the development of the Behaviours in Dementia Toolkit. Participants were asked to share their perspectives on information needs, terminology, and effective ways to promote the use of the library among their communities. We conducted an internal persona empathy mapping exercise (a collaborative visualization technique) to synthesize knowledge and gaps in knowledge about intended users (Kaplan 2023). This enabled us to humanize abstract and complex user data to solidify a shared understanding of users' information needs, motivations, and challenges (see Figure 2 for a completed example). This helped inform our decision-making throughout the project's development.

Initial Purpose Terms	**Revised Purpose Terms (I want to…)**	**Remarks**
Recognize	Understand dementia-related behaviour changes Access clinical guidelines	Insufficient distinction between these aspects within knowledge resources under consideration.
Understand		
Assess	Access clinical tools and assessments	Suggested by working group as relevant purpose for visiting site.
Manage	Respond to symptoms	
Treat	Support with medication and/or deprescribing	Formal care provider-oriented category
	Support without medication	Holistic, non-pharmacological approaches.
New	Learn from people with lived experience	Accommodated resources that provide valuable perspectives of people living with or caring for people living with dementia.
New	Practice self-care	Identified as important informal care partner information need supported by results of knowledge scan.
New	Take an e-learning course	Suggested by working group as relevant purpose for visiting site.

Table 5. Changes to Purpose Terms

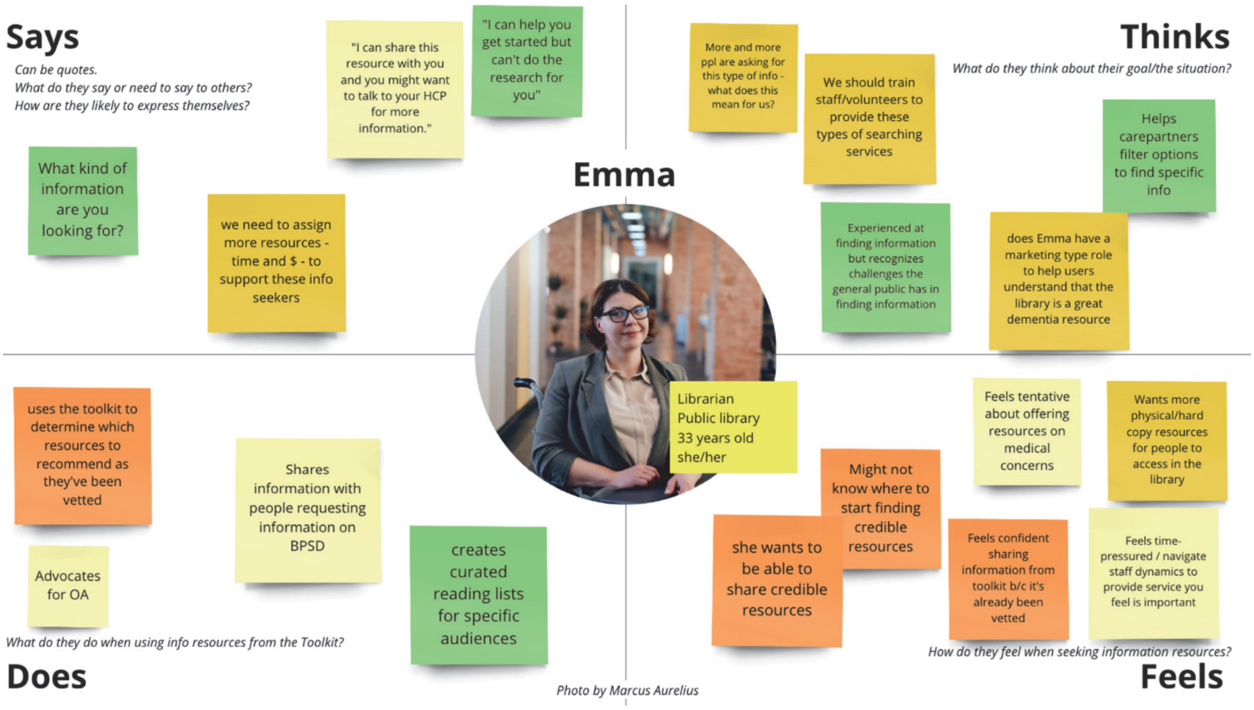
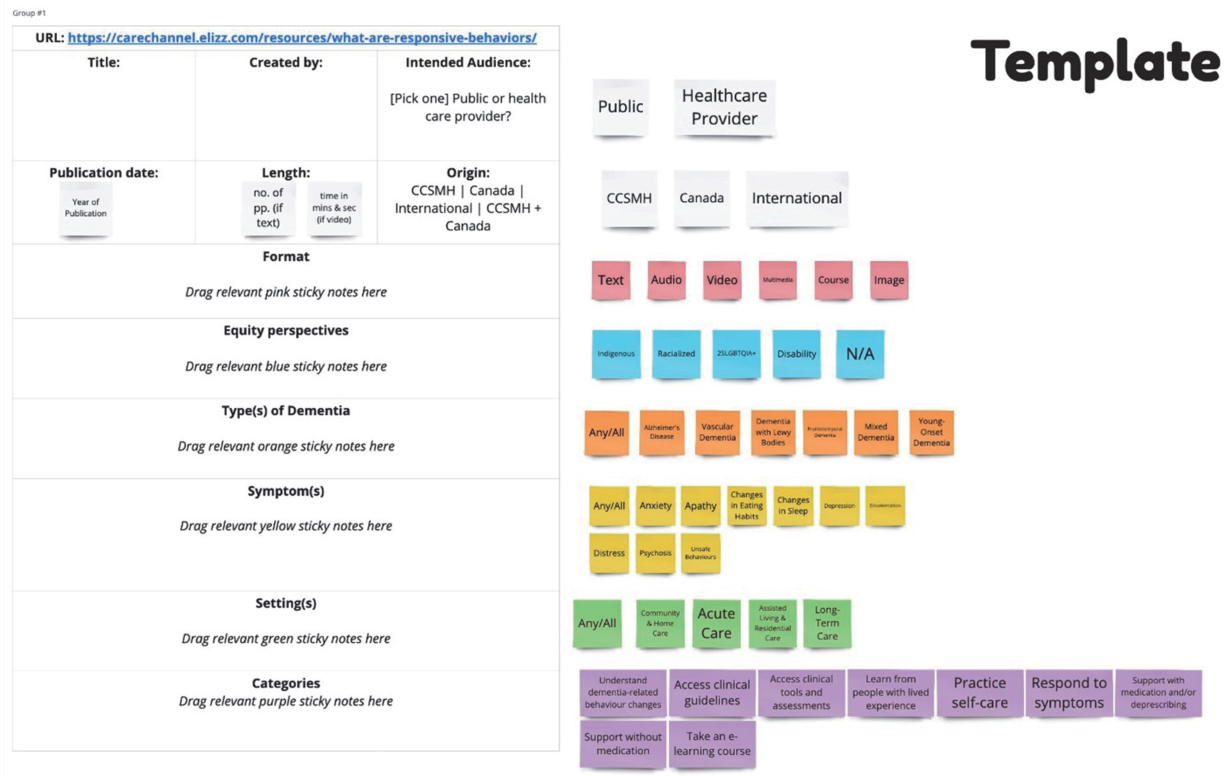


Figure 2. Example of Completed Persona Empathy Map – Emma the Librarian

We adapted the metadata-thon model into a reflective hands-on opportunity to test our emergent metadata schema with prospective non-librarian users (Bullard et al. 2023). The term "metadata-thon" is a portmanteau of "metadata" and "marathon" and was inspired by Wikipedia edit-a-thons, hackathons, and research sprints (STOREE 2019). Our metadata-thon sought to gain insight into both the backend perspective of the item cataloguer and the front-end perspective of the user. Alignment between cataloguer and user understanding of terms helps facilitate more fluid use of the system. Using a combination of an online meeting platform (Zoom) and collaborative whiteboard application (Miro), we conducted an internal team workshop that introduced participants to the concept and significance of metadata and facilitated a hands-on small group activity to assign metadata elements of a sample item. We asked participants to consider metadata that was responsive to both the nature of the item they were describing, and also to the user and their information needs. We posed the question: if you were a website user, would you be satisfied if you found this item at the end of your search journey? Participants were asked to drag and drop sticky notes with controlled vocabulary terms into their appropriate field (see Figure 3).

Upon completion of the activity, we asked participants to share their reflections on what intuitively worked and what did not. We purposefully did not include scope notes or definitions in order to test the ease with which non-librarian participants could interpret the terms we selected. Some participants added terms (e.g. "Physical" and "Verbal") to the symptom facet because they did not feel that these concepts were adequately addressed by existing terms. Generally, participants were able to complete the activity with a high level of ease, suggesting our selection of terms was on the right track.

This phase of development moved us towards more inclusive terminology choices that still lacked sufficient clarity and/or accuracy (see Table 6). While it is critical to avoid labeling people, clear and accurate labels are necessary to facilitate finding items in a collection. Although terms frequently found in dementia-inclusive language guides, such as "responsive behaviours," "personal expressions", and "expressions of risk," promote the personhood of the person living with dementia, we determined they are better suited to the health care contexts they are more commonly used in rather than creating a functional classification system. We also were concerned that when informal care partners encounter these euphemistic phrases, they are interpreted as jargon and may be confused or alienated by material intended for their use. Several changes (e.g. "Agitation" > "Distress" and "Wandering" > "Disorientation") demonstrate a shift towards describing the underlying experience of the person living with dementia. One drawback of this approach is that it also requires some level of interpretation. In other words, we would have required users to move beyond observable symptoms to understand and effectively navigate the library system. We were not certain all users would be able to make this connection in order to interpret what we meant by these terms and how they would be applied to classify items within the collection. Other revised terms included an important evolution towards describing dementia-related changes in a particular mood or behaviour as neutral, observable symptoms (e.g. "Eating disturbances" > "Changes in eating habits" and "Nighttime behaviour" > "Changes in sleep"). Finally, we also attempted to shift the



Group #1

URL: https://carechannel.elizz.com/resources/what-are-responsive-behaviors/

Title:	**Created by:**	**Intended Audience:** [Pick one] Public or health care provider?
Publication date: Year of Publication	**Length:** no. of pp. (if text) time in mins & sec (if video)	**Origin:** CCSMH | Canada | International | CCSMH + Canada
Format *Drag relevant pink sticky notes here*		
Equity perspectives *Drag relevant blue sticky notes here*		
Type(s) of Dementia *Drag relevant orange sticky notes here*		
Symptom(s) *Drag relevant yellow sticky notes here*		
Setting(s) *Drag relevant green sticky notes here*		
Categories *Drag relevant purple sticky notes here*		

Figure 3. Template for Internal Metadata-thon Activity

S/N	Initial Term	Revised Term	Remarks
1	Aggression	Unsafe behaviours	Aggression is an interpretation of observable behaviour that implies judgement about intent. Unsafe behaviours focuses more on the outcome instead and may be less stigmatizing. While potentially more inclusive and clear, this term may lack sufficient specificity to be considered accurate.
2	Agitation	Distress	Distress points to underlying experience of person living with dementia, rather than its expression. This is less consistent with other terms and may also lack accuracy.
3	Anxiety	Anxiety	See remarks in Table 4
4	Apathy	Apathy	
5	Depression	Depression	See remarks in Table 4
6	Eating Disturbances	Changes in eating habits	Removed potentially stigmatizing term "disturbances" to represent change in behaviour a more neutral manner.
7	Inappropriate Sexual Behaviour	Unsafe behaviours	See remarks on S/N 1. Inappropriate pathologizes sexual behaviour in general. Further, people living with dementia may not have the discernment required to determine what is and is not appropriate sexual behaviour.
8	Nighttime Behaviour	Changes in sleep	Nighttime behaviour is a broad, yet somewhat ambiguous term used to describe a variety of changes related to sleep.
9	Psychosis	Psychosis	See remarks in Table 4
10	Wandering	Disorientation	Wandering is a term that also implies judgement related to intent and is seen as stigmatizing among many involved in informal care of people living with dementia. Disorientation points closer to the underlying experience of the person living with dementia that may lead to challenges or safety concerns.
11	**new**	Any or all	Added to recognize the growing number of relevant resources that do not address one or several symptoms in particular.

Table 6. Changes to Symptom Terms from First to Second Major Iteration

focus of two of the most contested and stigmatizing labels, "Inappropriate sexual behaviour" and "Aggression", towards a more neutral descriptor of their potentially harmful outcomes: "Unsafe behaviour." However, we remained dissatisfied with the euphemistic nature of this phrase and felt concerned about using it to classify all resources related to physical and sexual intimacy among people living with dementia. Further, metadata-thon participants instead created new terms for behaviours that we had hoped this term would signify. This highlighted a significant tension between clarity and inclusivity: a shortcoming in our attempt to balance preferred terms with more commonly used terms across diverse users.

The revised list of terms reflects the complexity of accounting for a diverse range of users in our human-centered design. As we brought in additional perspectives, it complicated our approach to describing symptoms in an accurate, clear, and inclusive way that resulted in several unresolvable inconsistencies. Where certain medical terms felt satisfactory at the time, others had emerged as lacking clarity for informal care partners and risked perpetuating stigma and discrimination against people living with dementia. Our initial efforts to address these considerations led to an assembly of terms that lacked internal coherence. We felt these changes were necessary to balance clarity with inclusivity but grew concerned these would negatively impact the usability of the system. However, we needed to hear directly from users in order to continue refining our schema.

5.0 Usability testing and further refinement

During the next iteration of our metadata schema, we worked with our web developer to integrate our facets and fields into a search interface hosted on the beta version of the website. 20 sample items were described and added to the site in order to facilitate 12 usability testing sessions where we asked formal and informal care partner users to search for items, apply a filter, and access an item. Ethics was obtained for this study from the Baycrest Research Ethics Board (REB# 23-42). The usability study is discussed in detail in another publication (Ubels et. alsubmitted). Several relevant findings informed the continued evolution of our metadata schema. First, informal care partners found medical terminology (such as "non-pharmacological approaches") alienating, despite their resonance with formal care partners, who welcomed the holistic approach to dementia care this term signified to them. Second, words with negative connotations were perceived to be deficit-based and discouraged users. This reinforced our commitment to de-medicalizing the terminology used for this facet and throughout the Behaviours in Dementia Toolkit.

At this stage, we struggled to arrive at a coherent set of terms that would adequately address our three priorities of accuracy, clarity, and inclusivity. Through several rapid rounds of iteration and internal discussions, we found that terms that might work well ceased to be inclusive and person-centered when categorized as a "symptom." For example, "Anger" is a normal human emotion, and to frame this as a symptom dehumanizes people living with dementia. Yet it would be a clear and accurate term to describe an increase in this mood following a dementia diagnosis. This led to our most significant breakthrough: reframing and redefining the entire facet. We decided to step away from labelling behaviour and mood change as a "Symptom", and instead as a "Change in [mood or behaviour]." This removed a medicalizing lens and allowed for our terms to act as a more neutral, objective description of observable changes in mood or behaviour. This reframing itself communicated a valuable perspective shift to users of the website that affirmed the personhood of people with dementia (inclusivity) while still operating as a functional classification scheme (accuracy) that would be easy for all users to interpret and cataloguers to apply (clarity).

Once this facet was reframed, it allowed us to change much of our terminology accordingly (see Table 7). To test our updated list of terms, we consulted with two faculty members and a person living with dementia from the Flipping Stigma Action Group at the University of British Columbia. They supported our list but suggested further changes to move away from medicalizing terminology to terms that would be easier for informal care partners to identify (e.g. "Anxiety" to "Fear or Worry" and "Depression" to "Sadness").

6.0 Applying metadata

Satisfied with the accuracy, clarity, and inclusivity of these terms, we began applying descriptive metadata to more than 300 items selected for inclusion in the Behaviours in Dementia Toolkit library. At this stage, we needed to track whether the metadata schema sufficiently covered the range of topics included in the collection. This is where we grappled the most with the concept of aboutness in our classification schema. We revisited the question posed during our metadata-thon: would users be satisfied with the results at the end of a search using the identified term? This question prompted the addition of the "improve communication" term to the purpose category facet as many of the information resources selected for inclusion specifically addressed this topic. We aimed to ensure that each term would include a minimum of five results. Within the newly relabeled "Change in" facet, we made several changes (see Table 8). First, we removed the "Any or all" selection as a significant number of resources did not address specific

S/N	Beta Website Term	Pre-launch Website Term	Remarks
	Symptom	*Change in [mood or behaviour]*	Changed facet label.
1	Any or all	Any or all	
2	Distress, unsafe behaviours	Anger	Less euphemistic term that more accurately describes the underlying mood change.
3	Disorientation	Desire to move	Reflects normal human desire. More accurately describes the underlying need.
4	Changes in eating habits	Eating habits	Change in used as facet framing and removed from controlled term.
5	Anxiety	Fear or worry	Clearer to informal care partners, less medicalized.
6	Apathy	Interest in daily activities	More clear language friendly.
7	Distress	Repeating words or actions	More accurate, objective description.
8	Depression	Sadness	Clearer to informal care partners, less medicalized.
9	Changes in sleep	Sleep	Change in used as facet framing and removed from controlled term.
10	Unsafe behaviours	Social Interactions	Unsafe reframed in terms of impact on others (i.e. intimacy, sexuality, communication).
11	Psychosis	Thoughts, beliefs, or perceptions	Reflects less judgement, inclusive of wider range of cultural perspectives.

Table 7. Changes in Symptom Terms and Framing from Second to Third Major Iteration

S/N	Pre-launch Website Term	Launch Website Term	Remarks
	Change in [mood or behaviour]	Change in [mood or behaviour]	
1	Any or all	– Select –	Not all items in collection scope required specific symptom tags (e.g. improving communication, self-care for care partners).
2	Anger	Anger	
3	Desire to move	Desire to move	
4	Eating habits	Eating habits	
5	Fear or worry	Fear or worry	
6	* New *	Hygiene	A significant number of items addressed hygiene topics, including bathing, tooth care, washing up, and using the bathroom.
7	Interest in daily activities	Interest in daily activities	
8	Repeating words or actions	Repeating words or actions	
9	Sadness	Sadness	
10	Sleep	Sleep	
11	Social Interactions	Social Interactions	
12	Thoughts, beliefs, or perceptions	Thoughts, beliefs, or perceptions	
13	* New *	Other	A significant number of items addressed specific changes in mood or behaviours not adequately covered by other terms. However, the variety of these changes meant there was an insufficient number to justify adding an additional term (e.g. driving).

Table 8. Evolution of "Change in" Faceted Terms from Pre-Launch to Launch version

changes, but topics such as communication, holistic care, and self-care for care partners. Removing this requirement allowed these items to be more clearly classified. We supported this by creating the "Other" term to house items about changes in mood or behaviour where there were an insufficient number of items to justify adding a new term. Finally, we created the "Hygiene" term to accommodate the many resources related to topics such as bathing and other personal care activities.

Several KOS tools were used to ensure linguistic control during the description of items selected for inclusion in the Behaviours in Dementia Toolkit. Draft descriptions were first recorded in an Excel workbook using a custom template. The first sheet consisted of required and optional fields to be recorded for each item, while additional sheets were included for each facet that used a controlled vocabulary. Data control was enabled so that cataloguers could only select authority terms provided in each facet sheet from a drop-down menu. A custom macro script was enabled to allow multiple selections when permitted. Within each facet sheet, a thesaurus of equivalent terms and scope notes were provided for reference to ensure consistent application. Draft descriptions were sent to the librarian for review before input into the website via a custom WordPress configuration that reinforced linguistic control by providing drop-down and checkbox selections for metadata fields. A separate reference manual was created documenting this process and ensuring greater consistency between cataloguers.

7.0 Discussion

Engaging in a pragmatic, iterative, human-centered design approach for the Behaviours in Dementia Toolkit served this project well. An initial survey of user perspectives on the feasibility and impact of the website, described in a separate publication, indicated a high level of satisfaction with the library among users (Albrecht et. al submitted). Figure 4 demonstrates the significant evolution our terminology underwent from conception to website launch. The complex-

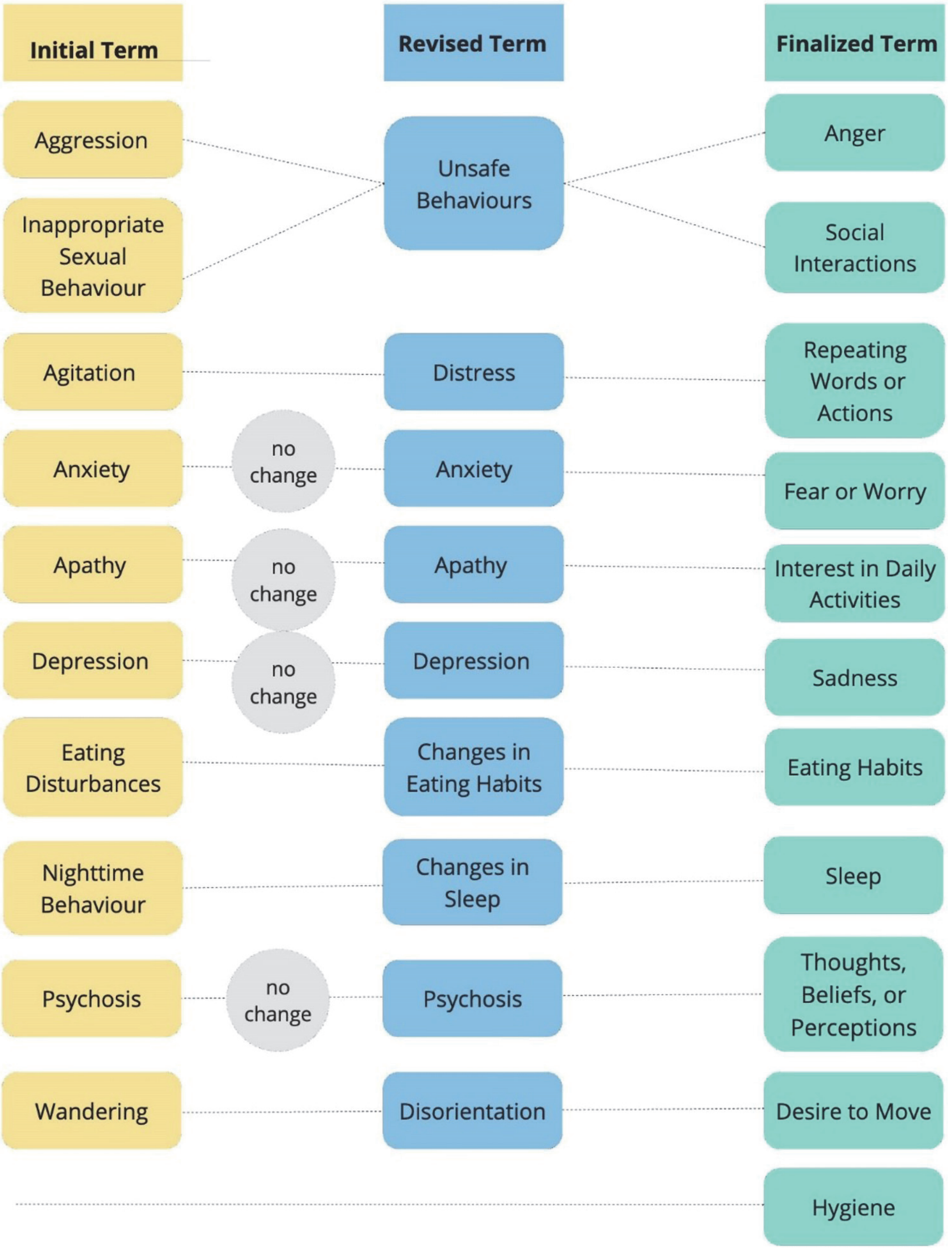


Figure 4. Evolution of Terms across Initial, Revised and Finalized Stages

ity of these iterations is best captured by the terms “Aggression” and “Inappropriate Sexual Behaviours.” These were initially two separate concepts/terms, but we combined them into “Unsafe Behaviours” in our first revision to avoid terms laden with judgement and stigma. However, as stated in an earlier section, the euphemistic nature of “Unsafe Behaviours” made us reconsider the use of this term as potentially vague, inaccurate, and even stigmatizing, depending on the nature of information resources classified under this term. For example, not every change in sexual behaviour risks compromising the safety of the person living with dementia and those around them. Revisiting these concepts with new terminology stemming from our reframing of the “Symptom” facet as “Changes in [mood or behaviour]” allowed us to assign different terms that were more accurate, clear, and inclusive: “Anger” and “Social Interactions”.

The development of our custom metadata schema illuminated significant challenges in creating terminology we hoped would be simultaneously accurate, clear, and inclusive. Many candidates fit two, but not three of these criteria. What may be deemed accurate from a medical perspective can be perceived as unclear to informal care partners and stigmatizing towards those living with dementia. While there is more work that could be done in the future, principled compromise between these values was required to arrive at the best possible system given our significant time constraints. Reframing the entire "Symptoms" facet as observable "Changes in" specific moods and behaviours allowed us to step away from disease/illness-oriented language to that of hope and agency while effectively meeting our goals for the usability of the website library. We debated whether this shift from clinical language would reduce the ease with which formal care partners could use the Behaviours in Dementia Toolkit in their practice, but recognized it was necessary to balance usability for formal and informal care partners while centering the personhood of people living with dementia. This exemplifies the negotiation required to meet the needs of two distinct user groups. This pivotal shift in framing ultimately led us to be able to more substantively claim that our approach was person-centered. Throughout the development of this project, we challenged our assumptions by repeatedly engaging with diverse user groups so that their perspectives were reflected in all major decisions. This specific change had cascading, structural impacts on the application of our other descriptive metadata, especially the clear language descriptions which moved away from a medicalized framework with the potential to pathologize to one that considered behaviour and mood changes in a way that humanized and contextualized the person experiencing them. Our commitment to our core values and enacting them in design practices that continually sought input from diverse perspectives enabled this critical change in framing to occur.

A person-centered approach to a project such as this one should be grounded in the experiences of people living with dementia. Yet our target users were instead their formal and informal care partners. This suggests a potential dissonance between person-centered and user-centered design approaches that was evident throughout our metadata construction and refinement process. We found the value of accuracy to be closely associated with literary warrant, while clarity was closely associated with user warrant. Inclusivity is weakly related to user warrant when considering the social appropriateness of certain terms (e.g. users' subjective perception of terms encountered when searching or browsing the library), but ultimately is derived more significantly from person-centered language principles than any well-established warrant. What distinguished this from user warrant was that the person at the centre of terminology decisions was not necessarily the person the system was designed to be used by, but instead the person(s) the resources being described were concerned with. In future studies, we suggest the exploration and further theoretical development of the concept of person-centered warrant: a foundation for the design of person-centered classification systems. This perspective is critical when representing equity-deserving groups whose knowledges, identities, and very humanity are frequently marginalized by mainstream systems such as the Library of Congress Subject Headings, Medical Subject Headings (MeSH), and the Dewey Decimal System. More robust theoretical development would further legitimize person-centered language as a credible basis for the construction of classification systems, whose metadata schemas exert subtle, yet far-reaching influence on the mental schemas of those that interact with them.

8.0 Conclusion

This case study describes the process and outcomes of navigating the complexity of creating, refining, and implementing person-centered terminology in the context of the Behaviours in Dementia Toolkit. We illustrate how we grappled with the scope, nature, meanings, and assumptions of terminology about mood and behaviour changes associated with dementia, and the decisions we undertook that guided us to our eventual launch version of the website. Our goals were directed towards selecting controlled terms that would best represent our values of accuracy, clarity, and inclusivity, which are closely tied to literary warrant, user warrant, and person-centered language, respectively. Through this study, we demonstrate that our design and end-to-end development of the Behaviours in Dementia Toolkit are anchored in the practice of both user-centered and person-centered approaches at their core, and that these values were embedded with thoughtfulness and careful consideration. These approaches were occasionally in tension, given that our primary users (i.e., formal and informal care partners) form distinct groups from the person(s) whose agency, dignity, and personhood we sought to centre. We suggest that the concept of person-centered warrant should be the subject of further scholarly attention and practical application, especially in health information libraries. Our pragmatic, iterative approach informed by diverse voices ultimately enabled us to craft a schema that sufficiently met each of our values. Our process for moving beyond stigmatizing terminology to humanizing, person-centered language may be adapted to future projects in other contexts across the library and information, health care, and knowledge mobilization fields.

Acknowledgements

We would like to thank the many people who contributed their time and expertise to the development of the Behaviours in Dementia Toolkit project. We wish to express our deep appreciation to members of the Behaviours in Dementia Toolkit working group for their leadership and guidance: Dallas Seitz, David Conn, Claire Checkland, Mark Rapoport, Gary Naglie, and Stacey Hatch. We are grateful for the many colleagues, older adults, health care providers, and professional organizations who thoughtfully provided input

and feedback throughout the development of this project, including but not limited to: Sarah Crane, Christine Roberts, Brenda Martinussen, Esther Koh, Carolyn Brandly, Youya Huang, Brenda Lesperance, Kara Wychnenka, Maya Patrich, Elder Larry Frost, Avneet Vats, and Peter Snow.

References

Adekoya, Adebusola A. and Lorna Guse. 2019. "Wandering Behaviour From the Perspectives of Older Adults with Mild to Moderate Dementia in Long-Term Care". *Research in Gerontological Nursing* 12, no. 5: 239-247. https://doi.org/10.3928/19404921-20190522-01

Albrecht, Lauren, Nick Ubels, Brenda Martinussen, Mark Rapoport, Gary Naglie, Dallas Seitz, Stacey Hatch, Claire Checkland, and David Conn. Submitted. "Supporting People Living with Dementia-related Mood and Behaviour Changes through the Behaviours in Dementia Toolkit: A Descriptive Study Evaluating the Implementation of an Online Resource Library". *Journal of Medical Internet Research.* https://doi.org/10.2196/preprints.62708

Allen, Katherine A., Victoria Charpentier, Marissa A. Hendrickson, Molly Kessler, Rachel Gotlieb, Jordan Marmet, Emily Hause, Corinne Praska, Scott Lunos, and Michael Pitt. 2023. "Jargon Be Gone – Patient Preference in Doctor Communication". *Journal of Patient Experience* 10. https://doi.org/10.1177/23743735231158942

Alzheimer Society of Canada. 2017. Person Centered Language Guidelines. https://alzheimer.ca/sites/default/files/documents/Person-centred-language-guidelines_Alzheimer-Society.pdf

American Psychological Association. 2013. *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.). https://doi.org/10.1176/appi.books.9780890425596

Barité, Mario. 2018. "Literary Warrant". *Knowledge Organization* 45, no. 6: 517-536. Also available in *ISKO Encyclopedia of Knowledge Organization*, ed. Birger Hjørland, coed. Claudio Gnoli. https://www.isko.org/cyclo/literary_warrant

Behavioural Supports Ontario. 2018. *BSO Person-centered Language Initiative.* https://behaviouralsupportsontario.ca/Content/Pledge/BSO_Person-Centred_Language_Initiative_Report%20_October_2018.pdf

Bullard, Julia, Nigel Town, Sarah Nocente, Aleha McCauley, and Heather O'Brien. 2023. "Thesaurus Construction for Community-Centered Metadata". *Proceedings from North American Symposium on Knowledge Organization* 9, no. 1: 51-66. https://doi.org/10.7152/nasko.v9i1.16307

Bullard, Julia. 2017. "Warrant as a Means to Study Classification System Design". *Journal of Documentation* 73, no. 1: 75-90. https://doi.org/10.1108/JD-06-2016-0074

Burley, Claire V., Anne-Nicole Casey, Lynn Chenoweth, and Henry Brodaty. 2021. "Reconceptualising Behavioral and Psychological Symptoms of Dementia: Views of People Living With Dementia and Families/Care Partners". *Frontiers in Psychiatry* 12. https://doi:10.3389/fpsyt.2021.710703

Canadian Coalition for Seniors' Mental Health. 2024. *Canadian Clinical Practice Guidelines for Assessing and Managing Behavioural and Psychological Symptoms of Dementia (BPSD).* https://ccsmh.ca/wp-content/uploads/2024/03/CCSMH-BPSD-Clinical-Guidelines_FINAL_March-2024.pdf

Cerejeira, Joaquim, L. Lagarto, and Elizabeta Mukaetova-Ladinska. 2012. "Behavioral and Psychological Symptoms of Dementia". *Frontiers in Neurology* 3 no. 73. https://doi.10.3389/fneur.2012.0007

Dementia Australia. 2024. *How to Talk About Dementia.* https://www.dementia.org.au/about-dementia/how-talk-about-dementia

Dementia Singapore. 2020. *Changing Words, Touching Lives: A book on Dementia Language Guidelines.* https://dementia.org.sg/wp-content/uploads/2021/03/ADA-Dementia-Language-2020-02.pdf

El Sherif, Reem, Pierre Pluye, Fidelia Ibekwe. 2022. "Contexts and Outcomes of Proxy Online Health Information Seeking: Mixed Studies Review With Framework Synthesis". *Journal of Medical Internet Research* 24, no. 6. https://www.jmir.org/2022/6/e34345

Flipping Stigma Action Group. n.d. Flipping stigma on its ear toolkit. https://www.flippingstigma.com/

Gaylie, Sasha. 2022. *Clear Language Description.* University of British Columbia School of Information. https://open.library.ubc.ca/media/stream/pdf/52387/1.0427388/9 [Graduate project]

Gilmore-Bykovskyi, Andrea, Shannon Mullen, Laura Block, Abigail Jacobs, Nicole Werner. 2020. "Nomenclature Used by Family Caregivers to Describe and Characterize Neuropsychiatric Symptoms". *The Gerontologist* 60, no. 5: 896-904. https://doi.org/10.1093/geront/gnz140

Guy, Andre Boy. 2017. Human-Centered Design as an Integrating Discipline. *Journal of Systemics, Cybernetics and Informatics* 15, no. 1. https://hal.science/hal-01927899/

Hauser, Elliot, and Joseph T. Tennis. 2019. "Episemantics: Aboutness as Aroundness". *Knowledge Organization* 46, no. 8. https://doi.org/10.7152/nasko.v7i1.15617

Isik, Ahmet Turan, Pinar Soysal, Marco Solmi, and Nicola Veronese. 2018. "Bidirectional Relationship Between Caregiver Burden and Neuropsychiatric Symptoms in

Patients with Alzheimer's Disease: A Narrative Review". *International Journal of Geriatric Psychiatry* 34, no. 9:1326-1334. https://doi.org/10.1002/gps.4965

Jacklin, Kristin, and Jennifer Walker. 2020. "Cultural Understandings of Dementia in Indigenous Peoples: A Qualitative Evidence Synthesis". *Canadian Journal on Aging* 39, no. 2. https://doi.org/10.1017/S0714980819 00028X

Jagoda, Thilanka, Samath Dharmaratne, and Sarath Rathnayake. 2023. "Informal Carers' Information Needs in Managing Behavioural and Psychological Symptoms of People with Dementia and Related mHealth Applications: A Systemic Integrative Review to Inform the Design of an mHealth Application". *British Medical Journal Open* 13, no. e06978. https://doi.org/10.1136/bmjopen-2022-069 378

Kalpan, Kate. 2023. "When to Use Empathy Maps". *Nielson Norman Group.* https://www.nngroup.com/articles/using-empathy-maps/

Macauley, Susan. 2018. "The Broken Lens of BPSD: Why We Need to Rethink the Way We Label the Behaviour of People Who Live with Alzheimer Disease". *Journal of American Medical Directors Association* 19, no. 2. https://doi.org/10.1016/j.jamda.2017.11.009

Olson, Hope A. 2002. The Power to Name: Locating the Limits of Subject Representation in Libraries. Dordrecht: Springer Netherlands.

Peterson, Kendra, Howard Hahn, Amber J. Lee, Catherine A. Madison, and Alireza Atri. 2016. "In the Information Age, Do Dementia Caregivers Get the Information They Need? Semi-Structured Interviews to Determine Informal Caregivers' Education Needs, Barriers, and Preferences". *BioMed Central Geriatrics* 16, no. 164. https://doi:10.1186/s12877-016-0338-7

STOREE. 2019. "Making Research Accessible Metadatathon". *University of British Columbia.* https://storee.ubc.ca/making-research-accessible-metadata-thon/

Taylor, Heather A., Dori Sullivan, Cydney Mullen, and Constance M. Johnson. 2011. "Implementation of a User-Centered Framework in the Development of a Web-Based Health Information Database and Call Center". *Journal of Biomedical Informatics* 44, no. 5: 897-908. https://doi.org/10.1016/j.jbi.2011.03.001

Ubels, Nick, and Lauren Albrecht. 2024. "Evidence Based Principles to Accelerate Health Information Flow and Uptake Among Older Adults". *Evidence Based Library and Information Practice* 19, no. 2: 109–118. https://doi.org/10.18438/eblip30529

Ubels, Nick, Lauren Albrecht, Esther Koh, and David Conn. Submitted. "Pragmatic Human Centered Design in Action: Assessing the Tone and Usability of the Behaviours in Dementia Toolkit".

van Velsen, Lex, Geke Ludden, and Chrisiane Grünloh. 2022. "The Limitations of User-and Human-Centered Design in an eHealth Context and How to Move Beyond Them". *Journal of Medical Internet Research* 24, no. 10. https://doi.org/10.2196/37341

van Wijngaarden, Els, Manna Alma, and Anne-Mei The. 2019. "'The Eyes of Others' are What Really Matters: The Experience of Living with Dementia from an Insider Perspective." *Public Library of Science ONE* 14, no. 4. https://doi.org/10.1371/journal.pone.0214724

Wells, David. 2021. "Online Public Access Catalogues and Library Discovery Systems". *Knowledge Organization* 48, no. 6. https://doi.org/10.5771/0943-7444-2021-6-457

Wolverson, Emma, Rose Dunn, Esme Moniz-Cook, Dianne Gove, and Ana Diaz-Ponce. 2021. "The Language of Behaviour Changes in Dementia: A Mixed Methods Survey Exploring the Perspectives of People with Dementia". *Journal of Advanced Nursing* 77, no. 4: 1992-2001. https://doi.org/10.1111/jan.14787

World Health Organization. 2023. *Dementia Factsheet.* https://www.who.int/news-room/fact-sheets/detail/dementia