CareDATA: Caregiving Diversity and Technology Assessment Tool

A practical tool for incorporating sex, gender and diversity within the caregiving digital technology development process

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CIHR IRSC
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Rehabilitation Sciences Institute
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CareDATA: Caregiving Diversity and Technology Assessment Overview

INCORPORATING SEX, GENDER AND DIVERSITY

A Reach out and **involve caregivers** from the beginning and throughout the product development process

- → *Consider and report any barriers or challenges*
- → *Involve caregivers with diverse characteristics (i.e. age, sex, gender, race/ethnicity, socio-economic status, various accessibility needs, etc.)*

B Reflect on and appropriately **address stereotypes** relating to diverse characteristics that might be present within the project

C Take steps to **acquire expertise** (both internal and external) in developing technology from a sex, gender and diversity lens

1) How to identify technology needs in caregivers?

- ☑ Establish a specific target audience for the project
- ☑ Collaborate with the target audience to identify a specific need that the product will address
- ☑ Design the product around this need

2) How to meet the preferences of caregivers?

- ☑ Consider the characteristics that caregivers value throughout the use of the product
- ☑ Incorporate these characteristics into the product
  - → *If not possible, is there a reason?*

3) How to break down barriers to technology adoption?

- ☑ Consider potential barriers of adoption related to the product
- ☑ Address these barriers that were identified
  - → *If not possible, is there a reason?*

4) How to enhance technology uptake?

- ☑ Consider how the product fits within:
  - → *The caregivers' social network?*
  - → *The caregiver-care recipient relationship?*
- ☑ Consider changing trends in the target audience with respect to technology adoption and attitudes

Learn more about the CareDATA Assessment Tool
https://abiresearch.utoronto.ca/research/caredata/

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What is CareDATA?

Caregiving, Diversity and Technology Assessment (CareDATA) is a self-assessment tool designed for technology developers and policy makers to assess the level of integration of sex, gender and other diversity characteristics within the caregiving digital technology development process.

CareDATA was developed by drawing information from a systematic literature review, a national survey of family caregivers, as well as conversations with both technology developers and a diverse group of caregivers (i.e. individuals taking care of an adult family member or friend).

This comprehensive tool aims to promote a greater awareness and incorporation of sex, gender and diversity within current and future digital technologies designed to assist informal caregivers.

Questions within the CareDATA are grouped into four components focusing on different stages of technology development and one crosscutting theme that applies across the stages, with sex, gender and diversity incorporated throughout.

SEX: biological or physiological characteristics of individuals that are typically used to classify them as male or female, such as chromosomal attributes, hormonal expression and reproductive anatomy (Tannenbaum, Greaves, & Graham, 2016).

GENDER: a socially constructed phenomenon whereby one's attitudes, behaviours and expressions are governed by the norms that are associated with assigned sex (Tannenbaum et al., 2016). These norms encompass our self-identity along the feminine-masculine continuum (i.e. gender identity), as well as our actions and expectations (i.e. gender roles), how we interact with and experience others and our society (i.e. gender relations), and the distribution of power and resources in society (i.e. institutionalized gender) (Tannenbaum et al., 2016). As gender cannot be separated from context, it can operate within a number of diversity characteristics, including race/ethnicity, socioeconomic status, age, ability and religion (Tannenbaum et al., 2016).

Thus, it is important to take a multifaceted approach that takes into consideration the diverse identities of one's target audience.

For more information on Health Canada's Sex and Gender Action Plan and guidelines for Sex- and Gender-based Analysis (SGBA+), please refer to Health Canada (2017), Canadian Institutes of Health Research (2019), Status of Women Canada (2018), and Centre of Excellence for Women's Health (2020).

CROSSCUTTING THEME:

Incorporating Sex, Gender and Diversity

The crosscutting theme relates to the consideration of sex, gender and diversity within the project and helps assess its level of incorporation on three distinct levels.

A WILL CAREGIVERS BE INVOLVED IN THE PRODUCT DEVELOPMENT PROCESS?

Connecting with caregivers is beneficial to technology development. By engaging caregivers, technology developers can gather feedback, which will be helpful in the creation of technologies that better fit needs and are more likely to be adopted. However, it is recognized that barriers to engaging caregivers are present, including:

- **RESEARCH ETHICS RESTRICTIONS:** complications in research ethics procedures that limit the ability to involve end users
- **INSUFFICIENT TRAINING:** lack of members within the project team with the know-how to conduct a sex- and gender-based analysis
- **UNDERMINING OF CAREGIVER PERSPECTIVES:** need for reflection on possible assumptions (e.g. developers are more knowledgeable than the end user)

It is important to recognize these barriers, and if possible, take steps to overcome them and bring caregivers into the technology development process.

Caregiving is a unique and personalized experience for both the care provider and recipient. There are a diverse range of factors that can influence caregiving experiences, all of which need to be taken into account when developing digital technologies. Specifically, caregivers report:

- **FAMILY DYNAMICS:** family structure, relationships, upbringing, etc.
- **RACE/ETHNICITY/CULTURE:** beliefs, traditions, religion, Indigeneity, experiences of immigration, language barriers, etc.
- **SOCIETAL NORMS AND EXPECTATIONS:** caregiving is often constructed as women's roles
- **SELF-CONCEPTUALIZATION OF THE CAREGIVING ROLE:** positioning oneself as a caregiver involves reflection on socialization, values and personal experiences

These are major drivers that shape caregiving experiences and expectations for caregivers' and care recipients' roles.

Additionally, technology developers have to also recognize the importance of diverse technology needs among caregivers, including but not limited to differences in:

- **AGE:** limitations or preferences that come with age (e.g. exposure to and comfort with digital technology, need for accessibility features, etc.)

- **EDUCATION:** level of health literacy, knowledge of or access to information about relevant technology, ability to adapt to technology products, etc.
- **SOCIO-ECONOMIC STATUS:** influence of economic accessibility on which products caregivers are able to purchase and adopt in their everyday lives
- **GEOGRAPHY:** influence of location on access to resources, personnel or infrastructure

Given these differences, it is important for technology developers to be aware of and make efforts to involve caregivers with diverse characteristics throughout the technology development process.

B WILL STEREOTYPES RELATING TO DIVERSE CHARACTERISTICS OF CAREGIVERS BE ADDRESSED?

Technology developers need to recognize and avoid making stereotypes about their target audience. Awareness needs to be drawn towards any assumptions made relating to technology needs, preferences and abilities:

- **MISCONCEPTIONS AND GENERALIZATION OF SEX AND GENDER:** need for reflection on understanding of technology needs and preferences across the sex and gender continuum

Technology developers should also be cognizant of possible assumptions about preferences or the ability to use digital technology, based on other characteristics, such as age, education, socio-economic status, etc. Involving end users with diverse characteristics, as outlined in (A), is one way to confront preconceived notions.

C WILL SEX, GENDER AND DIVERSITY EXPERTISE BE ACQUIRED?

Despite recognizing the need to incorporate sex, gender and diversity within technology development, technology developers may be limited in their ability to do so due to a number of barriers, including:

- **LACK OF AWARENESS:** paucity of available knowledge on sex and gender implications of one's project
- **COMPLEXITY OF INCORPORATING DIVERSITY FACTORS:** perceived amount of effort involved in analyzing sex, gender and diversity
- **INSUFFICIENT DATA:** lack of enough data points to effectively conduct sex and gender analysis (taking into account interactions with other socio-demographic factors)
- **LACK OF TRAINING:** need for more resources to help address unfamiliar variables (e.g. sex, gender and other socio-demographics) and methodologies (e.g. focus groups)

As such, involving individuals with expertise in sex, gender and diversity within the project team is crucial in overcoming these barriers and ensuring that appropriate steps are taken at each stage of the development process. Those who require an introduction to these concepts may also find it useful to consult the references section of this guide for an overview of SGBA+ in research.

Consider these Crosscutting Themes

A B C

It will be beneficial for technology developers to consider each of the questions above when reviewing the tool.

1

How to identify technology needs in caregivers?

Caregivers have reported use of technology to support a range of tasks, including but not limited to the items in this section.

- ☑ **COMMUNICATION:** ability to connect with others remotely/ on-the-go/on demand
- ☑ **OBTAINING UP TO DATE RESOURCES OR INFORMATION:** use of Webinars, internet, TED Talks, YouTube videos, etc.
- ☑ **SELF-CARE:** maintenance of physical and mental well-being to help cope with emotions arising from caregiving
- ☑ **PROVIDING A SENSE OF SECURITY:** use of home monitoring, GPS tracking devices, real-time updates about care recipient, etc. to ensure their safety and relieve caregiving burden
- ☑ **SUPPORTING REGULAR CHORES:** assistance with regular tasks, like meal preparation, cleaning, laundry, etc. within the context of caregiving
- ☑ **TIME MANAGEMENT:** ability to track tasks (e.g. calendar apps, etc.) for effective planning and management of each day

Given the multitude of roles technology can play in assisting with caregiving, it is imperative for technology developers to clearly establish the need and specific target audience that correspond to their product from the beginning and throughout the development process.

Commonly used models that developers can look to for guidance include user-centered design (Abras, Maloney-Krichmar, & Preece, 2004) and participatory action research (Kidd & Kral, 2005). In addition, developers can reflect on their development process (e.g. through regular check-ins with end users, recruitment of end users as experts, or formation of a user advisory group) to ensure that the product is designed around the identified need.

Remember to consider the Crosscutting Themes

A B C

2

How to meet the preferences of caregivers?

Caregivers seek specific features and characteristics for technology that they are willing to use on a regular basis. Caregivers have reported that, when present, these characteristics would enhance their perception towards a device and increase the likelihood for adoption.

Remember to consider the Crosscutting Themes

A B C

- ☑ **ACCESSIBILITY:** use of features like screen readers, speech recognition, adaptive keyboards, simplified language, etc. can address key accessibility concerns, including hearing, visual or mobility impairments, communication disorders, and learning disabilities (please refer to the Government of Canada's (2011) Standard on Web Accessibility for more information; developers can further consult their local accessibility guidelines and/or accessibility experts)
- ☑ **VALUE FOR MONEY:** cost effectiveness, longevity, widespread availability of parts and updates
- ☑ **ECO-FRIENDLINESS:** minimal environmental impact, recyclable, reduced carbon footprint
- ☑ **FAMILIARITY:** products that look and operate in a way that is familiar to the user, available in multiple languages
- ☑ **MULTI-FUNCTIONALITY:** ability to engage in multiple tasks at once, assisting with different caregiving responsibilities simultaneously
- ☑ **SEAMLESS OPERATION:** requiring minimal user input and interaction, integrates well with existing infrastructure, ability to have seamless communication among multiple caregivers, family members, healthcare professionals, etc.
- ☑ **REGULAR UPDATES:** consistent upgrades to software and hardware, up to date, at the forefront of technology
- ☑ **READILY AVAILABLE TRAINING:** 24-hour availability of support, including clear information on how support can be accessed, minimal wait times

3

How to break down barriers to technology adoption?

The adoption of existing products and technology is limited by how well they are received by caregivers. Specifically, caregivers face challenges related to technology uptake that stem from the items listed in this section.

- ☑ **SKILL LEVEL OR ABILITY:** varying levels of knowledge of types of technology, information on how to use it, and expertise in troubleshooting issues
- ☑ **SECURITY AND PRIVACY:** concerns about transparency regarding storage and use of data, prevention of care recipients' information being compromised, clear information about protection of privacy
- ☑ **INCOMPATIBILITY WITH VALUES AND/OR ROUTINES:** preference for technology that can be easily incorporated into established approaches to caregiving

As technology developers, it is important to recognize and take steps to address these barriers throughout the design and introduction of the technology.

Remember to consider the Crosscutting Themes

A B C

4

How to enhance technology uptake?

Caregivers consider the world around them when faced with technology decisions. The way technology is perceived and how likely it is to be adopted within the caregiving context is related to the items listed in this section.

☑ **FIT WITHIN THE CAREGIVER-CARE RECIPIENT RELATIONSHIP:** importance of considering the needs and preferences of care recipients within discussions of technology use and uptake

☑ **COLLABORATIVE USE OF TECHNOLOGY:** establishing perceptions towards devices through a two-way conversation between caregivers and care recipients

☑ **CAREGIVERS' SOCIAL NETWORKS AND CONNECTIONS:** major influence of peers, friends and other family members in helping caregivers gain awareness of technology

☑ **TECHNOLOGY PERCEPTIONS ARE DYNAMIC:** influence of unique personal upbringing and backgrounds on caregivers' perspectives towards technology adoption, shifting across time/age groups/etc. and varying considerably among individuals

In addition to the needs and preferences of caregivers, it may therefore be important to also consider their caregiving context and social networks when designing new products for them. This includes the diverse characteristics of care recipients and the dynamics of the caregiver-care recipient relationship (e.g. generational differences in perceptions to technology). A good grasp of relational influences on technology adoption, as well as the spectrum of technology attitudes among a given target audience, will help technology developers establish best practices for the promotion of their product, thereby optimizing the rate of technology uptake.

Remember to consider the Crosscutting Themes

A B C

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