## KONTAKT / Journal of nursing and social sciences related to health and illness

ටි

Original research article

# Translation and validation of the Omaha System into English language simplified Omaha System terms

Robin R. Austin <sup>1</sup> \* D, Christie L. Martin <sup>1</sup> D, Clarence R. Jones <sup>2</sup> D, Sheng-Chieh Lu <sup>3</sup> D, Ratchada Jantraporn <sup>1</sup> D, Igor Nestrasil <sup>4</sup> D, Karen S. Martin <sup>5</sup> D, Karen A. Monsen <sup>1</sup> D

#### **Abstract**

*Purpose*: COVID-19 has caused a shift toward consumer-facing technology such as mobile health (mHealth) applications. However, most mHealth apps do not use accessible language. Standardized terminologies have potential to solve this problem but have not been simplified for consumer use.

Methods: We used a standardized health terminology, the Omaha System, as the framework to develop the Simplified Omaha System Terms (SOST) for use within a mHealth application, MyStrengths + MyHealth. Plain language principles informed the SOST development in three phases, a community-validation focus group enabled feedback from diverse end-users, a readability assessment provide validation to the desired goal readability level.

Results: The community-validation members (n = 19) ages ranged from 22 to 74; 51% male, 84% people of color, and 21% college educated. The reading level of the final SOST averaged 3.86 on the Coleman–Liau Index (fourth grade). A case study showed meaningful whole-person health data were generated in a community-led study during COVID-19.

Conclusions: Community validation and readability assessment demonstrated accessible language for a clinical terminology. The SOST was deployed successfully in MyStrengths + My Health and in a community-led study. The Omaha System as a framework for the SOST may enable the data to be integrated with clinical datasets. Future research should focus on validation of SOST in additional languages and integration within electronic health platforms.

Keywords: Health literacy; Information science; Terminology

#### Introduction

The coronavirus, COVID-19, pandemic has resulted in an increased use of consumer-facing technologies, such as mobile health applications (mHealth apps) (AHRQ, 2020; Keesara et al., 2020; Webster, 2020). Use of mHealth apps has amplified the need for electronic health literacy skills (Norman and Skinner, 2006). Further, use of mHealth apps has enhanced the amount of data generated from mHealth apps (i.e., Consumer-Generated Health Data – CGHD) (Garner et al., 2018; Stec et al., 2019). However, most CGHD is unstructured and not readily available for individuals or healthcare providers (Gandomi and Haider, 2015; Mandel et al., 2016). Informatics solutions, such as use of standardized terminologies, provide structure to CGHD data that would enable shareable data between mHealth apps and health systems.

The growth of consumer-facing technologies has perpetuated a widening digital divide, as not all technologies are universally accessible (Banskota et al., 2020; Chesser et al., 2016; Ernsting et al., 2017; Huh et al., 2018; Mackert et al., 2016). mHealth apps are meant to be used by the general public and thus, should be inclusive and accessible to all, regardless of literacy level (Broderick et al., 2014; Cutilli et al., 2018; Roundtable on Health Literacy..., 2015). Plain language principles include the use of simplified language (at or below a sixth grade reading level) so that it is clear, concise, and accessible to lower literacy abilities (AHRQ, 2017; Plain Language. gov, n.d., 2015). Effective consumer-focused technology is not about what people should do, but how to make it easier to do the right thing for their health (Plow and Golding, 2017). For many consumers, accessible language makes it easier to do the right thing for their health (Kao and Liebovitz, 2017; Roundtable on Health Literacy..., 2015).

http://doi.org/10.32725/kont.2022.007

Submitted: 2021-08-06 • Accepted: 2022-03-01 • Prepublished online: 2022-03-09

KONTAKT 24/1: 48–54 • EISSN 1804-7122 • ISSN 1212-4117

 $@\ 2022\ The\ Authors.\ Published\ by\ University\ of\ South\ Bohemia\ in\ \check{C}esk\'e\ Bud\check{e}jovice,\ Faculty\ of\ Health\ and\ Social\ Sciences.$ 

This is an open access article under the CC BY-NC-ND license.

<sup>&</sup>lt;sup>1</sup> University of Minnesota, School of Nursing, Minneapolis, Minnesota, USA

<sup>&</sup>lt;sup>2</sup> Hue-Man Partnership, Minneapolis, Minnesota

<sup>&</sup>lt;sup>3</sup> University of Texas, MD Anderson Cancer Center, Department of Symptom Research, Houston, Texas, USA

<sup>&</sup>lt;sup>4</sup> University of Minnesota, Medical School, Minneapolis, Minnesota, USA

<sup>&</sup>lt;sup>5</sup> Martin Associates, Omaha, Nebraska, USA

<sup>\*</sup> Corresponding author: Robin R. Austin, 5-140 Weaver-Densford Hall, 308 Harvard Street S.E., Minneapolis, MN 55455, USA; e-mail: quis0026@umn.edu

The emergence of CGHD allows for consumers to contribute their health data to patient portals or electronic health records (EHRs) (Ancker et al., 2015; He et al., 2017; Turvey et al., 2014; Whitney et al., 2018). However, much of the CGHD is missing (not recorded), buried, or invisible (either recorded as free text, or as part of non-standard documentation options or paper forms) (Martin, 2005; Whitney et al., 2018; Zeng and Tse, 2006). Informatics methods, such as use of standardized terminology, seamlessly integrate CGHD into the broader informatics infrastructure like EHRs (He et al., 2017).

We used the Omaha System, a multidisciplinary standardized terminology, as the framework of this research to develop a consumer-facing plain language (i.e., Simplified Omaha System Terms [SOST]) used within the mHealth app, MyStrengths + MyHealth (MSMH). The Omaha System is a comprehensive, holistic framework that conceptualizes health within the context of the environment and interpersonal relationships. Previous studies provided rationale for refining the Omaha System for CGHD (Monsen et al., 2012; 2014; Pruinelli et al., 2014). The structure of the Omaha System consists of three related instruments: Problem Classification Scheme, Intervention Scheme, and Problem Rating Scale for Outcomes (Martin, 2005). The Problem Classification Scheme includes 42 problems (or concepts) categorized within the four domains of health (Environmental, Psychosocial, Physiological, and Health-related Behaviors) used to describe health and healthcare. Each of the 42 problems has a unique set of signs/symptoms (varying from 3 to 19 signs/symptoms per problem). The Omaha System concepts have been used to describe and classify consumer strengths, or positive attributes (Monsen et al., 2014, 2015). MSMH was designed to enable the self-report of strengths, challenges, and needs (whole-person health). In MSMH, the Omaha System Problems were renamed Concepts, Signs/Symptoms were renamed Challenges, and Interventions were renamed Needs. The four domains were renamed to My Living, My Mind & Networks, My Body, and My Self-care. The Intervention Scheme included four descriptive interventions: Teaching, Guidance, and Counseling, Treatments and Procedures, Case Management, and Surveillance. In MSMH, these were renamed Info/Guidance, Hands-on Care, Care Coordination, and Check-ins.

The purpose of this study was to engage various stakeholders and community members to validate a standardized, consumer-facing simplified language to be used in a mHealth app called, MyStrengths + MyHealth (MSMH). Our aims were to (1) engage various stakeholders and community-members to validate the plain language terms, and (2) conduct a readability assessment of the community-validated terms, and (3) describe the use of MSMH during COVID-19 to examine individual and community strengths (resilience), as well as health challenges and needs.

#### Materials and methods

We used an iterative consensus approach to translate the Omaha System into simplified terms and validate the SOST. The University of Minnesota Institutional Review Board deemed this study to have exempt status. We divided this work into three iterative phases consisting of two preliminary phases and one final phase: Preliminary (P)-SOST 1, P-SOST 2, and the Final SOST. We defined linguistic validation as the inves-

tigation of the reliability, conceptual equivalence, and content validity of the SOST terms (Language Scientific, 2020; Wild et al., 2005).

During the first phase of developing and validating the SOST, we derived a preliminary P-SOST 1 using the Omaha System framework (Aim 1). We engaged multiple stakeholders to develop and validate the SOST. Researchers (RRA, KAM, KSM) reviewed all Omaha System terms and revised the terms using a consensus approach. Terms were revised in accordance with plain language principles and existing definitions of the Omaĥa System terms. Plain language principles undergo iterative testing and revision to create simple, clear language, that is conducive to reading and comprehension and that appeals to diverse racial and ethnic groups (Broderick et al., 2014; Eichner and Dullabh, 2007; The National Academies Press, 2015). Omaha System term definitions are located in Appendix A of the Omaha System book, which is available in the public domain (see terms at www.omahasystem.org) (Martin, 2005; The Omaha System, 2021).

In the second phase, we validated the simplified language terms with community members. The community-validation exercise consisted of a two-hour community meeting with invited community members to review and discuss the P-SOST 1. Our community-academic partner, Hue-MAN, whose mission is to reduce health disparities, invited community members to participate in the validation exercise. Three researchers (RRA, KAM, RCJ) facilitated the two-hour community exercise. Each participant was given a paper copy of the P-SOST 1. A projector was used to display the terms on a large screen for the entire group, and then participants convened in small groups for five to ten minutes to review and discuss each concept and the associated signs/symptoms. Next, participants engaged in dialogue with the facilitators and made suggestions for improvement. We reached consensus that the simplified language version was understandable by the community. Based on feedback, we created P-SOST 2 by revising P-SOST 1.

In the third phase, we revised P-SOST 2 to create the Final SOST. Omaha System experts (RRA, KAM, KSM) reviewed all P-SOST 2 terms for adherence with plain language principles. One expert (KSM) re-reviewed the revised SOST terms for linguistic validity to ensure the revised terms aligned with Omaha System terms and definitions (Language Scientific, 2020; Martin, 2005; Wild et al., 2005).

To conduct the readability assessment (Aim 2), we used the Coleman–Liau index to assess readability and to validate the terms that had reached recommended readability levels, at or below sixth grade (Readability.org, 2021). The Coleman–Liau Index is used to approximate a reading level based on U.S. grade levels (a score of 3.86 indicates a readability level between the third and fourth grade) by considering the length of the word versus the number of syllables in each word (Readability.org, 2021). To assess readability, each term or phrase was entered into an online text reader (www.online-utility.org), which includes the Coleman–Liau Index. Coleman–Liau Index scores were recorded on an Excel spreadsheet to track the readability scores of all the terms for SOST and for the original Omaha System terms. We used descriptive and inferential statistics to analyze the readability data.

An exemplar of community-based research using SOST in MSMH (Aim 3) generated community data regarding whole-person health (strengths, challenges, and needs) during COVID-19 (Fig. 1).

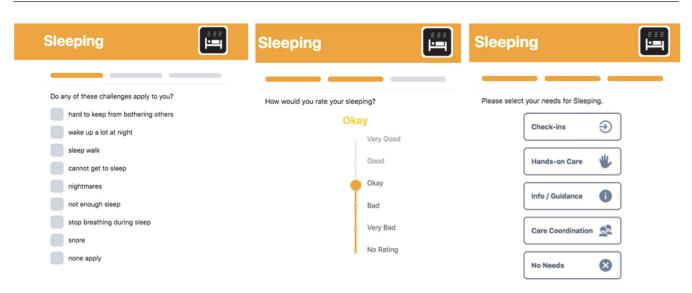


Fig. 1. MyStrengths + MyHealth application example for the Sleeping concept

This community was jointly defined and led by a collaboration of community organizations, university faculty and students, and a city public health department. Due to the COVID-19 pandemic we worked together virtually to accomplish our goals. Several webinar sessions were facilitated to identify the relevant SOST topics across domains of My Living, My Mind & Networks, My Body, and My Self-care, disseminate the survey, and disseminate findings to the community to interpret findings together with stakeholders.

#### **Results**

Aim 1 – The community-validation exercise included 19 individuals ranging from 22 to 74 years of age: a majority were male (51%), people of color (84%), and had an education level less than that of college (79%). In the first phase, we modified 96% of the original Omaha System terms to create P-SOST 1. In the second phase, we modified 34% of the P-SOST 1 terms and created P-SOST 2. In the third phase, we modified 3% of the P-SOST 2 terms (Table 1).

Table 1. Number and percentage of items changed during	
the simplified Omaha System term development and	
validation phases	

variation priabes			
Phases	Category	Number of items changed	% items changed
Dhara 1. Ossaha Costass	Concepts	32 330	76.2% 98.5%
Phase 1: Omaha System	Signs/symptoms		
to P-SOST 1	Categories	4	100.0%
	Domains	5	100.0%
Phase 2: P-SOST 1 to	Concepts	18	42.9%
P-SOST 2	Signs/symptoms	110	32.8%
(Community-validation	Categories	0	0.0%
exercise)	Domains	0	0.0%
	Concepts	0	0.0%
Phase 3: P-SOST 2 to	Signs/symptoms	10	3.0%
Final SOST	Categories	0	0.0%
	Domains	0	0.0%
P-SOST – Preliminary Simplified Omaha System Terms.			

Of the 42 Omaha System Problem concepts, RRA and KAM revised 31 terms, 11 remained as the original Omaha System term. After the community exercise, 10 of the terms were recommended to be reverted to the original Omaha System term, seven terms were revised to a new suggested term, and 14 remained as the P-SOST 1 (Fig. 2).

Of the Omaha System Signs and Symptoms (n=335), 323 terms were changed to P-SOST, and 12 terms remained the original Omaha System term. In the community exercise, participants agreed with 240 terms and recommended 84 new terms. Between the P-SOST 2 and Final SOST, Omaha System experts, further revised terms (Fig. 3).

Both the Intervention category (n = 4) and Domain (n = 4) terms were changed from the original Omaha System terms. These remained unchanged through the P-SOST 2 and Final SOST. The Omaha System and Final SOST problem concept terms with the number of signs are illustrated (Table 2).

 $Aim\ 2$  – The readability assessment using the Coleman–Liau Index showed a significant reduction in reading level from the Omaha System to the Final SOST. The Coleman–Liau Index score for the Final SOST problems and signs/symptoms was 3.41. Compared to the original Omaha System problems and signs/symptoms Coleman–Liau Index score was 16.72 (t=19.46, df = 767, p<0.001).

Aim 3 - Responses using SOST in MSMH included respondents (n = 576) from Minneapolis; Minnesota Zip codes (n = 283); other Zip codes (New York to California) (n = 264); and no reported Zip codes (n = 29). They were most often 25-44 years of age (68.4%); male (54%); Black/African American (23.1%), Hispanic/Latinx (24.3%); married (66.8%). Participants had an average of 7 Strengths [M = 6.89 (SD = 4.88)], 16 challenges [M = 16.85 (SD = 12.15)], and 6 needs (M = 5.64 (SD = 8.28)]. Using MSMH, participants reported many strengths despite the current pandemic. The most common Strengths reported were in Home, Spirituality or Faith, and Safe at home and work; Challenges in Emotions and Sleeping; Needs in Emotions, Substance use, and Sleeping. Minneapolis respondents had more strengths than respondents from elsewhere. Participants with one or more Challenges in Substance use had half as many Strengths, five times as many Challenges and four times as many Needs compared to those without Substance use challenges. We invited community stakeholders to interpret the study findings and plan the next steps.

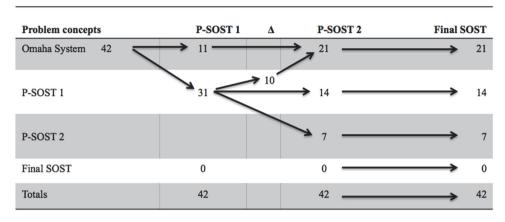


Fig. 2. Changes in problem concept terms across phases

Table 2. Omaha System and Final COST with number signs and symptoms					
Omaha System	Simplified Omaha System terms	Number signs/symptoms			
Environmental domain	My living				
Income	Income	4			
Sanitation	Cleaning	11			
Residence	Home	14			
Neighborhood/workplace safety	Safe at work and home	10			
Psychosocial domain	My mind and networks				
Communication with community resources	Connecting	11			
Social contact	Socializing	3			
Role change	Role change	3			
Interpersonal relationship	Relationships	8			
Spirituality	Spirituality or faith	4			
Grief	Grief or loss	4			
Mental health	Emotions	17			
Sexuality	Sexuality	8			
Caretaking/parenting	Caretaking	9			
Neglect	Neglect	6			
Abuse	Abuse	8			
Growth and development	Growth and development	4			
*	*	4			
Physiological domain	My body	_			
Hearing	Hearing	5			
Vision	Vision	8			
Speech and language	Speech and language	6			
Oral health	Oral health	7			
Cognition	Thinking	10			
Pain	Pain	6			
Consciousness	Consciousness	4			
Skin	Skin	10			
Neuro-musculo-skeletal function	Moving	13			
Respiration	Breathing	10			
Circulation	Circulation	16			
Digestion hydration	Digesting	11			
Bowel function	Bowel function	7			
Urinary function	Kidney/bladder	9			
Reproductive function	Reproductive health	7			
Pregnancy	Pregnancy	6			
Postpartum	Postpartum	6			
Communicable/infectious condition	Infections	8			
Health-related behaviors domain	My self-care				
Nutrition	Nutrition	11			
		8			
Sleep and rest patterns	Sleeping				
Physical activity	Exercising	3 9			
Personal care	Personal care				
Substance use	Substance use	9			
Family planning	Family planning	6			
Healthcare supervision	Health care	7			
Medication regimen	Medications	8			

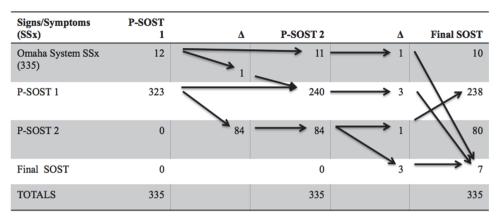


Fig. 3. Changes in sign/symptoms terms across phases

#### **Discussion**

In this linguistic validation study, we translated a rigorous standardized clinical terminology into simplified language using plain language principles. The Simplified Omaha System Terms (SOST) were found to be readable at fourth grade reading level, consistent with health literacy guidelines (AHRQ, 2017; Language Scientific, 2020; U.S. Department of Health..., 2020). This is the first known study to translate and validate a standardized clinical terminology into simplified language for use in a mHealth app. The exemplar highlights the use of SOST by a community to examine strengths, challenges, and needs, during the pandemic. Future studies should be conducted to confirm readability with consumers across literacy levels and languages.

The Omaha System is a simple, user-friendly, multi-disciplinary terminology thought to be suitable for use by consumers as well as healthcare providers and other groups (Martin, 2005). Therefore it is notable that in Phase 1 Omaha System terminology experts translated the vast majority of the Omaha System problems and signs/symptoms terms to enable use by consumers. This reveals how even the simplest clinical terminologies may not be consumer friendly. The Phase 2 finding that the community members helped to refine one-third of the P-SOST 1 terms suggests that it is critical to work with community members to develop community-friendly language. The finding that very few changes were needed in Phase 3 to adhere to terminology guidelines shows that a stable endpoint was reached.

The implications of developing a rigorous clinical terminology using a simplified language are numerous. While the original Omaha System terms were simplified to create SOST, the structure of the Omaha System remained unchanged (Martin, 2005). The SOST maintains the rigor of a recognized clinical terminology that aligns with national terminology standards, such as SNOMED CT and LOINC (Martin, 2005; Regenstrief Institute, 2020; SNOMED International, 2018). The data generated by the SOST may be analyzed with related clinical data (Monsen et al., 2021a). The SOST has the potential to transform healthcare encounters because consumers will be able to use simplified terms to fully describe their health-related strengths, challenges, and needs, using a rigorous ontology. Future research should focus on the implementation of consumer-facing language such as the SOST to examine consumer satisfaction, as well as the effects of using

the SOST on patient-provider communication in a clinical setting. Efforts are underway using these methods to translate SOST into additional languages (e.g. Dutch, Spanish, Czech, Slovak, Mandarin, Thai, and others), thus making these powerful whole-person health assessments and standardized data available worldwide.

Literature suggests that data generated from the consumer-friendly SOST will be useful to both consumers and researchers; and our experience confirms that this has been the case (Hsueh et al., 2017; PCORI Institute, 2019; Pruinelli et al., 2014). Use of the SOST consistently across platforms would enable consumers to contribute to large population health datasets and clinical data repositories (Monsen et al., 2021a, b). These structured CGHD can then be used by researchers to improve consumer-centered outcomes (PCORI Institute, 2019). For example, researchers have successfully used the SOST as CGHD to understand strengths, challenges, and needs related to the COVID-19 pandemic (Monsen et al., 2021a).

Our research is consistent with national and international initiatives to prioritize consumers' perspectives, to amplify the consumer voice within EHR data (Austin, 2018; Monsen et al., 2021b), as well as to develop and integrate consumer-friendly terms to help consumers easily report comprehensive health information (PCORI Institute, 2019; The Office of National Coordinator, 2020). The use of the Omaha System as a framework enabled the translation of a standardized consumer-facing language that has potential to include individual- and community-level data within the EHR. Next steps include policy development to support the use of consumer-facing terms such as the SOST to seamlessly integrate CGHD within current technology platforms to reveal the consumer's whole-person health perspective. The case study of the use of an informatics tool using simplified language demonstrates the use of CGHD for community-based participatory research, resulting in actionable whole-person data including strengths and resilience, globally (USAID, 2021; WHO, 2017).

#### Limitations

Threats to translation validity were addressed by reducing linguistic complexity through the use of simplified terms in alignment with plain language principles, while maintaining the original meanings of the Omaha System terms. We avoided idioms and employed an iterative methodology that incorporated multiple consumer perspectives in three phases. These methods should be replicated in translating and validating the Omaha System or any clinical terminology into plain language.

### **Conclusions**

This is the first study to translate the Omaha System to simplified terms readable at the fifth grade level. The Simplified Omaha System Terms provide structure and rigor for consumer-generated health data, to ensure that the consumer voice is represented in standardized data that has potential value during a clinical encounter and in population health datasets.

The community exemplar demonstrated there was interest in this standardized linguistic approach. During the COVID-19 pandemic, there has been particular interest to expand this approach globally, due to an increased international focus on whole-person health.

#### Ethical aspects and conflict of interests

The authors have no conflict of interests to declare.

# Překlad a ověření systému Omaha do anglického jazyka ve zjednodušených termínech téhož systému

#### Souhrn

*Cíl*: Covid-19 způsobil posun směrem k technologiím orientovaným na spotřebitele, jako jsou mobilní zdravotní aplikace (mHealth). Většina aplikací mHealth však přístupný jazyk nepoužívá. Standardizované terminologie mají potenciál tento problém vyřešit, ale nebyly zjednodušeny pro spotřebitelské použití.

*Metodika*: Použili jsme standardizovanou zdravotnickou terminologii, systém Omaha, jako rámec pro vývoj Simplified Omaha System Terms (SOST) pro použití v aplikaci mHealth, MyStrengths + MyHealth. Principy jednoduchého jazyka informovaly o vývoji SOST ve třech fázích, komunitní validační skupina umožnila zpětnou vazbu od různých koncových uživatelů, hodnocení čitelnosti poskytlo ověření požadované cílové úrovně čitelnosti.

Výsledky: Věk členů v komunitní validační skupině (n = 19) byl v rozmezí od 22 do 74 let; 51 % muži, 84 % lidí jiné barvy pleti a 21 % vysokoškolsky vzdělaných. Úroveň čtení konečného SOST byla v průměru 3,86 na Coleman–Liau Index (čtvrtý stupeň). Případová studie ukázala, že v komunitní studii během pandemie covidu-19 byly vygenerovány smysluplné údaje o celkovém zdraví člověka.

Závěr: Komunitní validace a hodnocení čitelnosti prokázaly přístupný jazyk pro klinickou terminologii. SOST byl úspěšně nasazen v MyStrengths + MyHealth a komunitní studii. Systém Omaha jako rámec pro SOST může umožnit integraci dat s klinickými datovými soubory. Budoucí výzkum by se měl zaměřit na validaci SOST v dalších jazycích a integraci v rámci platforem elektronického zdravotnictví.

Klíčová slova: informační věda; terminologie; zdravotní gramotnost

#### References

- AHRQ Agency for Healthcare Research and Quality (2017). AHRQ Health Literacy Universal Precautions Toolkit. [online] [cit. 2021-01-16]. Available from: https://www.ahrq.gov/health-literacy/improve/precautions/index.html
- AHRQ Agency for Healthcare Research and Quality (2020). Consumer-focused Digital Healthcare. [online] [cit. 2021-01-16]. Available from: https://digital.ahrq.gov/ahrq-funded-projects/current-priorities/consumer-focused-digital-healthcare?page=8%2C1
- 3. Ancker JS, Witteman, HO, Hafeez B, Provencher T, Van de Graaf, M, Wei E (2015). The Invisible work of personal health information management among people with multiple chronic conditions: qualitative interview study among patients and providers. J Med Internet Res 17(6): e137. DOI: 10.2196/jmir.4381.
- Austin R (2018). Picturing patterns in whole-person health: leveraging visualization techniques with structured consumergenerated mHealth data. University of Minnesota, School of Nursing. [online] [cit. 2018-12-21]. Available from: https:// conservancy.umn.edu/handle/11299/202216
- Banskota S, Healy M, Goldberg EM (2020). 15 smartphone apps for older adults to use while in isolation during the covid-19 pandemic. West J of Emerg Med 21(3): 514–525. DOI: 10.5811/ westjem.2020.4.47372.
- Broderick J, Devine T, Langhans E, Lemerise AJ, Lier S, Harris L (2014). Designing Health Literate Mobile Apps. NAM Perspectives. Discussion Paper, National Academy of Medicine, Washington, DC. DOI: 10.31478/201401a.
- 7. Chesser A, Burke A, Reyes J, Rohrberg T (2016). Navigating the digital divide: A systematic review of eHealth literacy in

- underserved populations in the United States. Inform Health Social Care 41(1): 1–19. DOI: 10.3109/17538157.2014.948171.
- Cutilli CC, Simko LC, Colbert AM, Bennett IM (2018). Health literacy, health disparities, and sources of health information in U.S. older adults. Orthop Nurs 37(1): 54–65. DOI: 10.1097/ NOR.0000000000000018.
- Eichner J, Dullabh P (2007). Accessible Health Information Technology (Health IT) for Populations With Limited Literacy: A Guide for Developers and Purchasers of Health IT. (Prepared by the National Opinion Research Center for the National Resource Center for Health IT). AHRQ Publication No. 08-0010-EF. Rockville, MD: Agency for Healthcare Research and Quality.
- Ernsting C, Dombrowski SU, Oedekoven M, O'Sullivan JL, Kanzler M, Kuhlmey A, et al. (2017). Using smartphones and health apps to change and manage health behaviors: A population-based survey. J Med Internet Res 19(4): 1–12. DOI: 10.2196/jmir.6838.
- 11. Gandomi A, Haider M (2015). Beyond the hype: Big data concepts, methods, and analytics. Int J Inf Manage 35(2): 137–144. DOI: 10.1016/j.ijinfomgt.2014.10.007.
- 12. Garner SL, Sudia T, Rachaprolu S (2018). Smart phone accessibility and mHealth use in a limited resource setting. Int J Nurs Pract 24(1): 1–5. DOI: 10.1111/ijn.12609.
- 13. He Z, Chen Z, Oh S, Hou J, Bian J (2017). Enriching consumer health vocabulary through mining a social Q&A site: a similarity-based approach. J Biomed Inform 69(1): 75–85. DOI: 10.1016/j.jbi.2017.03.016.
- 14. Hsueh P-Y, Cheung Y-K, Dey S, Kim KK, Martin-Sanchez FJ, Petersen SK, et al. (2017). Added value from secondary use of person generated health data in consumer health informatics. IMIA Yearbook 26(1): 160–171. DOI: 10.15265/IY-2017-009.
- 15. Huh J, Koola J, Contreras A, Castillo AK, Ruiz M, Tedone KG, et al. (2018). Consumer health informatics adoption among

underserved populations: thinking beyond the digital divide. Yearb Med Inform 27(1): 146–155. DOI: 10.1055/s-0038-1641217.

- Kao CK, Liebovitz DM (2017). Consumer mobile health apps: current state, barriers, and future directions. PMR 9(5S): S106– S115. DOI: 10.1016/j.pmrj.2017.02.018.
- Keesara S, Jonas A, Schulman K (2020). Covid-19 and health care's digital revolution. N Engl J Med 82(23):e82. DOI: 10.1056/NEJMp2005835.
- 18. Language Scientific (2020). What is linguistic validation? [online] [cit. 2021-01-22]. Available from: https://www.languagescientific.com/what-is-linguistic-validation/
- Mackert M, Mabry-Flynn A, Champlin S, Donovan EE, Pounders K (2016). Health literacy and health information technology adoption: the potential for a new digital divide. J Med Internet Res 18(10): e264. DOI: 10.2196/jmir.6349.
- Mandel JC, Kreda DA, Mandl KD, Kohane IS, Ramoni RB (2016). SMART on FHIR: a standards-based, interoperable apps platform for electronic health records. J Am Med Inform Assoc 23(5): 899–908. DOI: 10.1093/jamia/ocv189.
- Martin KS (2005). The Omaha system: A key to practice.
  Documentation and information management (2nd ed.). Health Connections Press.
- Monsen KA, Austin RR, Gorjor B, Pirth A, Jones CR, Mathiason MA, et al. (2021a). Exploring large commnity- and clinical-generated health datasets to understand resilience before and during COVID-19 pandemic. J Nurs Scholarsh 53(3): 262–269. DOI: 10.1111/jnu.12634.
- Monsen KA, Austin RR, Jones RC, Brink D, Mathiason MA, Eder M (2021b). Incorporating a whole-person perspective in consumer-generated data. Comput Inform Nurs 39(8): 402–410. DOI: 10.1097/cin.000000000000730.
- Monsen KA, Holland DE, Houger-Fung PW, Vanderboom CE (2014). Seeing the whole person: feasibility of using the Omaha System to describe strengths of older adults with chronic illness. Res Theory Nurs Pract 28(4): 299–315. DOI: 10.1891/1541-6577.28.4.299.
- Monsen KA, Peters J, Schlesner S, Vanderboom CE, Holland DR (2015). The gap in big data: getting to wellbeing, strengths, and a whole person perspective. Glob Adv Health Med 4(3): 31–39. DOI: 10.7453/gahmj.2015.040.
- Monsen KA, Westra BL, Paitich N, Ekstrom D, Mehle SC, Kaeding M, et al. (2012). Developing a shared personal health record for elders and providers: Technology and content. J Gerontol Nurs 38(7): 21–25. DOI: 10.3928/00989134-20120605-03.
- 27. Norman C, Skinner H (2006). eHealth literacy: essential skills for consumer health in a networked world. J Med Internet Res 8(2): e9. DOI: 10.2196/jmir.8.2.e9.
- PCORI Institute (2019). The PCORI methodology report. [online] [cit. 2021-01-22]. Available from: https://www.pcori.org/research-results/about-our-research/research-methodology/pcori-methodology-report
- 29. Plain Language.gov. (n.d.) (2015). Plain Language. [online] [cit. 2021-04-14]. Available from: https://www.plainlanguage.gov/
- Plow M, Golding M (2017). Using mHealth technology in a self-management intervention to promote physical activity among adults with chronic disabling conditions: randomized controlled trial. JMIR MHealth and UHealth 5(12): e185. DOI: 10.2196/mhealth.6394.
- Pruinelli L, Fu H, Monsen KA, Westra BL (2014). Comparison of consumer derived evidence with an Omaha System evidencebased practice guideline for community dwelling older adults. Stud Health Techn Inform 201: 18–24. DOI: 10.3233/978-1-61499-415-2-18.

- 32. Readability.org. (2021). Coleman–Liau Readability Index. [online] [cit. 2021-08-16]. Available from: https://www.online-utility.org/english/readability\_test\_and\_improve.jsp
- 33. Regenstrief Institute, I. (2020). LOINC. [online] [cit. 2021-01-15]. Available from: https://loinc.org/
- Roundtable on Health Literacy; Board on Population Health and Public Health Practice; Institute of Medicine; National Academies of Sciences, Engineering, and Medicine (2015). Health Literacy and Consumer-facing Technology. DOI: 10.17226/21781.
- 35. SNOMED International (2018). SNOMED CT. [online] [cit. 2021-10-15]. Available from: http://www.snomed.org/
- 36. Stec MA, Arbour MW, Hines HF (2019). Client-centered mobile health care applications: using the mobile application rating scale instrument for evidence-based evaluation. J Midwifery Womens Health 64(3): 324–329. DOI: 10.1111/jmwh.12941.
- 37. The National Academies Press (2015). Health Literacy and Consumer-Facing Technology. Health Literacy and Consumer-Facing Technology. DOI: 10.17226/21781.
- 38. Omaha System (2021). The Omaha System: Solving the Clinical Data-Information Puzzle. [online] [cit. 2021-08-16]. Available from: https://www.omahasystem.org/
- The Office of National Coordinator (2020). Interoperability Standards Advisory – ONC's resource for industry to reference standards and implementation specifications. [online] [cit. 2021-01-22]. Available from: https://www.healthit.gov/isa/
- 40. Turvey C, Klein D, Fix G, Hogan TP, Woods S, Simon SR, et al. (2014). Blue Button use by patients to access and share health record information using the Department of Veterans Affairs' online patient portal. J Am Med Inform Assoc 21(4): 657–663. DOI: 10.1136/amiajnl-2014-002723.
- 41. U.S. Department of Health and Human Services Office of Disease Prevention and Health Promotion (2020). Health literacy in Healthy People. Healthy People 2030. [online] [cit. 2021-01-25]. Available from: https://health.gov/our-work/healthy-people-2030/about-healthy-people-2030/health-literacy-healthy-people
- 42. USAID (2021). Blueprint for Global Health Resilience (Issue January). [online] [cit. 2021-01-21]. Available from: https://www.usaid.gov/global-health/health-systems-innovation/health-systems/resources/blueprint-resilience
- Webster P (2020). Virtual health care in the era of COVID-19. Lancet 395(10231): 1180–1181. DOI: 10.1016/S0140-6736(20)30818-7.
- Whitney RL, Ward DH, Marois MT, Schmid CH, Sim I, Kravitz RL (2018). Patient perceptions of their own data in mhealth technology-enabled N-of-1 trials for chronic pain: Qualitative study. JMIR MHealth and UHealth 6(10): e10291. DOI: 10.2196/10291.
- 45. WHO (2017). Strengthening resilience: A priority shared by Health 2020 and the Sustainable Development Goals. [online] [cit. 2021-08-16]. Available from: https://www.euro.who.int/en/countries/monaco/publications/strengthening-resilience-a-priority-shared-by-health-2020-and-the-sustainable-development-goals-2017
- 46. Wild D, Grove A, Martin M, Eremenco S, McElroy S, Verjee-Lorenz A, et al. (2005). Principles of good practice for the translation and cultural adaptation process for patient-reported outcomes (PRO) measures: report of the ISPOR task force for translation and cultural adaptation. Value in Health 8(2): 94–104. DOI: 10.1111/j.1524-4733.2005.04054.x.
- Zeng QT, Tse T (2006). Exploring and developing consumer health vocabularies. J Am Med Inform Assoc 13(1): 24–29. DOI: 10.1197/jamia.M1761.