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Towards Common Data Elements for International Research in Long-Term Care Homes:
 Advancing Person-Centered Care Across the Globe

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1 Special articles do not involve original research but instead provide novel interpretation or synthesis of information in
2 an area of general interest to readers of the journal. Examples of special articles include consensus statements,
3 clinical tools, practice guidelines, and discussion of new policies or regulations. Manuscripts may be solicited by the
4 editors or submitted at the initiative of authors. The body of the submission (excluding abstract and references)
5 should generally be limited to 3,000 words; it can include 3 tables or figures, and 50 references. An unstructured
6 abstract of up to 300 words is required, and specific headings to organize the text are not prescribed; however, the
7 text should conclude with a section entitled "Implications for Practice, Policy, and/or Research."

8 9 **ABSTRACT**

10 To support person-centered, residential long-term care internationally, a consortium of
11 researchers in medicine, nursing, behavioral and social sciences from 21 geographically and
12 economically diverse countries have launched the WE-THRIVE initiative to develop a common
13 data infrastructure. The consortium aims to identify measurement domains that are
14 internationally relevant, including in low and middle income countries, prioritize concepts to
15 operationalize domains, and specify a set of data elements to measure concepts that can be used
16 across studies for data sharing and comparisons. This article reports findings from consortium
17 meetings at the 2016 meeting of the Gerontological Society of America and the 2017 meeting of
18 the International Association of Gerontology and Geriatrics, to identify domains and prioritize
19 concepts, following best practices to identify CDEs that were developed through the U.S.
20 National Institutes of Health/National Institute of Nursing Research's common data elements
21 (CDEs) initiative. Four domains were identified, including organizational context; workforce and
22 staffing; person-centered care; and care outcomes. Using a nominal group process, WE-
23 THRIVE prioritized 21 concepts. Concepts converge and diverge with existing measurement
24 infrastructures. Conceptual convergence (e.g., concepts in the care outcomes domain of
25 *functional level* and *harm-free care*) provides further support of the critical foundational work in
26 LTC measurement endorsed and implemented by regulatory bodies. Conceptual divergence (e.g.,
27 concepts in the person-centered care domain of *knowing the person* and *what matters most to the*
28 *person*) highlights current gaps in measurement efforts and is consistent with WE-THRIVE's

29 focus on supporting resilience and thriving for residents, family and staff. In alignment with the
30 World Health Organization's call for comparative measurement work for health systems change,
31 WE-THRIVE's work to date highlights the benefits of engaging with diverse LTC researchers,
32 which includes those based in low and middle income countries, to accomplish a measurement
33 infrastructure that integrates aspirations of person-centered LTC.

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INTRODUCTION

Recently published position statements by the International Consortium of Professional Nursing Practice in Long-term Care Homes [1] and the International Association of Gerontology and Geriatrics Consensus Group [2] identify critical gaps in our empirical knowledge to support high-quality, person-centered residential long-term care (LTC). From a global perspective, key to accomplishing this agenda is the ability to develop international common data elements (CDEs) that facilitate LTC data sharing and aggregation, improve LTC data quality, and support common outcomes measures, among other benefits. In this article, we describe an effort that draws on the National Institutes of Health (NIH) CDE initiative [3] to identify CDEs for research in LTC homes that are relevant across countries and could be used internationally. The World Health Organization has identified such comparative measurement work as one of the most critical levers for health systems change [4, 5].

Defining characteristics of common data elements in relation to existing work

Our efforts to identify LTC CDEs for global use are grounded in a person-centered and strengths-based ethos [6] with the purpose of developing residential LTC systems that support resilience and thriving among LTC residents, families and staff. Our person-centered and strengths-based perspective contrasts with the predominant LTC measurement paradigm, which tends to emphasize frailty and deficits, often with a single-resident focus without accounting for the interactions and outcomes of staff, families, or other residents [1, 7]. Deficit-based measurement is conducted primarily for the purpose of ensuring regulatory compliance; importantly, the majority of comparative measurement infrastructures globally have emerged from this paradigm [8, 9]. This deficit-focused infrastructure has been and will continue to be instrumental in advancing patient safety and care quality. However, the underlying paradigm

57 limits our ability to shift to an international, person-centered LTC research infrastructure that
58 advances and supports well-being and quality of life among older adults, their families and care
59 workers.

60 To foster a shift to person-centered LTC research, we have created an international
61 consortium of LTC researchers, the Worldwide Elements To Harmonize Research In long-term
62 care liVing Environments (WE-THRIVE). The consortium includes researchers based in
63 geographically and economically diverse countries, to accomplish two preliminary goals. The
64 first goal of WE-THRIVE is to identify fundamental measurement domains and concepts of
65 residential LTC that are important internationally, and the second goal is to establish consensus
66 on core data elements to measures concepts within each domain. WE-THRIVE's overarching
67 goal is to collaboratively develop an international LTC research measurement infrastructure that
68 can be used efficiently in diverse, residential LTC settings for comparative research to advance
69 person-centered care for resilience and thriving among residents, staff, and family members.

70 **APPROACH TO CONSENSUS-BUILDING**

71 WE-THRIVE's overall approach was guided by best practices in CDEs developed by the
72 U.S. National Institute of Nursing Research-funded symptom science research centers [3]. Their
73 approach, developed in alignment with The International Organization for Standardization (ISO)
74 and International Electrotechnical Commission's standards for metadata registries [10],
75 encompasses three broad activities for developing and using CDEs, including ensuring
76 conceptual consistency, implementing group processes for identification and selection, and
77 developing data collection and management protocols.

78 WE-THRIVE was initiated in November 2016; to date, we have engaged in a
79 comprehensive, multi-step group process to identify core measurement domains of residential

80 LTC and corresponding concepts, which will inform the future selection of data elements, and
81 the development of data collection and management protocols. The consortium includes
82 researchers from 21 countries, including researchers from lower-middle, upper-middle, and high-
83 income countries who are conducting research on diverse types of LTC care homes (World
84 Bank, 2018). Our inclusive approach is congruent with the ISO Action Plan for Developing
85 Countries [11], developed in alignment with the United Nations' Sustainable Development Goals
86 [12].

87 **Identifying International LTC Measurement Domains**

88 *Convening workshop: Generating Domains.* WE-THRIVE first convened in a half-day
89 workshop at the 69th annual meeting of the Gerontological Society of America (GSA) in
90 November, 2016, in New Orleans, Louisiana. Participants included 27 LTC researchers from 11
91 countries, including Canada, China, Japan, Korea, Norway, Spain, Sweden, Switzerland,
92 Thailand, the United Kingdom, and the United States. During the workshop, we reviewed NIH's
93 CDEs framework, conducted breakout group discussions regarding critical domains for LTC
94 measurement, and reached consensus across participants on four domains for LTC measurement
95 that are salient internationally, including: (1) organizational context (external and internal to the
96 residential care setting), (2) workforce and staffing, (3) person-centered care, and (4) care
97 outcomes. During and following the GSA pre-conference workshop, WE-THRIVE membership
98 expanded with more researchers who are committed to our LTC CDEs development work.

99 *Post-workshop effort: Refining Domains, Engaging Stakeholders and Generating*
100 *Concepts.* Between GSA and the 21st meeting of the International Association of Gerontology
101 and Geriatrics (IAGG) in July, 2017, WE-THRIVE members met in the four, domain-specific
102 committees using a computer-based video-conference platform to begin identifying important

103 measurement concepts within each domain. Each domain committee included chairs or co-chairs
104 who facilitated domain-specific discussions. Domain-specific discussions focused on potential
105 concepts in each domain that were common to LTC settings across represented countries. The
106 domain committee chairs met in monthly WE-THRIVE steering committee meetings to report
107 updates and share challenges and ideas across subgroups. Figure 1 summarizes the
108 developmental timeline of WE-THRIVE's work, totaling 8 steering committee meetings and 9
109 domain committee meetings that occurred in preparation for IAGG 2017.

110 Because of the group's commitment to global inclusiveness, a standing item for the
111 steering committee and the domain committee meetings was to identify new WE-THRIVE
112 members, especially those from low and middle-income countries (LMICs), to vet the work to
113 date. We built an inclusive, flexible network of researchers with ongoing participation through
114 face-to-face or distance-based technology that was not limited to researchers who could attend
115 IAGG 2017. This approach is consistent with the ESSENCE on Health Research initiative's
116 principle of building collaborative networks to strengthen LMIC research capacity [13].
117 Through this effort, WE-THRIVE membership continued to expand in size and diversity.

118 *Second workshop: Nominal Group Process for Concepts.* Building on the GSA
119 workshop and the domain committee work, WE-THRIVE convened in a full-day pre-conference
120 workshop—*Common Data Elements for International Research in Long-Term Care*—at IAGG
121 in San Francisco on July 23, 2017. This workshop was open to all; participants included 55 LTC
122 researchers from 13 countries, including 4 LMICs.

123 Drawing upon all previous activities related to identifying core domains and concepts, the
124 consortium adopted a nominal group technique [14-16] to further specify a set of measurement
125 concepts within each of the four domains. The nominal group technique is a structured group

126 process to prioritize ideas and build consensus using both silent, idea-generating and group
127 discussion phases; it has been used previously by international groups for consensus-
128 development in both research and non-research settings [17, 18]. As such, this approach is
129 consistent with the consortium's inclusive approach to ensure all participants can contribute their
130 perspectives in a way that does not privilege any one culture's engagement style.

131 We convened the workshop by reviewing WE-THRIVE goals and the steps of the
132 nominal group process. Next, participants selected a domain group to join and domain committee
133 chairs facilitated the domain-specific nominal group process. Nominal group facilitation was
134 standardized in two ways. First, a nominal group process implementation manual was developed
135 for use by the domain group chairs. Second, each domain chair was assisted by a graduate
136 student or post-doctoral research fellow who was trained in using the manual prior to the
137 workshop. Domain groups completed the following 6 steps: individual, silent generation of
138 possible concepts within a domain (step 1); group turn-taking to share all ideas and eliminate any
139 duplicates (step 2); group discussion and feedback of generated concepts (step 3); individual,
140 confidential voting for the top 5 concepts considered the most important to measure across LTC
141 settings internationally (step 4); tally of votes (step 5); and discussion of results (step 6). These
142 steps were followed by a full-plenary session reporting out and discussion of the within-domain
143 group results.

144 Through the nominal group process, we established consensus on a key set of concepts to
145 be measured within each domain, and identified cross-country differences in the importance or
146 meaning of the measurement concepts. Throughout the subgroup discussions, domain chairs
147 ensured concepts identified by partners who were not present at IAGG were discussed, and
148 encouraged participants to ask questions and share divergent perspectives. As an additional

149 strategy for inclusivity, participants were encouraged to write on boards around the room any
150 thoughts not captured during the nominal group process, organized in accordance with
151 MyHomeLife's [19] collaborative sensemaking themes ([http://myhomelife.org.uk/wp-](http://myhomelife.org.uk/wp-content/uploads/2014/11/Collaborative-Sense-Making-Tool.pdf)
152 [content/uploads/2014/11/Collaborative-Sense-Making-Tool.pdf](http://myhomelife.org.uk/wp-content/uploads/2014/11/Collaborative-Sense-Making-Tool.pdf)).

153

154 RESULTS

155 Nominal Group Process: Domains and Concepts

156 Across the four LTC domains, participants prioritized 21 measurement concepts for
157 which CDEs could efficiently support international research on critical LTC issues. Within each
158 domain, the workshop participants prioritized five to six concepts.

159 **Organizational context.** Within the Organizational Context domain, participants (N=7)
160 from China, Japan, Sweden, the United Kingdom and the United States generated 87 candidate
161 concepts as relevant to the organizational context of residential long-term care in their countries.
162 Six concepts were prioritized as most important to measure. All 6 concepts were endorsed by
163 the full plenary (Table 1). Concepts included *social resources and support* for the organization;
164 *regulations* that affect the organization; characteristics of *funding* of care; organizational
165 *leadership hierarchy and role*; as well as the *interface between leadership and management*; and
166 characteristics of a *desirable working environment*.

167 **Workforce and staffing.** Within the Workforce and Staffing domain, participants (N=8)
168 from Brazil, Canada, Norway, the United Kingdom, and the United States generated 85
169 candidate concepts as relevant to workforce and staffing in residential long-term care in their
170 countries. After clarifying and prioritizing discussions, 5 measurement concepts were prioritized
171 as most important to measure and were endorsed by the full plenary (Table 1). Concepts

172 included *staff skills, attitudes, and knowledge* in relation to residents' needs; *staff collaboration*
173 *and teamwork*, which was discussed as including supervisory control and feeling supported;
174 *training and self-efficacy of staff*, including educational opportunities; *staff retention and*
175 *turnover*, including staff's sense of feeling valued, wage competitiveness, and the desire to stay
176 in the job; and *leadership and supervisory effectiveness*, including delegation and task allocation.

177 **Person-centered care.** Within the Person-Centered Care domain, participants (N=12)
178 from Canada, China, Japan, South Korea, Thailand, the United Kingdom, and the United States
179 generated 112 candidate concepts as relevant to person-centered care in their countries. Through
180 the clarification and voting process, 5 measurement concepts were prioritized as the most
181 important to measure and were endorsed by the full plenary (Table 1). Concepts included
182 *relationship*, with consideration for relationships among all persons who are part of the
183 residential care settings, including residents, staff, and family; *knowing the person*; identifying
184 and addressing *what matters most to the person*; supporting *meaningful engagement*; and
185 supporting a *positive environment*.

186 **Care outcomes.** Within the Care Outcomes domain, participants (N=11) from Hong
187 Kong, Jamaica, Japan, Sweden, Switzerland, the United Kingdom and the United States
188 generated 122 candidate concepts as relevant to care outcomes in residential long-term care in
189 their countries; 5 concepts were prioritized through the discussion and voting process as most
190 important to measure. All 5 were endorsed by the full plenary (Table 1). Concepts included
191 *symptom management*, especially pain management; *functional level*; *well-being*; *personhood*,
192 which was discussed as, 'letting people be people'; and *harm-free care*, including consideration
193 of pressure ulcers and falls.

194 **Collaborative Sensemaking Themes: Ideas for Reflection**

195 Participants posted 71 comments on boards in the meeting room. Of these, 35 comments
196 were similar across multiple participants, including the importance of resident pain (N=3
197 comments), outcomes that matter to residents (N=3 comments), relationships in residential care
198 settings (N=4 comments), and care staff outcomes (N=7). While each of these sets of comments
199 align with the final set of recommended concepts endorsed as most important, two additional sets
200 of comments raised unique issues. The first set of comments pointed out the importance of
201 recognizing and challenging our underlying assumptions about the role of families in care
202 settings as positive and desired (N=6). For example, comments included discussion of how
203 families may not always be desired by residents in care settings. The second set of comments
204 (N=8) identified barriers to inclusion in the WE-THRIVE process; this was the largest set of
205 comments. Identified barriers included the following: meeting attendance costs and time away
206 from home institutions pose significant barriers for face-to-face LMIC-based researchers'
207 participation; the assumption of the importance of person-centered care that is embedded in a
208 cultural context that may be difficult to challenge; the risk that one may lack effective strategies
209 to explore ontological assumptions in others' worldviews and therefore focus on what is relevant
210 to one's culture alone; and the tension between making decisions to move forward as a group and
211 the need for ongoing, iterative engagement, especially with LMIC-based researchers, over time.

212 **IMPLICATIONS FOR PRACTICE, POLICY AND/OR RESEARCH**

213 Advancing a parsimonious set of common data elements that could be applicable across
214 diverse residential long-term care settings internationally, requires questioning the extent to
215 which our current measurement paradigms embrace more global aspirations of supporting
216 thriving among older adults, their families, and care staff. Our WE-THRIVE Consortium
217 identified four domains with related concepts for measurement that both converge and diverge

218 with the predominant, deficits-based framework. Convergence highlights the critical
219 foundational work in long-term care measurement conducted by researchers and endorsed and
220 implemented by regulatory bodies, such as InterRAI,[20], yet divergence invites us to consider
221 key gaps needed to specify a person-centered, strengths-based measurement framework that can
222 be meaningfully applied internationally.

223 The Organizational Context domain working group identified key parameters historically
224 captured in organizational studies of residential long-term care settings, such as regulation and
225 funding (see, for example [21]), but also prioritized components of the social context of care and
226 the work environment. This prioritization is consistent with more recent measurement and
227 empirical work of the context of care from non U.S.-based research teams [22].

228 Similarly, the Workforce and Staffing domain working group endorsed historically
229 relevant concepts of staffing ratios or turnover in long-term care, while highlighting the extent to
230 which staff are integrated into teams with effective leadership support and opportunities to learn.
231 This latter emphasis also is consistent with recent findings from non U.S.-based research teams,
232 about the direct effects of how staff are supported and developed on both staff and resident care
233 outcomes[23].

234 The Person-centered Care domain working group coincided with U.S. DHHS/CMS
235 issued regulatory changes that require documentation of resident preferences for person-centered
236 care [24]. Our findings indicated that measuring preferences, while salient, may be of lower
237 priority internationally than measuring the quality of the relationships among residents, family,
238 and staff. This finding is consistent with more recent international consensus statements of the
239 quality of relationships, or relationship-centered care, as fundamental drivers of person-centered
240 care in residential LTC [1].

241 Similarly, during a time of important growth in technical capacity and administrative will
242 to support expansion of MDS-like data registries across multiple countries [25], the Care
243 Outcomes domain working group prioritized conceptually consistent measures of functional
244 level and harm-free care, yet also prioritized symptom management as most important, and
245 added well-being and personhood. These latter concepts are consistent with the European
246 Union’s framework of the PROGRESS Programme’s recommendations for residential LTC
247 measures [26]. Findings support the importance of refining how symptom experience and
248 symptom management are meaningfully included, as well as understanding the
249 interconnectedness of care outcomes with personhood.

250 Accomplishing the larger goal of WE-THRIVE requires building on these initial efforts
251 to move from candidate concepts to well-defined concepts with measures that have been broadly
252 vetted across diverse socio-cultural contexts and with multiple LTC stakeholders. The purpose of
253 CDEs is not to generate a comprehensive battery of recommended measures, but rather to
254 endorse a parsimonious subset of data elements that can be embedded within current and future
255 LTC research data collection efforts. Engaging with more researchers based in LMIC-countries,
256 and engaging with those in residential LTC settings, therefore, will be essential to take these next
257 steps. Such vetting and selection will require in-depth consideration of issues of inclusion to
258 foster transparency and deliberative dialogue of underlying assumptions within each domain,
259 such as those limitations raised by participants in our collaborative sensemaking exercise.

260 Ultimately, our ability as a scientific community to support a rapidly evolving, global
261 residential long-term care infrastructure will require new ways of engaging with our peer-
262 researchers, especially those based in LMIC settings, and the development of a measurement
263 infrastructure that integrates aspirational perspectives of thriving and resilience in aging. The

264 WE-THRIVE Consortium's work to date indicates both the potential of this approach to begin to
265 build inclusive networks, as well as our shared capacity to leverage and enhance rather than
266 replace existing measurement tools.

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Table 1. Domain Concepts and Prioritization Votes

Domain	Concept	Votes
Organizational Context	1. Social resources and support	21
	2. Regulation	21
	3. Funding	15
	4. Leadership hierarchy and role	10
	5. Leadership & management interface	9
	6. Desirable working environment	9
Workforce and Staffing	1. Staff skills, attitudes, and knowledge	36
	2. Staff collaboration and teamwork	17
	3. Training and self-efficacy of staff	16
	4. Staff retention and turnover	11
	5. Leadership and supervision effectiveness	9
Person-Centered Care	1. Relationship	39
	2. Knowing the person	24
	3. What matters most to the person	13
	4. Meaningful engagement	12
	5. Positive environment	9
Care Outcomes	1. Symptom management	33
	2. Functional Level	26
	3. Well-being	23
	4. Personhood	16
	5. Harm-free care	9

Figure 1. Overview of WE-THRIVE timeline to identify domains and concepts

