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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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Authorship Statement: The following are members of WE-THRIVE (**W**orldwide **E**lements to **H**armonize **R**esearch in Long Term Care Living **E**nvironments): *[To insert all participants in domain discussions and IAGG-GSA session who wish to be included; we are following the ICMJE guidelines for consortium authorship, as operationalized by BMJ*

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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 69<sup>th</sup> 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 21<sup>st</sup> 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) ).

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## 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

