WE-THRIVE CDE 1

Towards Common Data Elements for International Research in Long-Term Care Homes:

Advancing Person-Centered Care

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1 ABSTRACT

2	To support person-centered, residential long-term care internationally, a consortium of
3	researchers in medicine, nursing, behavioral and social sciences from 21 geographically and
4	economically diverse countries have launched the WE-THRIVE initiative to develop a common
5	data infrastructure. WE-THRIVE aims to identify measurement domains that are internationally
6	relevant, including in low, middle, and high income countries, prioritize concepts to
7	operationalize domains, and specify a set of data elements to measure concepts that can be used
8	across studies for data sharing and comparisons. This article reports findings from consortium
9	meetings at the 2016 meeting of the Gerontological Society of America and the 2017 meeting of
10	the International Association of Gerontology and Geriatrics, to identify domains and prioritize
11	concepts, following best practices to identify common data elements (CDEs) that were
12	developed through the U.S. National Institutes of Health/National Institute of Nursing
13	Research's CDEs initiative. Four domains were identified, including organizational context;
14	workforce and staffing; person-centered care; and care outcomes. Using a nominal group
15	process, WE-THRIVE prioritized 21 concepts across the four domains. Several concepts showed
16	similarity to existing measurement structures, while others differed. Conceptual similarity
17	(convergence; e.g., concepts in the care outcomes domain of functional level and harm-free care)
18	provides further support of the critical foundational work in LTC measurement endorsed and
19	implemented by regulatory bodies. Different concepts (divergence; e.g., concepts in the person-
20	centered care domain of knowing the person and what matters most to the person) highlights
21	current gaps in measurement efforts and is consistent with WE-THRIVE's focus on supporting
22	resilience and thriving for residents, family and staff. In alignment with the World Health
23	Organization's call for comparative measurement work for health systems change, WE-

- 24 THRIVE's work to date highlights the benefits of engaging with diverse LTC researchers,
- 25 including those in low, middle, and high income countries, to develop a measurement
- 26 infrastructure that integrates aspirations of person-centered LTC.

27 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 a set of international common data elements (CDEs) that facilitates LTC data sharing and aggregation, improves LTC data quality, and supports common outcomes measures, among other benefits. In this article, we describe our efforts that draw on the National Institutes of Health (NIH) CDE initiative to support CDEs in research, through providing resource guides, an online repository, and supporting the development and use of CDEs in NIH-funded studies, [3] to identify CDEs for research in LTC homes that are relevant across countries and could be used internationally. The World Health Organization (WHO) 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 the larger context [1, 7]. Deficit-based measurement has frequently been deployed with an emphasis on supporting regulatory compliance and reimbursement; importantly, the majority of comparative measurement

infrastructures globally have emerged from this paradigm [8, 9]. Recent examples include the US Centers for Medicare and Medicaid's quality measures of post-acute care, such as percentage of residents who were re-hospitalized after a nursing home admission, and/or had an emergency department visit [10], which emphasize outcomes linked to monetary penalties without attention to person-centered care goals [11] or an older adult's trajectory of intrinsic capacity [12]. Similarly, England's National Health Service [13] recently implemented an electronic Frailty Index (eFI) as the basis of mandated and compliance-regulated assessment of older people with progressive frailty by General Practitioners. This deficit-focused infrastructure has been and will continue to be instrumental in advancing patient safety and care quality. However, the underlying paradigm limits our ability to shift to an international, person-centered LTC research infrastructure that advances and supports well-being and quality of life among older adults, their families and care workers. This shift is consistent with WHO's World Report on Ageing and Health [14] and call for a move towards a focus on capacity rather than frailty. To foster a shift to person-centered, strengths-based LTC research, we have created an international consortium of LTC researchers based in 21 geographically and economically diverse countries, the Worldwide Elements To Harmonize Research In long-term care liVing

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international consortium of LTC researchers based in 21 geographically and economically diverse countries, the <u>Worldwide Elements To Harmonize Research In long-term care liVing Environments (WE-THRIVE) consortium. WE-THRIVE's overarching goal is to collaboratively develop an international LTC research measurement infrastructure that can be used efficiently in diverse, residential LTC settings for comparative research to advance personcentered care for resilience and thriving among residents, staff, and family members. To achieve this overarching goal, our work is carried out in two sequential phases. The first phase focuses on identifying fundamental measurement domains and concepts of residential LTC that are important internationally, and the second phase focuses on establishing consensus on core data</u>

elements to measures concepts within each domain. This paper reports the process and findings related to phase one.

#### APPROACH TO CONSENSUS-BUILDING

WE-THRIVE's overall approach is guided by best practices in CDEs developed by the U.S. National Institute of Nursing Research-funded symptom science research centers [3]. Their approach, developed in alignment with The International Organization for Standardization (ISO) and International Electrotechnical Commission's standards for metadata registries [15], encompasses three broad activities for developing and using CDEs, including ensuring conceptual consistency, implementing group processes for identification and selection, and developing data collection and management protocols.

WE-THRIVE was initiated in November 2016; to date, we have engaged in a comprehensive, multi-step group process to identify core measurement domains of residential LTC and corresponding concepts (phase 1), which will inform the future selection of data elements, and the development of data collection and management protocols (phase 2). The consortium includes 59 researchers from 21 countries, including researchers from lower-middle, upper-middle, and high- income countries who are conducting research in diverse settings of residential LTC. While the majority of participants are from only 2 of the 21 countries (US=14; UK=11), there is a relatively equal distribution of researchers from the Americas (21), Europe (17), and the Western Pacific and Southeast Asia (21) regions. We do not yet have collaborators from the Eastern Mediterranean and African WHO regions. Regarding discipline, the majority of participants are from nursing (N=43); other represented disciplines include medicine (N=5), and social and behavioral sciences (N=11). Our inclusive approach is congruent with the ISO Action Plan for Developing Countries [16], developed in alignment with the United Nations'

Sustainable Development Goals [17].

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# **Identifying International LTC Measurement Domains**

WE-THRIVE's phase 1 work to identify measurement domains and concepts has included: beginning with convening as a group in 2016 to generate domains; forming domain sub-committees and conducting a series of eight steering committee and nine domain sub-committee meetings; and convening again as a full group in 2017.

Convening workshop: Generating Domains. WE-THRIVE first convened in a half-day workshop at the 69<sup>th</sup> annual meeting of the Gerontological Society of America (GSA) in November, 2016, in New Orleans, Louisiana. Sponsored by the GSA Interest Group on LTC Systems Research, participants included 27 LTC researchers from 11 countries, including Canada, China, Japan, Korea, Norway, Spain, Sweden, Switzerland, Thailand, the United Kingdom, and the United States. Participants were invited through GSA's pre-conference workshop marketing materials, the GSA Interest Group's list-serv, and one-on-one invitations by interested Interest Group members to non-members who have previously conducted research in the LTC measurement arena. During the workshop, we reviewed NIH's CDEs framework, conducted breakout group discussions regarding critical domains for LTC measurement, and reached consensus on four domains for LTC measurement that are salient internationally, including: (1) organizational context (external and internal to the residential care setting), (2) workforce and staffing, (3) person-centered care, and (4) care outcomes. Following the GSA preconference workshop, WE-THRIVE membership expanded as participants reached out to discuss the session with colleagues who were not present at GSA, and who expressed interest in the LTC CDEs development work.

Post-workshop effort: Refining Domains, Engaging Stakeholders and Generating

Concepts. Between GSA and the 21<sup>st</sup> meeting of the International Association of Gerontology and Geriatrics (IAGG) in July, 2017, WE-THRIVE members met in sub-committees representing the four domains using a computer-based video-conference platform to begin identifying important measurement concepts within each domain. Each domain committee included chairs or co-chairs who facilitated domain-specific discussions. Domain-specific discussions focused on potential concepts in each domain that were common to LTC settings across represented countries. The domain committee chairs met in monthly WE-THRIVE steering committee meetings to report updates and share challenges and ideas across subgroups.

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Because of the group's commitment to global inclusiveness, a standing item for the steering committee and the domain committee meetings was to identify new WE-THRIVE members, especially those from low and middle-income countries (LMICs), to vet the work to date. We reviewed professional networks to identify LMIC-based colleagues for one-on-one outreach; two of the schools represented by the steering committee are WHO Collaborating Centres with enhanced networks. New colleagues were invited to attend distance-based meetings via computer conference calls. IAGG marketing and communications disseminated information globally about our second workshop; we provided limited scholarships to LMIC colleagues to support attendance, as well as encouraged those who could not attend to continue to participate asynchronously pre- and post- the IAGG workshop. We built an inclusive, flexible network of researchers with ongoing participation through face-to-face or distance-based technology that was not limited to researchers who could attend IAGG 2017. This approach is consistent with the ESSENCE on Health Research initiative's principle of building collaborative networks to strengthen LMIC research capacity [18]. Through this effort, WE-THRIVE membership continued to expand in size and diversity.

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

Drawing upon all previous activities related to identifying core domains and concepts, the consortium adopted a nominal group technique [19-21] to further specify a set of measurement concepts within each of the four domains. The nominal group technique is a structured group process to prioritize ideas and build consensus using both silent, idea-generation and group discussion phases; it has been used previously by international groups for consensus-development in both research and non-research settings [22, 23]. This approach is consistent with the consortium's inclusive approach to ensure all participants can contribute their perspectives in a way that does not privilege any one culture's engagement style.

We convened the workshop by reviewing WE-THRIVE goals, presenting summaries of the background work to date, including descriptions of the domains, and describing the steps of the nominal group process. Next, participants selected a domain group to join and domain committee chairs facilitated the domain-specific nominal group process. Nominal group facilitation was standardized in two ways. First, a nominal group process implementation manual was developed for use by the domain group chairs. Second, each domain chair was assisted by a graduate student or post-doctoral research fellow who was trained in using the manual prior to the workshop. Domain groups completed the following six steps: individual, silent generation of possible concepts within a domain (step 1); group turn-taking to share all ideas and eliminate any duplicates (step 2); group discussion and feedback of generated concepts

(step 3); individual, confidential voting for the top 5 concepts considered the most important to measure across LTC settings internationally (step 4); tally of votes assigning rank scores of 5 to 1 for each individual's ranked concepts from highest ranked concept (score of 5) through fifth ranked concept (score of 1) (step 5); and discussion of results (step 6). These steps were followed by a full-plenary session reporting out and discussion of the within-domain group results. Bringing domain group results to the full plenary for discussion facilitated a vetting of candidate concepts within each domain by all researchers participating in the workshop across 13 countries, rather than the subset of researchers within each domain subgroup.

Through the nominal group process, we established consensus on a key set of measurement concepts within each domain and identified cross-country differences in the importance or meaning of the measurement concepts. Throughout the subgroup discussions, domain chairs ensured concepts identified by partners who were not present at IAGG were discussed, and encouraged participants to ask questions and share divergent perspectives. As an additional strategy for inclusivity, participants were encouraged to write on boards around the room any thoughts not captured during the nominal group process, organized in accordance with MyHomeLife's [24] Collaborative Sensemaking Tools (<a href="http://myhomelife.org.uk/wp-content/uploads/2014/11/Collaborative-Sense-Making-Tool.pdf">http://myhomelife.org.uk/wp-content/uploads/2014/11/Collaborative-Sense-Making-Tool.pdf</a> ).

183 RESULTS

#### **Nominal Group Process: Domains and Concepts**

Across the four LTC domains, participants prioritized 21 measurement concepts for which CDEs could efficiently support international research on critical LTC issues. Within each domain, the workshop participants prioritized five concepts. Table 1 summarizes the prioritized

concepts following the nominal group process. Total rank score for each concept reflect the sum of rank scores across all domain group members. Because we established a priori that participants should vote for the top 5 priority concepts, domain groups varied considerably in terms of the extent to which all 5 concepts were selected as of relatively equal weight (that is, total rank scores were similar) versus domains with 1 or 2 concepts for which there were markedly higher ranking scores, relative to the remaining prioritized concepts.

Organizational context. Within the Organizational Context domain, participants (N=7) from China, Japan, Sweden, the United Kingdom and the United States generated 87 candidate concepts as relevant to the organizational context of residential LTC in their countries. Six concepts were prioritized as most important to measure. All six concepts were endorsed by the full plenary (Table 1). Concepts included *social resources and support* for the organization; *regulations* that affect the organization; characteristics of *funding* of care; organizational *leadership hierarchy and role*; as well as the *interface between leadership and management*; and characteristics of a *desirable working environment*. Of these concepts, external contextual factors of social resources and support, regulation, and funding, were given similar ranks by participants (sharing 20%, 20%, and 14 % of total rank scores, respectively), and ranked higher overall than internal contextual factors related to concepts of leadership and work environment.

Workforce and staffing. Within the Workforce and Staffing domain, participants (N=8) from Brazil, Canada, Norway, the United Kingdom, and the United States generated 85 candidate concepts as relevant to workforce and staffing in residential long-term care in their countries. After clarifying and prioritizing discussions, five measurement concepts were prioritized as most important to measure and were endorsed by the full plenary (Table 1). Concepts included *staff skills*, *attitudes*, *and knowledge* in relation to residents' needs; *staff* 

collaboration and teamwork, which was discussed as including supervisory control and feeling supported; training and self-efficacy of staff, including educational opportunities; staff retention and turnover, including staff's sense of feeling valued, wage competitiveness, and the desire to stay in the job; and leadership and supervisory effectiveness, including delegation and task allocation. Staff skills, attitudes and knowledge was ranked higher overall than all other workforce and staffing concepts, as the dominant concept from this domain, garnering 30% of total rank scores.

Person-centered care. Within the Person-Centered Care domain, participants (N=12) from Canada, China, Japan, South Korea, Thailand, the United Kingdom, and the United States generated 112 candidate concepts as relevant to person-centered care in their countries. Through the clarification and voting process, five measurement concepts were prioritized as the most important to measure and were endorsed by the full plenary (Table 1). Concepts included *relationship*, with consideration for relationships among all persons who are part of the residential care settings, including residents, staff, and family; *knowing the person*; identifying and addressing *what matters most to the person*; supporting *meaningful engagement*; and supporting a *positive environment*. Relationship was the primary concept ranked as most important in this domain, with 21% of total rank scores, followed by knowing the person, with 13% of scores. All other concepts had considerably lower proportions of scores.

Care outcomes. Within the Care Outcomes domain, participants (N=11) from Hong Kong, Jamaica, Japan, Sweden, Switzerland, the United Kingdom and the United States generated 122 candidate concepts as relevant to care outcomes in residential long-term care in their countries; five concepts were prioritized through the discussion and voting process as most important to measure. All five were endorsed by the full plenary (Table 1). Concepts included

symptom management, especially pain management; functional level; well-being; personhood, which was discussed as, 'letting people be people'; and harm-free care, which was discussed as the absence of several avoidable, adverse outcomes, including pressure ulcers, falls, and medication errors. Symptom management was the highest ranked concept, with 20% of total possible rank scores. Functional level and well-being also were higher, with similar rankings of 16 and 14% of total rank scores, respectively.

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

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Participants posted 71 comments on boards in the meeting room during the nominal group process session. Of these, two sets of comments raised unique issues that were not otherwise discussed during the nominal group process and therefore not captured in the final set of ranked concepts. The first set (N=8 comments) identified barriers to inclusion in the WE-THRIVE process; this was the largest set of comments. Identified barriers included the following: meeting attendance costs and time away from home institutions pose significant barriers for face-to-face LMIC-based researchers' participation; the assumption of the importance of person-centered care as culturally embedded and difficult to challenge; the risk that one may lack effective strategies to explore ontological assumptions in others' worldviews and therefore focus on what is relevant to one's culture alone; and the tension between making decisions to move forward as a group and the need for ongoing, iterative engagement, especially with LMIC-based researchers, over time. The second set (N=6 comments) pointed out the importance of recognizing and challenging our underlying assumptions about the role of families in LTC settings as positive and desired. For example, comments included discussion of how families may not always be desired by residents in care settings.

## IMPLICATIONS FOR PRACTICE, POLICY AND/OR RESEARCH

Advancing a parsimonious set of CDEs that could be applicable across diverse residential long-term care settings internationally, requires questioning the extent to which our current measurement paradigms embrace more global aspirations to support thriving among older adults, their families, and care staff. Our WE-THRIVE Consortium identified four domains with related concepts for measurement that both converge and diverge with the predominant, deficits-based framework. Convergence and divergence were defined as the degree to which our findings agree or disagree with residential long-term care measurement constructs from extant research using other approaches, consistent with a mixed-methods approach to integrating data [25, 26]. Concepts that converge with extant measurement efforts Convergence highlight the critical foundational work in long-term care measurement conducted by researchers and endorsed and implemented by regulatory bodies, such as InterRAI,[27]. Concepts that diverge yet divergence invite us to consider key gaps needed to specify a person-centered, strengths-based measurement framework that can be meaningfully applied internationally.

The Organizational Context domain working group identified key parameters historically captured in organizational studies of residential long-term care settings, such as regulation and funding (see, for example [28]), but also prioritized components of the social context of care, leadership and the work environment. This prioritization is consistent with more recent measurement and empirical work of the context of care from non U.S.-based research teams, such as Estabrooks et al's [29] work identifying eight contextual concepts of residential long-term care settings that have been related to outcomes such as symptom burden.

Similarly, the Workforce and Staffing domain working group endorsed historically relevant concepts of staffing ratios or turnover in long-term care, while highlighting the extent to which staff are integrated into teams with effective leadership support and opportunities to learn.

This latter emphasis also is consistent with recent findings from non U.S.-based research teams, about the direct effects of how staff are supported and developed on both staff and resident care outcomes [30].

The Person-centered Care domain working group coincided with U.S. DHHS/CMS issued regulatory changes that require documentation of resident preferences for person-centered care [31]. Our findings indicated that measuring preferences, while salient, was not ranked in the top five concepts. The highest ranked concept, relationships, was the predominant concept of person-centered care. This finding is consistent with more recent international statements of the quality of relationships, or relationship-centered care, as fundamental drivers of person-centered care in residential LTC [1].

Similarly, during a time of important growth in technical capacity to support expansion of MDS-like data registries across multiple countries [32], the Care Outcomes domain working group prioritized conceptually consistent measures of functional level and harm-free care, which was operationalized as the absence of a variety of avoidable, adverse outcomes such as pressure ulcers and falls, that are commonly associated with outcomes indicators [10]. This operationalization relates to the National Health Service in England's harm-free care composite measure that draws upon pressure ulcers, falls, urinary tract infection, and venous thromboembolism [33]. The working group also prioritized symptom management as most important, and added well-being and personhood. These latter concepts are consistent with the European Union's framework of the PROGRESS Programme's recommendations for residential LTC measures [35]. Findings support the importance of refining how symptom experience and symptom management are meaningfully included, as well as understanding the interconnectedness of care outcomes with personhood to ensure quality of life.

The construct of functional level in the care outcomes domain also relates to the WHO operationalization of functional capacity [12], which arises from an older adult's intrinsic capacity in relation to environment and contrasts with a frailty and deficits-based model. Situated in a broader international debate that is starting to emphasise constructs such as resilience [34] as having explanatory value in care of older adults, consideration of intrinsic capacity and resilience in our next steps may facilitate moving beyond historic approaches to capturing function in a way that is consistent with the strengths-based ethos of WE-THRIVE.

Next steps to accomplish the larger goal of WE-THRIVE include building on these initial efforts to move from candidate concepts to well-defined concepts with measures that have been broadly vetted across diverse socio-cultural contexts and with multiple LTC stakeholders. The purpose of CDEs is not to generate a comprehensive battery of recommended measures, but rather to endorse a parsimonious subset of data elements that can be embedded within current and future LTC research data collection efforts. Such vetting and selection will require in-depth consideration of issues of inclusion to foster transparency and deliberative dialogue of underlying assumptions within each domain, addressing the limitations raised by participants in our collaborative sensemaking exercise as well as in previous studies of limitations in cross-cultural measurement efforts. [36, 37]

Therefore, it will be essential to engage with stakeholders in residential LTC settings, including direct care staff, residents and their families, consistent with established frameworks for patient and public involvement (e.g., the UK National Institute for Health Research's National Standards for Public Involvement [38]). Drawing upon Huber et al [39], we might anticipate that domains may be weighted differently by stakeholder perspective, concepts within domains may be ranked differently, and that there may be omitted domains and/or concepts.

Additionally, we will need to engage with more researchers based in LMICs, including countries from the Eastern Mediterranean and African WHO regions, and strengthening the interdisciplinarity of the consortium, while employing new strategies of engagement that move beyond more traditional academic-researcher approaches to international research collaborations. For example, modest scholarships do not effect systemic barriers to travel to international conferences where our working sessions have been conducted, video-conferencing does not ameliorate a lack of slack resources to engage in domain working groups in an ongoing basis, and engaging in a consortium with a previously-developed platform necessarily limits opportunities to raise issues of domain and concept equivalence across different ontological or axiological worldviews.

Ultimately, our ability as a scientific community to support a rapidly evolving, global residential long-term care infrastructure will require new ways of engaging with our peer-researchers across low, middle and high income countries, and the development of a measurement infrastructure that integrates aspirational perspectives of thriving and resilience in aging. The WE-THRIVE Consortium's work to date indicates both the potential of this approach to begin to build inclusive global networks, as well as our shared capacity to leverage and enhance, rather than replace, existing measurement tools.

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Table 1.

Domain Concepts and Prioritization Rank Scores (N=55 plenary participants)

Concept	Rank Scores (%) <sup>1</sup>
1. Social resources and support	21 (20.0)
2. Regulation	21 (20.0)
3. Funding	15 (14.3)
4. Leadership hierarchy and role	10 ( 9.5)
5. Leadership & management interface	9 ( 8.6)
6. Desirable working environment	9 ( 8.6)
1. Staff skills, attitudes, and knowledge	36 (30.0)
2. Staff collaboration and teamwork	17 (14.2)
3. Training and self-efficacy of staff	16 (13.3)
4. Staff retention and turnover	11 ( 9.2)
5. Leadership and supervision effectiveness	9 ( 7.5)
1 Relationshin	39 (21.2)
<u> </u>	24 (13.3)
	13 ( 7.2)
	12 ( 6.7)
5. Positive environment	9 ( 5.0)
1. Symptom management	33 (20.0)
2. Functional Level	26 (15.8)
3. Well-being	23 (13.9)
4. Personhood	16 ( 9.7)
5. Harm-free care	9 ( 5.5)
	<ol> <li>Regulation</li> <li>Funding</li> <li>Leadership hierarchy and role</li> <li>Leadership &amp; management interface</li> <li>Desirable working environment</li> <li>Staff skills, attitudes, and knowledge</li> <li>Staff collaboration and teamwork</li> <li>Training and self-efficacy of staff</li> <li>Staff retention and turnover</li> <li>Leadership and supervision effectiveness</li> <li>Relationship</li> <li>Knowing the person</li> <li>What matters most to the person</li> <li>Meaningful engagement</li> <li>Positive environment</li> <li>Symptom management</li> <li>Functional Level</li> <li>Well-being</li> <li>Personhood</li> </ol>

<sup>&</sup>lt;sup>1</sup> Rank score percentages do not total 100, as only the 5 highest scoring concepts are presented in the table