



# MEASURING PERSON-CENTREDNESS OF CARE

TOOLS FOR **DEMENTIA** PRACTICE & RESEARCH

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MEASURING

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## Definition of Person-Centred Care

Person-Centred Care (PCC) is a philosophy that views individuals using healthcare and social services as equal partners in planning, developing, assessing, and monitoring care to ensure it meets their needs.<sup>1</sup> This means placing individuals and their families at the centre of all decisions, and viewing them as experts of their own preferences, values, family social circumstances, and lifestyles. These individuals and their families work together with care professionals to achieve the best care outcomes.<sup>1</sup> Research has demonstrated the importance of PCC in developing a high quality of care which enhances outcomes for both care recipients and care professionals. PCC can improve individuals' experience of care, motivate them to lead a healthier lifestyle, and be more involved in decisions concerning their care. This results in a positive impact on their health.<sup>2,3</sup> Similarly, offering care with a person-centred approach can enhance care professionals' levels of job satisfaction, confidence, and accomplishment.<sup>4</sup>

Although the various models and approaches of PCC share the same recognition of the care recipient as a central and active agent in their care, there are differences in their components/dimensions and emphasis, depending on the populations in which they are practiced in.<sup>5</sup> For example, PCC for persons with disabilities places values in their rights, especially self-determination and normalisation. On the other hand, PCC in the field of dementia care emphasises the upholding of personhood for persons living with dementia and persons with severe intellectual disabilities. This emphasis is in response to some cultural associations between progressive or severe cognitive impairment with some degree of deterioration or loss in aspects of self and identity.<sup>5</sup> This article on [Person-Centred Dementia Care](#) sums up literature and resources discussing the principles and application of PCC for persons living with dementia and the benefits of person-centred dementia care.

For years, academics, healthcare practitioners, and policy makers have attempted to define and operationalise PCC. However, due to the multifaceted and subjective nature of PCC, there remains no universal agreement on its definition nor a “gold standard” tool that sufficiently measures all aspects of PCC in the existing pool of literature.<sup>1</sup> This is also true of the measurements in the field of dementia care.

With the above in view, it is important for care practitioners to understand and define, for each specific care setting: what a desired PCC approach is, the reasons for measuring PCC, and the desired outcomes through the adoption of this specific approach to PCC. Taking the above points into account will help practitioners to determine and select the most appropriate PCC measurement tools and approaches which are best aligned with their goals.

## Measurements of Person-Centred Dementia Care

There are many existing measures of PCC. Some measures focus on PCC as a broad, holistic concept, while others measure specific subcomponents of PCC, such as communication or shared decision making. Since there is no single, perfect ‘silver-bullet’ tool that measures all aspects of PCC, researchers have used empirical evidence to evaluate PCC measurement tools for greater understanding about their strengths and limitations; they also recommend using a combination of tools and methods to act as more robust measures of PCC relative to using just one measure. A robust approach is important for testing and differentiating worthwhile strategies and initiatives which help care providers provide better person-centred care.<sup>1</sup> Surveys used together with proxy indicators, interviews, and observations may provide a more holistic picture of PCC. To effectively measure care outcomes, there must be, firstly, a thorough evaluation and careful selection of tools that have valid psychometric properties, and secondly, information triangulated from care recipients, their families and care professionals to corroborate information and thus mitigate subjective biasness associated with self-reporting measures.<sup>1</sup>

An extensive review<sup>1</sup>, which screened more than 200,000 studies that measured PCC and which eventually reviewed a total of 921 studies, summarised and discussed commonly used approaches and tools measuring PCC. A list of 160 most researched measurement tools (with embedded hyperlinks to the abstracts of the journal articles) has also been created. It is available for downloading at <https://www.health.org.uk/publications/helping-measure-person-centred-care>. The table below provides an overview on measures of PCC, as summarised in this review:<sup>1</sup>

Who measures PCC?	Why is PCC measured?	Where is PCC measured?	What is measured?	How is PCC measured?	When is PCC measured?
Mostly academics in collaboration with healthcare teams	To measure: <ul style="list-style-type: none"> <li>Quality of services</li> <li>Benefits of a specific improvement initiative</li> <li>Whether individuals’ needs and preferences are met</li> </ul>	<ul style="list-style-type: none"> <li>Most have been conducted in hospital settings</li> <li>Others have been done in primary and community care settings, nursing homes and care centres</li> </ul>	<ul style="list-style-type: none"> <li><b>Definitions:</b> How care recipients or care professionals define PCC</li> <li><b>Preferences:</b> Care recipients’ care preferences, or care professionals’ attitudes and values</li> <li><b>Experiences:</b> The level of person-centredness of care</li> <li><b>Outcomes:</b> Impact of PCC</li> </ul>	Four common ways: <ul style="list-style-type: none"> <li>Surveys and interviews to gather care professionals’ opinions</li> <li>Surveys and interviews to gather opinions and preferences from care recipients</li> <li>Observations from clinical encounters</li> <li>Examinations of care recipients’ records</li> </ul>	Different PCC measures are used at various points in care recipients’ care continuum. For example, surveys and proxy indicators can be administered and collected more frequently on a routine basis, while interviews and observations can be conducted annually.

Amongst the existing studies conducted on PCC, several studies have also reviewed tools commonly used in the evaluation of care delivery and services for older adults, as well as persons living with dementia. A combination of these measures has been similarly administered in long-term care, acute care and home care settings to evaluate the multiple components and outcomes of their care approaches and interventions.<sup>6-8</sup> Across the studies reviewed, person-centred dementia care was measured through:

1. Proxy indicators, such as the prevalence of challenging behaviours, use and dosage of psychotropic medications, and quality of life;
2. Systematic observations of the care and services provided;
3. Perceptions of care recipients and their families;
4. Perceptions of care professionals working in the care setting;
5. Evaluation of the physical environment of the care setting; and/or social environment (*for more information on instruments that solely assess the physical environment of a care setting, please refer to this article on [Dementia-Inclusive Design Principles](#).*)
6. Evaluation of the family's involvement in care.<sup>6-8</sup>

Some of these instruments are extensive and require more resources (e.g. manpower and time) to administer, while others are shorter and easier to administer, and require less time to complete. The table below lists the instruments, which reviews<sup>6-8</sup> have summarised, compared, and discussed regarding their (1) purposes, (2) how they are used, and (3) their psychometric properties:

Tools used to observe the care and services provided	Tools that measure PCC according to care recipients' own judgement	Tools that measure PCC according to the setting's care professionals	Tools used to evaluate family involvement in care
<ol style="list-style-type: none"> <li>1. Dementia Care Mapping 8<sup>th</sup> Edition (DCM8)</li> <li>2. The Care Observational tool (CARES)</li> <li>3. The Observational Measure of person-centred care for spouses of people with dementia</li> </ol>	<ol style="list-style-type: none"> <li>1. Resident Person-Centred Practices in Assisted Living (Resident PC-PAL)</li> <li>2. Preferences for Everyday Living Inventory (PELI)</li> <li>3. The English Person-centred Climate Questionnaire – Patient version (PCQ-P)</li> <li>4. Client-Centred Care Questionnaire (CCCQ)</li> <li>5. The Person-Centered Inpatient Scale</li> </ol>	<ol style="list-style-type: none"> <li>1. The English Person-centred Climate Questionnaire – Staff version (PCQ-S)</li> <li>2. Person-centred Care Assessment Tool (P-CAT)</li> <li>3. Staff Assessment Person-Directed Care (PDC)</li> <li>4. Measures of Individualized Care (IC)</li> <li>5. Staff Person-Centred Practices in Assisted Living (Staff PC-PAL)</li> </ol>	<ol style="list-style-type: none"> <li>1. Family involvement in care</li> </ol>

## Tools that have been used in the Singapore Context

At Dementia Singapore, the Dementia Care Mapping 8<sup>th</sup> Edition (DCM8)<sup>9</sup>, the VIPS Assessment Tool<sup>14</sup>, and the Person-Directed Dementia Care Assessment Tool (PDDCAT)<sup>16</sup> are instruments that are frequently used to evaluate the person-centeredness of care and services provided at New Horizon Centres and other intermediate and long-term care settings, and programmes developed in collaboration with other institutions. These tools were chosen as they are specific to dementia care.

These instruments are designed to be used for different purposes. While the DCM is used to observe the well-being of persons living with dementia and the quality of care provided by care professionals, the VIPS Assessment Tool and the PDDCAT are qualitative tools that offer a holistic and extensive evaluation on multiple domains of a care environment for persons living with dementia. Despite the currently insufficient evidence on their psychometric properties, the latter two instruments are very detailed measures which have the principal objectives of guiding care settings to evaluate and improve their care models and facilitating care professionals to self-evaluate and to develop plans to improve various aspects of their care provision in order to implement the PCC approach.<sup>8</sup>

The choice of these instruments is supported by a study by Tew et al. (2021), where a group of dementia care practitioners and researchers measured and explored the relationships between the quality of life, well-being and person-centred care of residents in seven nursing homes in Singapore. The study used a combination of tools listed below to measure and analyse their respective elements:

- Residents' quality of life was measured using the proxy EQ-5D-5L version completed by direct care staff;
- DCM was used to observe residents' well-being and care quality;
- The Resident Satisfaction Survey was administered on residents with communication ability; and
- PDDCAT was adopted as a measure and improvement tool for PCC, where each domain was independently assessed by groups of care staff.<sup>17</sup>

The following content provides more details on the DCM, the VIPS Assessment Tool and the PDDCAT. Click on the names of the tools (with embedded hyperlinks) to directly access them:

1. Dementia Care Mapping 8<sup>th</sup> Edition (DCM8)<sup>9</sup>

- **Who uses the tool:** Health and social care professionals who are certified DCMappers
- **Where the tool is used:** A range of care settings, including hospitals and intermediate and long-term care services (i.e., day care centres and nursing homes)
- **Why the tool is used:** Care professionals have used the tool for purposes including:
  - Quality improvement projects to monitor and evaluate existing and new programmes and services;
  - To improve the organisation of care for groups of residents in a care setting;
  - Assessments and care planning for individual persons; and
  - Staff development and training needs analyses.<sup>10</sup>
- **What the tool measures:** This observational tool records (1) the well-being of persons living with dementia, (2) their behaviours, and (3) the interactions between persons living with dementia and their care professionals. Scores describe the well-being of persons living with dementia.
- **How to use the tool:** DCM observations involve continual observations of 5-6 participants living with dementia over a sustained period. Two types of codes are recorded down at 5-minute intervals throughout the observation period:
  - Behavioural Category Code (BCC, 23 behavioural categories): The category of activity or behaviour (under the DCM system's behaviour categorisation system) that the participant is mainly engaged in during a 5-minute time frame; and
  - Mood and Engagement (ME) Value: The level of engagement or positive or negative mood that indicates the state of well-being the participant experiences while engaging in the activity or behaviour. This is on a 6-point scale ranging from very distressed and very great signs of negative mood (-5) to very happy, cheerful and very high positive mood (+5).
- Additionally, staff members' behaviours and interactions with the participant, known as Personal Detractors (PDs) and Personal Enhancers (PEs) are recorded as well. PDs have the potential to undermine the personhood of persons living with dementia, while PEs support their personhood.<sup>11</sup> These are recorded in qualitative notes by the mapper and not coded in a systematic manner.
- **Strength(s) of the tool:**
  - May come closer to viewing Quality of Life (QoL) from the perspective of the person living with dementia than many other available measures;<sup>12</sup> and
  - DCM has widespread clinical appeal; is extensively used in dementia care practice.<sup>12</sup>
- **Psychometric properties of the tool:** A study by Cooke & Chaudhury (2012) summarises the results of studies assessing DCM's psychometric properties. This study concludes that there is mixed evidence on DCM's validity and reliability. More research is required to further establish the following types of validity and reliability (listed in the table below) for the DCM:<sup>13</sup>

Validity	Reliability
<ul style="list-style-type: none"> <li>● <b>Face validity:</b> Studies collecting staff responses through questionnaires and discussions upon the presentation of DCM results discovered that these staff believed DCM to be a valuable indicator of resident well- or ill-being and that the tool was reflective of the relationship between well- or ill-being and care delivery. Staff also believed DCM results would help enhance quality of care.</li> <li>● <b>Content validity:</b> It is difficult to determine the tool’s content validity as it is related to sampling characteristics such as the duration of the mapping period and the number of participants. However, these characteristics vary across the different studies reviewed by Cooke &amp; Chaudhury (2012), which also made different recommendations.</li> <li>● <b>Concurrent validity:</b> The studies reviewed found significant associations between higher WIB scores and positive outcomes of engagement, pressure area care, care planning and care staff satisfaction. However, correlations between WIB and quality of life scores ranged from weak to strong.</li> <li>● <b>Construct validity:</b> Several studies reported that DCM can measure well-being separately from other constructs like cognitive, behavioural and functional impairments, where negative associations were found between WIB scores and these constructs.</li> <li>● <b>External validity:</b> Studies show that DCM scores vary across different settings. Mean group and individual WIB scores were higher in assessment and day hospitals, assisted living facilities, and adult day centres than in continuing care and respite settings, like nursing homes. One study reported that residents in small, dementia-specific assisted living facilities experienced lower mean group WIB scores and a lower diversity of interactions and activities than those in large, non-dementia specific sites.</li> </ul>	<ul style="list-style-type: none"> <li>● <b>Good internal consistency:</b> It is difficult to assess the tool’s internal consistency, likely because DCM is not a summative rating scale. At the same time, one study has established DCM’s internal consistency by examining the association between key DCM indicators, where statistically significant correlations were found between WIB scores and activity participation (time spent actively or passively engaging in activities believed to promote well-being), and WIB scores and social withdrawal (time spent in BCCs along with social withdrawal, unattended distress, communicating without a response, and repetitive self-stimulation).</li> <li>● <b>Considerable to moderate test-retest reliability:</b> Only one study has established the tool’s test-retest reliability; results reflected the presence of considerable test-retest agreement between WIB scores and more moderate agreement for activity participation and social withdrawal.</li> <li>● <b>High inter-rater reliability:</b> The DCM’s protocols stipulate that multiple raters must reach a high level of inter-rater agreement (at least 70%) by simultaneously observing and coding the same participants for at least an hour prior to actual data collection. Many studies reported concordance coefficients ranging from .70 to .80.</li> </ul>

- **Permission to use the tool:** To use the tool, health and social care professionals must first attend a DCM training course to be a certified DCMapper by the Bradford Dementia Group. Please visit [Dementia Singapore Academy’s page](#) to find out more and sign up for the DCM training courses in Singapore.

## 2. [The VIPS Assessment Tool](#)<sup>14</sup>

- **Who uses the toolkit:** Health and social care professionals.
- **Where the tool is used:** Used in a range of care settings such as hospitals, home care services, nursing homes, day care centres and community programmes.
- **When is the toolkit used:** The toolkit can be used any time, repeatedly, for care professionals to monitor the progress of their care and services.<sup>14</sup>
- **What the toolkit measures:** The VIPS framework is an evidence-based structure to guide good practices in person-centred dementia care in care settings. It guides care professionals to reflect and enhance their interactions and communications with persons living with dementia and their families to be more person-centric from early diagnosis to palliative care. The framework has a list of 25 indicators grouped in four categories (Values, Individuals, Perspective and Social) that care professionals can use as a benchmark to measure the person-centredness of their care delivery and services for persons living with dementia and their families.<sup>15</sup> The table below lists down the 25 VIPS indicators.<sup>14</sup>

<u>V</u> alues	<u>I</u> ndividuals	<u>P</u> erspective	<u>S</u> ocial
V1. Vision	I1. Individual Support and Care	P1. Communication	S1. Inclusion
V2. Human Resources	I2. Recognising and Responding to Change	P2. Empathy and Acceptable Risk	S2. Respect
V3. Management Ethos	I3. Personal Possessions	P3. Physical Environment	S3. Warmth
V4. Training and Practice Development	I4. Individual Preferences	P4. Physical Health Needs	S4. Validation
V5. The Service Environments	I5. Life Histories	P5. Challenging Behaviour as Communication	S5. Enabling
V6. Quality Assurance	I6. Activity and Occupation	P6. Advocacy	S6. Part of the Community
			S7. Partners, Families, Friends and Relatives

- **How to use the toolkit:** The [Care Fit for VIPS website](#) provides an online assessment toolkit, the VIPS Assessment Tool, that is free to access and use. This tool allows care professionals to rate their care delivery and services according to its 25 indicators. The website also provides online resources that can assist care professionals in developing quality improvement action plans after completing the assessment tool. The tool is an evaluation toolkit that enables care professionals to, on their online accounts, change their ratings any time to understand how their care delivery and services may have progressed. The toolkit can be completed in its entirety at once, or in steps, having each VIPS area assessed at a time.
- **Permission to use the tool:** Care professionals will have to register for an online account with the Care Fit for VIPS website to access the VIPS Assessment Tool.



3. [Person-Directed Dementia Care Assessment Tool](#)<sup>16</sup>

- **Who uses the tool:** Health and social care professionals.
- **Where the tool is used:** Long-term care settings for persons living with dementia.
- **What the tool measures:** The tool helps to identify an initial baseline of strengths and areas for improvement in a dementia long-term care setting that the care team can then use to develop action plans to enhance **nine** aspects of the care setting (as listed in the box below). Over time, the tool can be used to re-assess and measure the progress, and/or identify new areas of focus across these nine aspects:

1. Environment	2. Language and Communication	3. Care Plans
4. Activities	5. Problem Solving Processes for Working with Behavioural Communication	6. Communication and Leadership
7. Team Structure and Roles	8. Policies and Procedures	9. Staff Knowledge and Training

- **How to use the tool:**
  - The numbered scale is for evaluators to indicate the presence or absence of the item, and whether it is a strength or a weakness that needs to be worked on (the number is an indicator of that one item, and NOT a numerical value to be added to others and scored);
  - The columns “Strengths” and “Improvement Areas” are for evaluators to indicate the exact situation witnessed, comment made, or example for the working document; and
  - The tool can be divided into individual sections and assigned to one or more people who do not work in the environment being observed and evaluated, as they may discover the most important information in the environment. Obtaining multiple perspectives during different shifts is ideal too. To minimise skewed information, the follow-up observations and evaluations should be done by all or some of the same people who did the first observation.
- **Strength(s) of the tool:**
  - Evaluates multiple aspects of a long-term dementia care setting in detail; and
  - Provides several resources for the management and staff of a care setting to refer to as they work to improve their care practices and culture.
- **Psychometric properties of the tool:** Not established, as this tool is not meant to be a licensing document or a prescriptive standard, and not meant to be scored.
- **Permission to use the tool:** Cite the State of Wisconsin, Department of Health, to use the tool; no other permissions are required.

## Conclusion

These reviews and studies on measures of person-centred dementia care were conducted in countries outside Singapore. More research is needed to examine and establish their quality and usefulness in this local context. Additionally, some of the above tools which are specific to the field of dementia have been noted to have mixed support for their respective psychometric properties. Similarly, some of them may not have had their reliability and validity substantially established. However, these instruments still offer an adequate foundation for the journey to build and enhance the person-centredness of a dementia care environment.

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