

# Analysis of tools that measure enablement:

excerpt from the Evidence Check on Consumer Enablement

## 1. Patient Activation Measure

### 1.1. Development and validation

Hibbard and colleague [131] sought to develop a measure of 'patient activation' within the US healthcare system. No specific *a priori* theoretical model used to drive initial development of the concept of activation. A review of published articles on skills and knowledge needed to successfully manage a chronic illness was conducted. Articles on self-care, self-management, doctor–patient communication, and using comparative information to inform health care choices were reviewed. Six domains were initially extracted. Consensus with experts was undertaken, then focus groups with patient to reword ideas into layman’s terms. An item pool was developed and subjected to Rasch analysis to generate four ordered (low activation to high activation) hypothetical stages: (1) believes active role is important, (2) confidence and knowledge to take action, (3) taking action, and (4) staying the course under stress. 75 items were developed to cover each of these domains.

The initial tool was subjected to a range of studies and was reduced to a 13 item scale, the PAM-13 where respondents answer a four point, strongly disagree to strongly agree, scale. The PAM13 is now widely used and has been subjected to a limited number of validation studies.

The tool has been widely used (original tool cited 365 times) and has potential clinical application and has undergone adaptation, translation and validation in Canada [132], Germany [18, 19], Denmark [20] and the Netherlands [21]. Similarly, validation has been reported in a range of client groups and settings including mental health [22], elective lumbar spine surgery [23], multi-morbid older adults [24] and in rural settings [25].

Validation studies are rarely done in settings without the original author, and until recently the license agreement prohibited independent testing the PAM. The PAM is a commercial product and licenses are available from Insignia Health Inc. ([www.insigniahealth.com](http://www.insigniahealth.com)).

One of the only independent validation studies was recently undertaken in Canada where the authors concluded:

*In conclusion, our results suggest that PAM-13 provides a suitably reliable and valid instrument for research in patients with neurological conditions. However, our study suggests potential for measurement error and bias at low levels of activation. The implications of this error and bias may be of particular importance in clinical applications of the tool. Our study also suggests that measurement of activation may benefit from items and scaling tailored to specific diagnostic groups, recognizing their unique attributes and management challenges [132].*

The PAM has been widely adopted in the [English NHS](#) where a national license was purchased. No specific guidance was provided to Clinical Commissioning Groups and practitioners regarding its application however an [evaluation](#) of the application of the tool is underway and will be available in 2017.

In a 2013 review by the Hibbard and Greene [133], report that improvements in activation scores as a result of interventions have been small - on average between 2.5% to 6.5% and have associated with improvements in:

- health-related quality of life;
- clinical indicators, such as low-density lipoprotein and blood pressure; adherence to treatment;
- improved health-related behaviour;
- increased participation in care;
- and reduced symptoms, hospital readmissions, overnight hospital stays, and use of the emergency department.

#### *Items of the PAM13*

1. When all is said and done, I am the person who is responsible for managing my health condition.
2. Taking an active role in my own health care is the most important factor in determining my health and ability to function.
3. I am confident that I can take actions that will help prevent or minimize some symptoms or problems associated with my health condition.
4. I know what each of my prescribed medications do.
5. I am confident that I can tell when I need to go get medical care and when I can handle a health problem myself.
6. I am confident that I can tell a doctor concerns I have even when he or she does not ask.
7. I am confident that I can follow through on medical treatments I need to do at home.
8. I understand the nature and causes of my health condition(s).
9. I know the different medical treatment options available for my health condition.
10. I have been able to maintain the lifestyle changes for my health condition that I have make.
11. I know how to prevent further problems with my health condition.
12. I know how to prevent further problems when new situations or problems arise with my health condition.
13. I am confident that I can maintain lifestyle changes, like diet and exercise, even during times of stress.

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## **1.2. Applicability in Australia**

There are no known validation studies in Australia. The PAM has been used in one prominent Australian research study, the Queensland Living with Diabetes Study [Aung 2015, 2015 , Begum 2011, Donald 2011] [134] [135] [136]. These studies explored associations between the PAM and other measures such as quality of care and glycaemic control and found modest relationships.

	Related scales	Utility of scale
Physical capacity		
Cognitive capacity	(1) believes active role is important	
Motivational capacity	(2) confidence and knowledge to take action, (3) taking action, and (4) staying the course under stress.	A single scale that classifies respondents into four levels.
Relational capacity		
Overall	Single hierarchical scale where a low score maps to some elements of Cognitive capacity and higher score maps to Motivational elements	Easily administered, 13 items, some uncertainty about utility of low score.

### 1.3. Recommendations

Given that there have been no specific validation studies in Australia, and that there is some uncertainty about the accuracy of the tool in people with low activation, it is recommended that local validation work be undertaken before wide application, and the outcomes of the UK evaluation are considered (2017).

The cost of a license is available upon request from [www.insigniahealth.com](http://www.insigniahealth.com).

## 2. Beliefs and Behaviour Questionnaire (BBQ)

### 2.1. Development and validation

The BBQ is 30 item questionnaire measuring beliefs, experiences and adherent behaviour on five-point Likert type scales. The tool does not explicitly state that it is measuring consumer enablement, however it is measuring related aspects, specifically pharmacologic and non-pharmacologic management and adherence. This can be considered a distal outcome.

The authors suggest it may be useful for identifying reasons behind intentional and unintentional nonadherence to both pharmacologic and non-pharmacologic management in patients with various chronic diseases [137] however several scales had unacceptably low reliability and the scale has not undergone further work and it has not been taken up in research or clinical settings so limited data exists to support its utility.

### 2.2. Applicability in Australia

Developed in Australia but has not received sufficient testing

	Related scales	Utility of scale
Physical capacity		
Cognitive capacity		
Motivational capacity	Confidence (patient's confidence in disease management) Concerns (about their disease management).	Unclear
Relational capacity		
<b>Overall</b>		

### 2.3. Recommendations

Not recommended

### 3. Test of Functional Health Literacy in Adults (TOFHLA)

#### 3.1. Development and validation

The Test of Functional Health Literacy in Adults (TOFHLA) was developed in the US in 1999 by an expert committee to measure “functional health literacy,” defined as assessing reading, writing, and numeracy skills, in relation to health care [138]. Items were chosen from hospital texts by a literacy expert. A self-administered reading comprehension component includes three passages of texts and contains 50 items. It uses the modified Cloze procedure, where every fifth to seventh word in a passage is omitted, and the respondent selects a response from four options. An interviewer-administered numeracy component includes 17 items, where individuals are presented with cues and respond to questions based on hospital forms and prescription labels to test a patient’s capacity to comprehend and follow instructions around monitoring their condition (e.g., blood glucose), taking medication, keeping clinic appointments, and obtaining financial assistance.

Scores for the numeracy domain are transformed to a score out of 50 and added to the score from the reading comprehension domain (range: 0-100).

The raw score for the TOFHLA is converted to one of three categories: inadequate, marginal, or adequate health literacy. These categories were derived from an interpretation of the scores of 2,659 predominantly indigent and minority patients presenting for acute care at two urban hospitals in Atlanta and California, although the method is not explained [139].

A short version, S-TOFHLA, includes 36 reading comprehension and four numeracy items and are also converted to three categories [138].

#### 3.2. Applicability in Australia

The TOFHLA requires participants to be able to read and write and was designed to be administered within 22 minutes however it has been observed to take 20 to 40 minutes in clinical settings in Australia [140]. It has substantial ceiling effects (i.e., many respondents score the maximum score (>60%) and for people with low literacy levels, they have found the completion of written tests stigmatising [140]. An Australian version of the TOFHLA is available [141].

	Related scales	Utility of scale
Physical capacity		
Cognitive capacity	Health-related reading skills Health-related numeracy skills	
Motivational capacity		
Relational capacity		
<b>Overall</b>	Limited breadth	Acceptable psychometric properties but low practicality in clinical settings

#### 3.3. Recommendations

The TOFHLA is a robust measure of functional health literacy which is a component of enablement. It is freely available but is not practical in clinical settings due to being interviewer administered and the length of time it takes to complete. It has not been tested for sensitivity to change or for monitoring.

## 4. Health Literacy Questionnaire (HLQ)

### 4.1. Development and validation

The HLQ is a licensed tool owned by Deakin and Monash Universities. It currently incurs a nominal license fee of \$250 per project payable to Deakin University. The licensing is in transition where the intention is to make the license free of charge to not for profit organisations by the end of 2016.

The HLQ was developed in Australia and is a multidimensional health literacy measure with nine independent questionnaires with 4-6 items. It has been rigorously validated in a wide range of healthcare and community settings. It was designed for, and being used for, surveys, evaluation, service improvement, quality monitoring and quality improvement. Across the dimensions, it is both a measure of elements of an individual's ability to understand, find and engage with health information and health services, and a measure of their lived experience of engaging with services and practitioners [142].

It was developed using a 'validity-driven' instrument development approach. Grounded consultations (workshops and interviews) were used to identify broad conceptually distinct domains. Item development from consultations following a strict process. Psychometric analyses included both classical test theory and item response theory. Cognitive interviews were used to test questions. Items and scales were initially tested in a calibration sample of 634 people from community health, home care and hospital settings. A replication sample of 405 people who were recently discharged from an emergency department (Barwon Health).

A follow-up study was undertaken to explore the psychometric properties of the HLQ with respondents from a diverse range of community-based-organisations with the principal goal of contributing to the development of a soundly validated evidence base for its use in community health settings [143]. Most analyses were conducted using Bayesian structural equation modelling that enables rigorous analysis of data but with some relaxation of the restrictive requirements for zero cross-loadings and residual correlations of 'classical' confirmatory factor analysis. Scale homogeneity was investigated with one-factor models that allowed for the presence of small item residual correlations while discriminant validity was studied using the inter-factor correlations and factor loadings from a full 9-factor model with similar allowance for small residual correlations and cross-loadings. Measurement invariance was investigated scale by scale using a model that required strict invariance of item factor loadings, thresholds, residual variances and co-variances. The HLQ is highly reliable, even with only 4 to 6 items per scale. It provides unbiased mean estimates of group differences across key demographic indicators. While measuring relatively narrow constructs, the 9 dimensions are clearly separate and therefore provide fine-grained data on the multidimensional area of health literacy. These analyses provide researchers, program managers and policymakers with a range of robust evidence by which they can make judgements about the appropriate use of the HLQ for their community-based setting [143].

Two HLQ scales have been used in the Danish National Health Survey [144]. Recently the New Zealand Government purchased a license for its inclusion in the New Zealand National Health Survey (Personal communication; Chloe Lynch, Senior Advisor, Health Survey, Health and Disability Intelligence Unit, Client Insights and Analytics, NZ Ministry of Health).

A large study among Danish people with diabetes (N=1399) as shown that higher HLQ levels are associated with better glycaemic control – 8 of the 9 HLQ were associated with HbA1c levels. This study provided new insights into potential targets for future diabetes self-management support interventions and into how practitioners and organisations can respond to the health literacy needs of people with diabetes (Kasper Olsen, Steno Diabetes Centre, Denmark, submitted for publication).

Intensive psychometric studies have been undertaken in diverse community settings in Denmark [145], including the Danish national health survey [144], in Slovak Republic [146] with further studies underway in Germany, Netherlands, France and Canada.

#### **4.2. Applicability in Australia**

The HLQ was developed in Australia, cited 43 times since 2014, and several validation studies have been undertaken.

In an attempt to obtain data on the interpretation of the HLQ from both the patient and clinician perspective in-depth qualitative interviews were undertaken in the Barwon Health Hospital Admission Risk Program (HARP) setting. Sixteen patients with complex needs (i.e., low and very low enablement) completed the HLQ and were interviewed to explore the reasons for their answers. Also, the clinicians of each of these patients completed the HLQ about their patient, and were interviewed to discuss the reasons for their answers. Thematic analysis of HLQ scores and interview data determined the extent of concordance between patient and clinician HLQ responses, and the reasons for discordance. Concordance was found to be high, however where non-concordance was observed, useful insights that demonstrate the reasons for patient-clinician differing views were exposed. This study shows that the HLQ can act as an adjunct to clinical practice to help clinicians understand a patient's health literacy challenges and strengths early in a clinical encounter. Importantly, clinicians can use the HLQ to detect differences between their own perspectives about a patient's health literacy and the patient's perspective, and to initiate discussion to explore this [147].

The HLQ has been used as an evaluation tool within an Ophelia (OPTimising HEalth LIteracy and Access) intervention by the Royal District Nursing Service [148]. The HLQ supported a structured method for the healthcare services to co-design interventions to respond to the health literacy needs of their clients.

Psychometric questionnaires are often difficult to interpret as a result of benchmarks or clinically significant cut points. The HLQ was recently administered to a population-based sample of adults in the South East Melbourne Primary Care Network (n=1500). These other data are currently being collated to support development of percentile norms to assist program managers and researchers to easily understand each of the scales benchmarked against national norms.

	Related scales	Utility of scale
Physical capacity		
Cognitive capacity	2. Having sufficient information to manage my health 5. Appraisal of health information 7. Navigating the healthcare system 8. Ability to find good health information 9. Understanding health information well enough to know what to do	Each scale has minimum items (4-6) and are highly reliable
Motivational capacity	3. Actively managing my health	Scale has minimum items (4) and is highly reliable
Relational capacity	1. Feeling understood and supported by healthcare providers 4. Social support for health 6. Ability to actively engage with healthcare providers	Each scale has minimum items (4-5) and are highly reliable
<b>Overall</b>	Substantial breadth	One or more scales are useful to measure elements of enablement

### 4.3. Recommendations

The HLQ scales provide substantial coverage of the enablement concept. Specific scales can be selected to inform quality and monitoring initiatives.

## 5. Health Education Impact Questionnaire (heiQ)

### 5.1. Development and validation

The heiQ is a licensed tool that incurs a license fee based on the number of administrations. While this is an exclusion criterion, a brief summary of its properties is provided.

The heiQ is a self-report patient outcomes measure that was developed 10 years ago in Victoria to be a user-friendly, relevant, and psychometrically sound instrument for the comprehensive evaluation and quality monitoring of patient education programs and related activities [149]. It has been cited 145 times since 2007. The present version (Version 3) measures 8 constructs by multi-item composite scales:

1. Health Directed Activities (HDA),
2. Positive and Active Engagement in Life (PAEL),
3. Emotional Distress (ED),
4. Self-monitoring and Insight (SMI),
5. Constructive Attitudes and Approaches (CAA),
6. Skill and Technique Acquisition (STA),
7. Social Integration and Support (SIS) and
8. Health Services Navigation (HSN).

The heiQ was developed following a grounded approach that included the generation of a program logic model for health education interventions and concept mapping workshops to identify relevant constructs [149]. Based on the results of the workshops, candidate items were written and tested on a large construction sample drawn from potential participants of patient education programs and persons who had recently completed a program. The number of items was reduced to a 42-item questionnaire measuring 8 constructs and again tested on a replication sample drawn from a broader population of attendees at a general hospital outpatient clinic and community-based self-management programs. Confirmatory factor analysis (CFA) supported by IRT analysis was used for item selection and scale refinement. In subsequent revisions leading to Version 3, the number of Likert-type response options was reduced from 6 to 4 on advice from users (they are now strongly disagree, disagree, agree, strongly agree with slightly options removed) and the number of items was reduced to 40.

The general eight-factor structure of the original version of the heiQ was replicated by Nolte [150] who investigated its factorial invariance [151] across a traditional baseline to follow-up (pre-test, post-test) design as well as across a post-test compared with a retrospective pre-test ('then-test') design. Nolte's results supported the stability of the factor structure across measurement occasions and questionnaire formats (configural invariance) and the equivalence of item factor loadings (metric invariance) and intercepts/thresholds (scalar invariance) of the heiQ when used in the traditional pre-post design. More recently, the factor structure and factorial invariance of the 40 items that constitute Version 3 of the heiQ was investigated using a large sample of 3,221 archived responses [152]. The original eight-factor structure was again replicated and all but one of the scales (4. SMI) was found to consist of unifactorial items with reliability of  $\geq 0.8$  and satisfactory discriminant

validity. Nolte’s findings of satisfactory configural, metric and scalar invariance were replicated across baseline to follow-up for all scales, and strict measurement invariance was also strongly supported across important population sub-groups (sex, age, education, ethnic background). Further, it has also recently been demonstrated that change scores on the heiQ scales are relatively free from social desirability bias [153].

These findings support the high level of interest in the heiQ in the evaluation of health education and self-management programs, particularly for use as a baseline to follow-up measure in experimental studies, other evaluation designs and system-level monitoring and evaluation. In particular, they give users confidence that all heiQ scales are providing relatively unbiased and equivalent measures across baseline to follow-up data. Norms and benchmarks have also been developed to support the practical but appropriate interpretation of both individual and group data from the application of the heiQ in community and health service settings in Australia [154].

The heiQ scales are all independent questionnaires and may be used separately when specific impact elements are being analysed. It has been found to be a sensitive measure of change and provides a profile that directly informs quality improvement activities in the chronic disease self-management sector. It is used as part of a national quality approach in England through *Self Management UK* [see report \[155\]](#).

The heiQ has undergone extensive psychometric testing in several countries and has been consistently found to be robust across Western cultures such as Germany, France, Denmark, and Canada. Evaluations have shown that it is robust for comparing across chronic conditions (France [156], Germany [157] [158, 159], and has been demonstrated to be a robust measure of empowerment in cancer (Canada [160]).

## 5.2. Applicability in Australia

Except where stated, the above studies have been undertaken in Australia. The heiQ is available in many of the common languages of migrants living in Australia.

	Related scales	Utility of scale
Physical capacity		
Cognitive capacity	4. Self-monitoring and Insight 6. Skill and Technique Acquisition	Each scale has minimal items (5) and are highly reliable
Motivational capacity	1. Health Directed Activities 2. Positive and Active Engagement in Life 3. Emotional Distress 5. Constructive Attitudes and Approaches	Each scale has minimal items (4 - 6) and are highly reliable
Relational capacity	7. Social Integration and Support 8. Health Services Navigation	Each scale has minimal items (5) and are highly reliable
<b>Overall</b>	<b>Substantial breadth</b>	<b>One or more scales are useful to measure elements of enablement</b>

### **5.3. Recommendations**

The heiQ was designed specifically to measure outcomes of chronic disease programs and to support quality improvement. Each scale appears to measure some element of enablement. Each scale has been validated and can be used as an independent questionnaire to cover specific elements of enablement.

## 6. Chronic Disease Self-Efficacy Scales (CDSSES)

### 6.1. Development and validation

The concept measured within self-efficacy scales is based on Bandura’s social cognitive theory [161] Miles et al [162] summarise self-efficacy as “a concept describing a set of beliefs about oneself, specifically about one’s ability to perform certain behaviours within a particular environment. Self-efficacy is not only related to specific behaviours but also to the beliefs that people have about how they can cope in adverse situations”.

A wide range of questionnaires have been developed to measure self-efficacy in people with chronic conditions however most have been found to have psychometric limitations [163]. A review by Miles et. Al. 2011 [162] found 13 scales and undertook an evaluation of five with sufficient publications on their measurement properties; the Arthritis Self-Efficacy Scale, the Chronic Disease Self-Efficacy Scale, the Pain Self-Efficacy Questionnaire, the Chronic Pain Self-Efficacy Scale, and the Self-Efficacy Scale. Each had some gaps, although all had reasonable reliability. The most widely used in the chronic disease self-management sector are scales developed at Stanford University and applied in the Stanford Chronic Disease Self-management program [164]. This tool was based on an earlier longer version for people with arthritis [165], however no further specific studies that explore its psychometric properties or utility were identified.

Self-efficacy remains a popular process measure in the health sector. There is a plethora of disease-specific and context-specific scales available with 15 to 20 new publications per year providing evidence related to these conditions or contexts. This intensity of research reflects a move away from a focus on ‘general self-efficacy’, which is probably difficult for people (especially people with low enablement) to conceptualise, to more tangible and specific actions or behaviours in one’s daily life.

### 6.2. Applicability in Australia

The CDSSES scale was used in a controlled trial of a new self-management program developed by Arthritis NSW and evaluated by the University of NSW [166]. Self-efficacy improved similarly in the intervention and control groups. The CDSSES was also applied in a large national convenience sample of attendees of the Arthritis Self-management course [22].

	Related scales	Utility of scale
Physical capacity		
Cognitive capacity		
Motivational capacity	Self-efficacy	Various, brief scales
Relational capacity		
<b>Overall</b>	One element of enablement	Single score provided

### 6.3. Recommendations

Systematic measurement of general self-efficacy is unlikely to provide instructive data that will provide insights into enablement, drive quality improvement and improve outcomes.

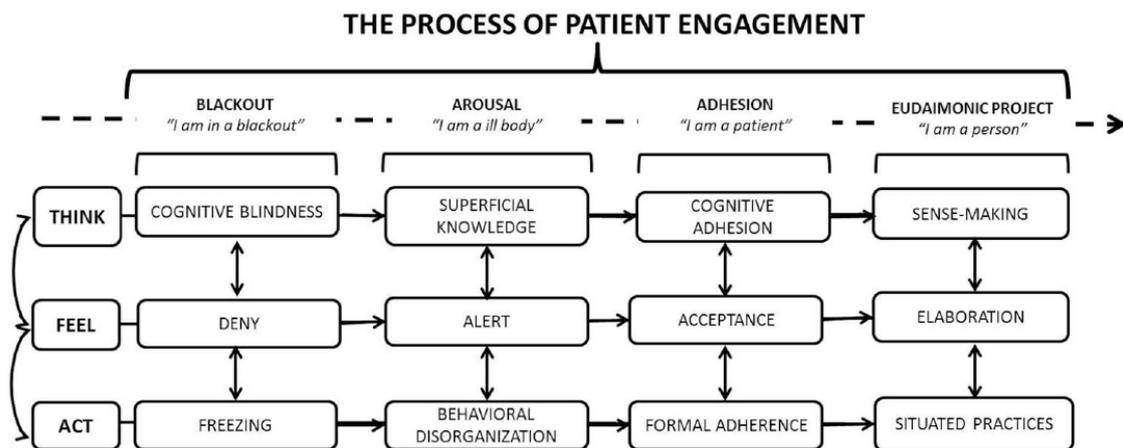
## 7. Patient Health Engagement Scale (PHE)

### 7.1. Development and validation

The PHE is a new scale first published in 2015. Graffigna et al 2015 [167] claim that the concept of engagement offers a more holistic consideration of the psychological elaboration of the patient about his/her health condition and presents a multi-stage development [168]. Precisely, patient engagement is a “process-like and multi- dimensional experience, resulting from the conjoint cognitive (think), emotional (feel), and conative (act) enactment of individuals toward their health management”. In this process, patients go through 4 subsequent positions (i.e., blackout, arousal, adhesion, and eudaimonic project; see Figure 9).

The PHE is a valuable contribution to the concept of enablement given its careful inclusion of individuals who are profoundly not engaged. The questionnaire has nine items that generate a single score. The scale was developed using the above *a priori* theoretical model and application of classical and Rasch psychometric techniques. Nine items were applied in a small pilot (n=48) and five items were then validated in a larger sample of people with chronic conditions (n=382) [167] [169].

Figure 1: The patient health engagement model



### 7.2. Applicability in Australia

The questionnaire was developed in Italy and no published studies are available beyond the initial validation. The tool appears to be freely available.

	Related scales	Utility of scale
Physical capacity	Unclear	
Cognitive capacity	Unclear	
Motivational capacity	Unclear	
Relational capacity		
<b>Overall</b>		Many items are somewhat complex Measures an extremely wide breadth of engagement

### 7.3. Recommendations

The PHE has promising concepts but insufficient validation and utility data are currently available.

## 8. Health Distress Scale (HDS)

### 8.1. Development and validation

The HDS is part of the Stanford University [recommended set of questionnaires](#) for evaluating chronic disease self-management programs [164]. It is a modified version of the MOS health distress scale [170] where 4 of the original 6 items are used. It is a simple scale with high reliability. No further specific studies that explore its psychometric properties or utility were identified.

Items include:

1. were you discouraged by your health problems?;
2. were you fearful about your future health?;
3. was your health a worry in your life?; and
4. were you frustrated by your health problems?

### 8.2. Applicability in Australia

The HDS was used in a controlled trial of a new self-management program developed by Arthritis NSW and evaluated by the University of NSW [166]. Health distress improved similarly in the intervention and control groups.

	Related scales	Utility of scale
Physical capacity		
Cognitive capacity	Health distress	
Motivational capacity	Health distress	
Relational capacity		
<b>Overall</b>		Short narrow scale that probably picks up low levels of enablement.

### 8.3. Recommendations

Health distress is a component of enablement. The scale provides limited information on enablement but has had limited use.

## 9. University of Rhode Island Change Assessment Questionnaire (URICA)

### 9.1. Development and validation

The University of Rhode Island Change Assessment (URICA) [171] is one of the most commonly used measures of motivation to change – an important component of enablement.

The URICA captures data on four of the five theoretical stages of change: precontemplation, contemplation, action, and maintenance. It includes eight questions for each of the four stages, i.e., a total of 32 items. The measure can be scored to provide a continuous measure of readiness to change, often referred to as a composite score, or to provide stage profiles. The URICA has undergone several psychometric evaluations indicating it has, generally, acceptable theoretical consistency, concurrent, and discriminant validity [172] [173]. Many studies of its factor structure suggest some inconsistencies and it has generally not been found to have adequate predictive validity [174] [175] [176].

The four theoretically-derived subscales are, precontemplation (e.g. “I am not the problem one, it doesn’t make sense for me to be here”), contemplation (e.g. “I have a problem and I really think I should work on it”), action (e.g. “I am finally doing some work on my problem”), and maintenance (e.g. “It worries me that I might slip back on a problem I already have, so I am here to seek help”).

### 9.2. Applicability in Australia

The URICA has been used in Australia mainly in the rehabilitation and mental health sector, including in addiction and in eating disorders. Laplante-Lévesque et al 2013 examined the URICA in the audiology setting and identified a different factor structure compared with the original however other properties were acceptable [177]. The tool appears to be mainly used to explore the stages of change theory, and to inform application and adherence to some psychological interventions.

	Related scales	Utility of scale
Physical capacity		
Cognitive capacity	Precontemplation, contemplation	May inform psychological interventions
Motivational capacity	Precontemplation, contemplation, action, maintenance	May inform psychological interventions May explain success of some treatments
Relational capacity		
<b>Overall</b>		Limited

### 9.3. Recommendations

While stages of change remain a popular and measurable concept, it may not have sufficient utility to inform enablement strategies or improve quality and impact of interventions. Not recommended.

## 10. Rapid Estimate of Adult Literacy in Medicine (REALM)

### 10.1. Development and validation

The Rapid Estimate of Adult Literacy in Medicine (REALM) was developed in the United States to assist physicians to identify adults with limited reading skills in the primary care setting [178]. It was modelled on the Wide Range Achievement Test (WRAT), a standardized literacy test that assesses the pronunciation of a list of words that the respondent reads aloud [178]. The 125 words, chosen from materials used in primary care, are arranged in three columns according to the number of syllables in ascending order of difficulty. A point is allocated for each correctly pronounced word. A shortened version, the REALM-S, comprising 66 items, was developed to reduce administration time and enhance uptake within the clinical setting [179]. It takes 1 to 2 minutes to complete. The raw score for the REALM-S (0 to 66) is converted to a US school grade estimate of reading ability.

The REALM focuses on functional health literacy and has been criticised for weak psychometric properties [180] [181] including not being sensitive to change over time and that it is potentially humiliating to complete for those with low health literacy or low enablement. Importantly, while respondents may be able to recognise and pronounce a word, the test does not distinguish between those who do and do not understand what the words mean [182].

### 10.2. Applicability in Australia

The REALM has had limited application in Australia [141] and appears to have limited utility [181] [141].

	Related scales	Utility of scale
Physical capacity		
Cognitive capacity	Functional health literacy (reading ability)	Easy to administer (per interview), may cause embarrassment for those who cannot read.
Motivational capacity		
Relational capacity		
<b>Overall</b>		Limited

### 10.3. Recommendations

The REALM is not recommended as it is interviewer administered, potentially disempowering for people with low literacy, and measures a limited range of enablement elements.

## 11. Empowering Speech Practices Scale (ESPS)

### 11.1. Development and validation

The ESPS, a 44-item instrument, assesses enablement in the hospital setting, from the patients' and nurses' perspectives [183] [184]. The tool is filled out by patients and nurses to assess counselling sessions for their empowering characteristics for patients.

The developers constructed the ESPS based on empowerment theory. The tool was developed in four stages: 1) a conversation analytic was developed on the empowering orientation of counselling. 2) A questionnaire was designed based on this with 65 statements and six clusters:

- a) setting expectations for discussion,
- b) offering individualised information and advice,
- c) facilitating reflection,
- d) constructing a positive atmosphere,
- e) respecting and bringing up the patient's competence concerning health, and
- f) the patient's assertiveness.

The questionnaire was designed to be completed by both nurse and patient post counselling in parallel (the same statements used). At stage 3) simulated interviews were held with 5 patients and 5 nurses who watched videotaped sessions and used the tool. The tool was then modified down to 58 statements. At stage 4) the altered measurement was tested on 4 patients in a hospital ward.

The tool was tested in 17 wards and polyclinics in the Central Finland Health Care District. The construct validity was not well demonstrated (hypothesised constructs did not match the empirical constructs identified using factor analysis) and the reliability of the scales was poor (alpha 0.52-0.75).

### 11.2. Applicability in Australia

No studies identified outside Finland

	Related scales	Utility of scale
Physical capacity	respecting and bringing up the patient's competence concerning health	
Cognitive capacity	offering individualised information & advice facilitating reflection	
Motivational capacity	constructing a positive atmosphere the patient's assertiveness	
Relational capacity	setting expectations for discussion	
<b>Overall</b>	Some coverage of each domain	Limited information, co-administered by practitioner-patient

### 11.3. Recommendations

The ESPS has potentially valuable dimensions that may measure enablement. The tool required further development and testing.

## 12. Patient Empowerment Scale (PES)

### 12.1. Development and validation

The field of empowerment research is rapidly growing, with numerous reviews, conceptual models and new questionnaires to measure the concept [185]. A wide range of questionnaires have been developed in recent years yet few have been well validated and implemented.

The PES was initially generated through a review of the literature and items were constructed to cover an a priori conceptual model [186]. The scale construction approach followed an “unfolding” model by Mitchell 1994 [187]. Item development was also informed by in-depth interviews (n=13). Fourteen themes were identified, and operationalised as 28 statements. The scale was then applied to a pilot sample of 100 cancer patients. Responses were analysed using Rasch measurement to generate a robust unidimensional scale.

The dimensions include many indicators of enablement, which is promising, however because the tool generates a total score, the utility of the tool is problematic in the health system improvement setting. The fourteen themes are:

Information relating to illness	Involvement in decision-making process
Family support	Patient perceived usefulness to family
Complementary therapies	Patient perception of GP ability to manage illness
Support of friends	Patient perceived usefulness to friends
Paid employment	Acceptance and adaptability to illness
Relationship with GP them	Patient perception of health professionals’ willingness to include them
Spiritual beliefs	Resources

### 12.2. Applicability in Australia

The PES, while developed in Western Australia in 2006, has rarely been used in research and has not undergone further testing. One cancer study used it as an outcome measure in a study of shared care in people with cancer [188]. PES, and several other psychological measures did not find any effects in the treatment group compared with controls. The tool did not identify people with low empowerment, which may have been a reflection of the items of the tool or the sample recruited.

	Related scales	Utility of scale
Physical capacity		
Cognitive capacity		
Motivational capacity	Empowerment (sense of control over the illness)	28 statements high burden
Relational capacity		
<b>Overall</b>	Dimensions cover a wide range but appear to organised to focus on empowerment	Does not seem to capture low enablement

### 12.3. Recommendations

Insufficient testing has been undertaken on the PES and scoring requires further work.

## 13. Patient Enablement Instrument

### 13.1. Development and validation

The Patient Enablement Instrument (PEI) developed in 1998 by Howie et al [189] has been suggested as a measure of a clinical consultation, but going beyond patient satisfaction. The instrument focuses on the impact of a consultation on a patient’s self-perceived ability to understand and cope with health issues and disease. The original PEI version was developed from literature reviews and patient interviews to evaluate enablement after a clinical consultation in primary health care. The PEI consists of 6 questions that ask patients to respond specifically to the consultation they just received with a healthcare professional. The questions are:

- |                                    |                                  |
|------------------------------------|----------------------------------|
| 1. able to cope with life          | 4. able to keep yourself healthy |
| 2. able to understand your illness | 5. confident about your health   |
| 3. able to cope with your illness  | 6. able to help yourself         |

The instrument has been described to be related to, but different from, measures of satisfaction [189]. The original PEI has been translated and evaluated in several countries, generally exhibiting high internal reliability across a range of setting including in France, China, Poland and Sweden [190] [191] [192] [193] [194].

The Swedish study found that a large proportion of respondents characterized at least one of the questions as irrelevant (39%). They concluded that the “PEI has high internal consistency and moderate to good reliability. It can be used in research but is not recommended as a measure of quality of care. The instrument could benefit from further development and validity testing” [194].

One of the largest studies using the PEI was in Scotland among over 3000 patients across 26 GPs within high and low socio-deprivation areas. PEI was lower in patients with multimorbidity of 3 or more long-term conditions (reflecting poor chronic general health), and those consulting about a long-standing problem [72].

### 13.2. Applicability in Australia

Two small cross-sectional research studies were undertaken by Australian authors, both were in primary care clinics and explored GP style and predictors of enablement [195] [196]. It has had limited uptake and may not have high credibility in the Australian GP setting. A further study by Desborough et al (2014) sought to generate a “Patient enablement and satisfaction survey” and combined the PEI with a satisfaction survey [197]. This survey is considered in detail in the next section.

	Related scales	Utility of scale
Physical capacity		
Cognitive capacity	Patient enablement	6 simple items
Motivational capacity	Patient enablement	
Relational capacity		
<b>Overall</b>	Captures some elements of enablement	Single score, easy to apply, but focusses ‘the consultation’

### 13.3. Recommendations

The PEI has primarily been used as a research tool to explore quality in primary care. It may not detect gaps in enablement and change over time. Not recommended.

## 14. Patient Enablement Satisfaction Survey (PESS)

### 14.1. Development and validation

Desborough et al (2014) sought to develop a survey to evaluate the satisfaction and enablement of patients receiving nursing care in Australian general practices [198]. They developed the PESS, a combination the PEI (discussed above) except the question about 'coping' was removed, and the Client Satisfaction Tool (CST) developed by Bear and Bowers 1998 [198]. These questionnaires were chosen because they were "considered a valuable foundation due to: their origins in primary health care; their acknowledgement of client singularity, central to the concept and delivery of client-focussed care; the CST for its grounding in nursing theory; and the ease with which they could be scored and applied in a variety of practice settings [198]. The initial development and validation included rudimentary face validity data and peer endorsement. The tool requires basic psychometric evaluation.

Question	Measure
a. The nurse/s were understanding of my personal health concerns	Affective support
b. The nurse/s gave me encouragement in regard to my health problem	
c. I felt comfortable to ask the nurse/s questions	Health information
d. My questions were answered in an individual way	
e. I was included in decision-making	Decisional control
f. I was included in the planning of my care	
g. The treatments I received were of a high quality	Professional/technical competencies
h. Decisions regarding my health care were of high quality	
i. The nurse/s were available when I needed them	Access to health care
j. The nurse appointment times were when I needed them	
k. The nurse/s spent enough time with me	Time
l. I was confident with the nurse/s' skills	Professionalism
m. The nurse/s were very professional	
n. Overall, I was satisfied with my health care	Overall satisfaction
o. The care I received from the nurse/s was of high quality	

### 14.2. Applicability in Australia

While the original questionnaires were developed in other countries, the adaption was undertaken in Australia. Apart from the initial development paper, only one other published study was identified and was undertaken by the creators [199]. This study found all patients had high satisfaction, which may be a reflection of the sample tested, the items are affected by social desirability, or are insensitive to low satisfaction levels. The tool is relatively specific to primary care nursing in Australia but could be adapted for wider application.

	Related scales*	Utility of scale
Physical capacity		
Cognitive capacity	Partial	
Motivational capacity	Partial	
Relational capacity		
<b>Overall</b>		PHC Nursing-specific, single score.

\* see PEI above. Unclear where satisfaction concepts fit across enablement concepts.

### 14.3. Recommendations

The PESS (i.e., the PEI and CST) require further evaluation prior to wider application. They also require adaptation to settings beyond primary care nursing.

## 15. Partners in Health Scale (PIH)

### 15.1. Development and validation

The PIH was developed at Flinders University in 2003 to assist with chronic condition self-management practice [200], i.e., to be used by primary health care professionals and their patients. The construction and initial conceptualisation was based a review of the literature which derived a definition of self-management that guided its development:

*Self-management involves the individual working in partnership with their carer(s) and health professionals so that (s)he can:*

1. Know their condition and various treatment options.
  2. Negotiate a plan of care; (i.e., Care Plan).
  3. Engage in activities that protect and promote health.
  4. Monitor and manage the symptoms and signs of the condition(s).
  5. Manage the impact of the condition on physical functioning, emotions and interpersonal relationships.
- Eleven items were developed to cover all elements of the definition. It was administered to 20 patients in a pilot study and was found to have acceptable reliability and exploratory factor analysis suggested there were three factors among the 11 items [200]. The original tool has been cited 70 times since 2003.

A revised version was published in 2010 and included an additional item *Adopt lifestyles that promote health*. The 12 items were applied in a larger sample (n=249) of patients with a range of co-morbid chronic conditions including diabetes, cardiovascular disease and arthritis [201]. Good internal consistency was found and exploratory factor analysis suggested four factors (knowledge, coping, management of condition and adherence to treatment) across the twelve items. A recent validation study provided further information on the PIH reliability [202]. The authors conclude that a range of further studies are required:

*“The PIH scale may help health professionals to introduce the concept of self-management to their patients and provide assessment of areas of self-management. A limitation is the narrow range of validated PIH measurement properties to date. Further research is needed to evaluate other important properties such as test–retest reliability, responsiveness over time and content validity” [202].*

#### **Knowledge**

1. Overall, what I know about my health condition(s) is
2. Overall, what I know about my treatment, including medications for my health condition(s) is

#### **Partnership in treatment**

3. I take medications or carry out the treatments asked by my doctor or health worker.
4. I share in decisions made about my health condition(s) with my doctor or health worker.
5. I am able to deal with health professionals to get the services I need that fit with my culture, values and beliefs
6. I attend appointments as asked by my doctor or health worker.

#### **Recognition and management of symptoms.**

7. I keep track of my symptoms and early warning signs (e.g. blood sugar levels, peak flow, weight, shortness of breath, pain, sleep problems, mood)
8. I take action when my early warning signs and symptoms get worse

#### **Coping**

9. I manage the effect of my health condition(s) on my physical activity (i.e. walking, household tasks)
10. I manage the effect of my health condition(s) on how I feel (i.e. my emotions and spiritual well-being)
11. I manage the effect of my health condition(s) on my social life (i.e. how I mix with other people)
12. Overall, I manage to live a healthy life (e.g. no smoking, moderate alcohol, healthy food, regular physical activity, manage stress)

A validation study has also been undertaken in Mexico [203]. The PIH scale has been included as a secondary outcome in randomised controlled trials however very few have been completed.

### 15.2. Applicability in Australia

The PIH was developed in Australia and has been applied in several studies and is integral to the widely applied Flinders Model of self-management support approach ([www.flindersprogram.com](http://www.flindersprogram.com)).

	Related scales	Utility of scale
Physical capacity		
Cognitive capacity	Recognition and management of symptoms, Knowledge	
Motivational capacity	Coping	
Relational capacity	Partnership in treatment	
<b>Overall</b>	PIH captures several aspects of enablement	Many items may not be relevant to people with low enablement

### 15.3. Recommendations

The PIH scale is mainly used to support the clinical-patient interaction. It was not conceptualised as an outcomes tool and is not well tested for that purpose. Recommended as a clinical decision-making tool only.

## 16. Patient Assessment of Chronic Illness Care (PACIC)

### 16.1. Development and validation

In 2005 a team from the Kaiser Permanente and Group Health Cooperative [204] reported on a self-report instrument to assess the extent to which patients with chronic illness receive care that aligns with the Chronic Care Model [205]. The tool, the Patient Assessment of Chronic Illness Care (PACIC) sought to measure whether care is patient-centered, proactive, planned and includes collaborative goal setting; problem-solving and follow-up support.

A 20-item tool was developed from 5 a priori scales based on the key components of the CCM. These subscales were hypothesised to be:

1. Patient activation;
2. Delivery system design and decision support;
3. Goal setting and tailoring;
4. Problem-solving and contextual counselling;
5. Follow-up and coordination.

The PACIC have been influential, highly cited (274 cites since 2005) and widely adapted. Initially developed in English, PACIC versions in Danish, Dutch, French, German, Slovenian and Spanish, tested in patients presenting diverse chronic diseases (e.g. diabetes, arthritis, elderly and chronic lung diseases), are available (see Iglesias et al [206] and Rick et al [207] for review).

The PACIC dimensions have been widely debated. In general, authors have suggested that the five hypothesised dimensions are not well represented in empirical data and users should consider working with individual items and an overall total score [206] [207].

### 16.2. Applicability in Australia

The PACIC was tested in Australia [208] within the Teamwork study, it was a cluster-randomized trial involving 60 practices in urban and rural New South Wales, Victoria and the Australian Capital Territory [209]. This study aimed to evaluate the impact of facilitating an enhanced role for non-general practitioner (GP) staff in the management of patients with chronic illness. These were recruited from 16 Divisions of General Practice. This study did not reproduce the original five factors, rather two factors were found; (1) shared decision making and self-management, and (2) planned care (referral and follow-up). The two dimensions were discriminative enough to distinguish between respondents with a single illness and those with two or more illnesses; or low and high socioeconomic status; or good and poor general health; or longer and shorter duration of the disease. Patients with high socio-economic status (well-educated and employed) were less satisfied with care.

These data, and other international studies make it somewhat unclear how the PACIC should be used in Australia. While the items and dimensions have face validity, further work is required to understand how the tool can drive quality improvement and whether it can detect change. The PACIC is likely to be useful for understanding if, from patients' perspective, whether services and systems are in place that would support people with low enablement.

	Related scales	Utility of scale
Physical capacity		
Cognitive capacity		
Motivational capacity		
Relational capacity	PACIC	
<b>Overall</b>	Comprehensive focus on the clinical and practitioner-patient interaction	Item-level use of PACIC likely to assist with improvement, including patient's perspective with low enablement. 20 items, i.e., low burden.

### 16.3. Recommendations

The PACIC is likely to be useful in service improvement initiatives. It focuses on the experience of care, not on patient-level enabling capabilities.