

Welsh Health Measures Scoping Review And Survey

FINAL REPORT

Prepared for the
National Institute for Social Care
and Health Research (NISCHR)

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December 2013

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BACKGROUND

- Health measures are being used increasingly in clinical and research settings to monitor the health status of patients and assess the impact of service provision and interventions. (MRC, 2009). Nevertheless, in order to maximise their impact and effectiveness in clinical decision making and research, they need to be meaningful to patients as well as being reliable, valid and generalisable (Bowling, 2005; Streiner and Norman, 2008; MRC, 2009).
- For bilingual speakers, communicating in a way that responds to their particular language and cultural needs helps explore their personal dimensions of health and provides a more accurate rendering of their health status (Attarriba & Morier 2004). Moreover, sharing the same language offers a way of establishing common ground for communication and understanding that helps capture the reality of the patient's perspective.
- Thus, for example, in the bilingual context of Wales, it is important that health measures are offered in Welsh as well as English, according to individual need, and in accordance with statutory regulations (Welsh Language Measure, 2011); governance procedures (Welsh Government, 2009; 2012a); and policy (Welsh Government 2012b). Nevertheless, access and availability of authorized Welsh language versions of health measures remains poor (Roberts, *et al.* 2012). This suggests that the health status of some Welsh speakers may be mis-interpreted; and this can jeopardise their care management and challenge the rigour of research conducted in a bilingual context.
- This scoping review is part of a wider project to increase the availability and accessibility of Welsh language versions of health measures for health researchers and practitioners across Wales. This is a two year programme of work led by LLAIS (the National Institute for Social Care and Health Research Language Awareness Infrastructure Support Group) in collaboration with NWORD (the North Wales Organisation for Randomised Trials in Health). The review included a brief on-line survey to seek the views of respondents on prioritising the health measures in need of Welsh translation. The findings will help guide the project to target the areas of greatest need.

METHODS

- The 14-item on-line survey instrument was developed using the Bristol on-line survey software. The questionnaire was divided into six sections, as follows:
 - Section 1: Your priorities
 - Section 2: Your organisation
 - Section 3: About you
 - Section 4: Your Welsh language profile
 - Section 5 : Your use of health measures
 - Section 6: Validation of health measures.

- It was anticipated that the survey would take approximately 10 minutes to complete; and all questions had to be answered before respondents could move onto the next question, thus ensuring that there were no missing data.
- Advance notice of the survey was disseminated to the clinical research infrastructure at the NISCHR Conference held in Cardiff on 24th April 2013. The link to the online survey was then circulated on 27th June 2013 and closed on 31st August 2013. The circulation list included managers and leads of:
 - All the NISCHR Trials Units
 - All the NISCHR Registered Research Groups
 - All the NISCHR Infrastructure Support Groups
 - All NHS Wales R&D departments
 - HE Academic leads
- Four reminder emails were circulated on 31st July 2013, 7th August 2013, 14th August 2013 and 21st August 2013.

ANALYSIS

- All data were anonymised and analysed using SPSS for Windows (version 15.0).

SAMPLE

- The characteristics of the study sample are outlined in Table 1. Twenty-three respondents in all participated in the on-line survey. Eight of them were Welsh speakers; 6 were beginner level learners of Welsh; whilst the remaining 9 did not speak Welsh.
- The majority of the respondents represented a higher education institution (17). Representations were also seen from local health boards (5), NHS trusts (1) and the NISCHR Clinical Research Infrastructure (3). Multiple representations are given in 3 cases.
- Eight respondents represented two of the Welsh clinical trials units (NORTH and SEWTU). All but one of these also represented a higher education institution. Two respondents represented a NISCHR infrastructure support group (HIRU and WHESS). Ten of the respondents represented a NISCHR RRG with OPAN (3) and NEURODEM-Cymru (4) being the most frequent.
- Eleven respondents stated that they have a role in clinical practice. These included a clinical psychologist, GPs, nurses, physicians, NHS manager, health governance researcher and health economist.

- Nineteen respondents had a role in higher education. These ranged from research assistants to professorial level.
- With the exception of one isolated respondent, all had a role in research, from research assistant to principal investigator.

Table 1 Characteristics of the study sample

| Characteristic N | Sample 23 | |
|--|---|-----------------------------------|
| Welsh language proficiency, n=23 | Welsh-speaker | 8 |
| | Welsh-learner | 6 |
| | Non-Welsh-speaker | 9 |
| *Organisation, n=23 | Higher Education Institute | 17 |
| | Local Authority | 0 |
| | Local Health Board | 5 |
| | NHS Trust | 1 |
| | NISCHR Clinical Research Infrastructure | 3 |
| | NISCHR Clinical Research Infrastructure, n=20 | NISCHR Trials Unit |
| NIISCHR Infrastructure Support Group | | 2 |
| NISCHR Registered Research Group | | 10 |
| Clinical practice role, n=7 | | Physician |
| | Nursing and allied health | 5 |
| Higher education role, n=19 | Reader / Professor | 7 |
| | Senior Lecturer /Senior Research Fellow | 4 |
| | Lecturer / Research Fellow | 2 |
| | Research Officer / Co-ordinator | 6 |
| | Research role, n=22 | Clinical / Principal Investigator |
| Clinical Studies / Research Project Officer | | 5 |
| Statistician | | 2 |
| Trial / R&D Manager | | 2 |

*Total >23 due to multiple representations

FINDINGS

Prioritising health measures for translation

- Just over half (13) of the respondents were aware of measures in need of Welsh translation. A further 6 were not sure and the remaining 4 were not aware of any measures needing translation. The measures identified by the respondents are listed in Table 2.

Table 2 Health measures listed by respondents (n=13) in order of priority for Welsh translation

| | First Priority | Second Priority | Third Priority |
|-----------|---|---|--|
| 01 | Hospital Anxiety and Depression Scale (HADS) | Short- form 12 (SF-2v2) | ABC Cancer Awareness Measure (ABC) |
| 02 | EuroQoL 5D-5L (EQ-5D-5L) | EQ-5D Youth version (EQ-5D-Y) | Short form 6D (SF-6D) |
| 03 | Short- form 12 (SF-12v2) | Addenbrookes Cognitive Examination (ACE III) | Quality of Life in Alzheimers Disease (QoL-AD) |
| 04 | ONS National Well-being Measure | Perceived Stress Scale (PSS-10) | Rosenberg Self-Esteem Scale (RSES) |
| 05 | Dermatology Life Quality Index (DLQI) | | |
| 06 | Short- form 12 (SF-12v2) | General Health Questionnaire (GHQ) | Orebro Musculoskeletal Pain Questionnaire (OMPQ) |
| 07 | Quality of life in Alzheimers disease (QoL-AD) | | |
| 08 | Seattle Angina Questionnaire (SAQ-7) | Rose Dyspnoea Scale | Patient Health Questionnaire - (PHQ-2) |
| 09 | The Revised Illness Perception Questionnaire (IPQ-R) | Generalised Self-Efficacy Scale (GSES) | GAINS |
| 10 | Hospital Anxiety and Depression Scale (HADS) | Frenchay Aphasia Screening Test (FAST) | Assessment of Life Habits (LIFE-H) |
| 11 | Short- form 12 (SF-12v2) | Western Ontario and McMaster Universities Arthritis Index (WOMAC) | Roland Morris Disability (RMDQ) |
| 12 | Attention Deficit Disorder (ADHD) Test | | |
| 13 | Positive and Negative Symptoms in Schizophrenia (PANSS) | Camberwell Assessment of Needs (CANE) | 7-day Physical Activity Recall (PAR) Scale |

- Given the health measures listed in Table 2, and applying a priority scoring formula where first priority = 3; second priority = 2; and third priority = 1; the results reveal that *Short form 12 (SF-12v2)* has the highest priority score overall with an overall rank of 11, followed by the *Hospital Anxiety and Depression Scale (HADS)* with 6 and *Quality of life in Alzheimer's disease (QoL-AD)* with 4. By nature of the list, those scoring below this were only voted for by one respondent.
- Table 3 shows that the measures are associated with a range of clinical domains, but the majority (n=11) relate to the mental health context; with 5 of these measures scoring a priority score >3 by the survey respondents. A number of generic measures (n=7), such as those evaluating quality of life, are also identified to be in need of Welsh translation and adaptation, with 3 of these measures scoring a priority score >3.

Table 3 Priority health measures grouped according to clinical domains

| Health Measure | | | | | | | |
|--|---|--|---|---|--|--|-----------|
| Generic | Mental Health | Stroke | Musculo-skeletal | Dermatology | Cardiovascular | Cancer | Other |
| Short form 12 (SF-12v2) (11) | Hospital Anxiety and Depression Scale (HADS)(6) | Frenchay Aphasia Screening Test (FAST) (2) | Western Ontario and McMaster Universities Arthritis Index (WOMAC) (2) | Dermatology Life Quality Index (DLQ1) (3) | Seattle Angina Questionnaire (SAQ-7) (3) | ABC Cancer Awareness Measure (ABC) (1) | GAINS (1) |
| EuroQoL 5D-5L (EQ-5D-5L) (3) | Quality of life in Alzheimer's disease (QoL-AD) (4) | | Orebro Musculoskeletal Pain Questionnaire (OMPQ) (1) | | Rose Dyspnoea Scale (2) | | |
| ONS National Well-being Measure (3) | Attention Deficit Disorder (ADHD) Test (3) | | Roland Morris Disability (RMDQ) (1) | | 7-Day Recall Physical Activity Scale (1) | | |
| EuroQoL 5D Youth version (EQ-5D-Y) (2) | Positive and Negative Symptoms in Schizophrenia (PANSS) (3) | | | | | | |
| General Health Questionnaire (GHQ) (2) | Revised Illness Perception Questionnaire (IPQ-R) (3) | | | | | | |
| Short form 6D (SF-6D) (1) | Addenbrookes Cognitive Examination (ACE III)(2) | | | | | | |
| Assessment of Life Habits (LIFE-H) (1) | Camberwell assessment of needs (CANE) (2) | | | | | | |
| | Perceived Stress Scale (PSS-10) (2) | | | | | | |
| | Generalised Self-Efficacy Scale (GSES) (2) | | | | | | |
| | Patient Health Questionnaire - (PHQ-2) (1) | | | | | | |
| | Rosenberg Self-Esteem Scale (RSES) (1) | | | | | | |

() = Priority score

- The next task asked respondents to indicate, *from a given list*, those health measures that they felt were in need of translation. From this list, all measures had at least two respondents, although two respondents did indicate that every measure was in need of translation. If we exclude these two responses, then the Test of Everyday Attention (TEA) is the only one that loses all its scoring. Table 4 outlines the measures identified and these are grouped according to clinical domains.

Table 4 Number of respondents who identified health measures in need of Welsh translation according to clinical domains

| Clinical Domain | Measure | Number of Respondents |
|----------------------|--|-----------------------|
| Generic | Short-form 12 (SF-12) | 13 |
| Mental Health | Health related quality of life in people with dementia (DEMQOL) | 9 |
| | Cornell Scale for Depression in Dementia (CSDD) | 8 |
| | Clinical Dementia rating (CDR) | 7 |
| | Alzheimer's disease cooperative study group activities of daily living (ADCS-ADL) | 6 |
| | Delis-Kaplan Executive Function System: Verbal Fluency tasks (DKEFS) | 6 |
| | Health related quality of life in people with dementia (DEMQOL) | 6 |
| | Quality of the Care giver Patient relationship (QCPR) | 6 |
| | Rating Anxiety in Dementia (RAID) | 6 |
| | Relatives stress scale (RSS) | 6 |
| | Neuropsychiatric Inventory (NPI) | 5 |
| | Patient Enablement Instrument (PEI) | 5 |
| | Patient Health Questionnaire 2 (PHQ-2) | 4 |
| | Neuropsychiatric Inventory with Caregiver Distress Scale (NPI-D) | 3 |
| | Test of Everyday Attention - subtests Elevator Counting, Elevator Counting with Distraction, Visual Elevator and Elevator Counting with Reversal (TEA) | 2 |
| Other | Multi-Attribute Health Status Classification System: Health Utilities Index Mark 2 (HUI2) | 1 |
| | Multi-Attribute Health Status Classification System: Health Utilities Index Mark 3 (HUI3) | 1 |
| | ICECAP | 1 |

- By considering both responses to those listing priority and those voted for, the *SF-12v2* has the highest rated priority for translation and this is followed by a number of mental health measures, particularly those relating to the field of dementia.

Current use of health measures

- Table 5 outlines the health measures currently in use by the respondents and these are grouped according to clinical domains. The most commonly used health measure is the generic measure, SF-12v2. This is currently being used by eight respondents. The next most commonly used measures relate to the dementia field, that is, the Clinical Dementia Rating (CDR) (used by 3 respondents); and the Cornell Scale for Depression in Dementia (CSDD) (used by 2 respondents). Whilst the respondents identified the use of 4 further generic health measures, the remaining measures in use are largely related to the field of mental health, followed by stroke, dermatology and diabetes.

Table 5 Current use of health measures amongst respondents according to clinical domains

| Clinical Domain | Measure | Number of Respondents | |
|---|---|---|---|
| Generic | Short form 12 v2 (SF12) | 8 | |
| | Clinical dementia rating (CDR) | 3 | |
| Mental Health | Cornell Scale for Depression in Dementia (CSDD) | 2 | |
| | Delis-Kaplan Executive Function System: Verbal Fluency tasks (DKEFS) | 2 | |
| | Health related quality of life of people with dementia (DemQol) | 1 | |
| | Neuropsychiatric inventory (NPI) | 1 | |
| | Neuropsychiatric inventory with care giver distress (NPI-D) | 1 | |
| | Patient enablement instrument (PEI) | 1 | |
| | Patient health questionnaire (PHQ-2) | 1 | |
| | Quality of care giving relationship (QCPR) | 1 | |
| | Rating anxiety in Dementia (RAID) | 1 | |
| | Relatives stress scale (RSS) | 1 | |
| | EuroQol -5 dimensions (EQ-5D) | 1 | |
| | Multi-Attribute Health Status Classification System: Health Utilities Index Mark 2 (HUI2) | 1 | |
| | Other | International Physical Activity Questionnaire (IPAQ SF-36 v2) | 1 |
| | | Perceived Stress Scale (PSS-10) | 1 |
| Rosenberg Self-Esteem Scale Personal Well-being Index (PWI) | | 1 | |
| Physical Activity Enjoyment Scale (PACES) | | 1 | |
| Interpersonal Support Evaluation List (ISEL-12) | | 1 | |
| Briding & Bonding Social Capital Scale (BBSCS) | | 1 | |
| Dermatology life quality index (DLQI) | | 1 | |
| Childrens dermatology life quality index (CDLQI) | | 1 | |
| Audit of Diabetes Dependent Quality of Life (ADDQoL), | | 1 | |
| Audit of diabetes knowledge (ADKnowL) | | 1 | |
| Barthel Index Geriatric Depression Scale (Barthel), | | 1 | |
| Assessment of Life Habits (LIFE-H) | | 1 | |
| Nottingham Leisure questionnaire (NLQ) | | 1 | |
| General Health Questionnaire v12 (GHQ-12) | | 1 | |

- Table 6 shows the Welsh health measures that are currently in use by the 9 respondents who confirmed that they made use of Welsh measures. The most commonly used Welsh measure in current use is the EQ-5D-3L

Table 6 Welsh health measures currently in use amongst respondents

| Measure | Response |
|---|----------|
| EuroQol Group 5-Dimension Self-Report Questionnaire 3L (EQ-5D-3L) | 3 |
| Hospital Anxiety and Depression Scale (Y Raddfa Iselder a Phryder Ysbytai) (HADS) | 2 |
| Short Form 36v2 Health Survey (Arolwg Iechyd Ffurf Fer) (SF - 36v2) | 2 |
| Barthel Index of Activities of Daily Living (Mynegai Gweithgarwch Byw Bob Dydd Barthel) | 1 |
| Beck Depression Inventory-II (Rhestr Iselder Beck-II) (BDI-II) | 1 |
| Cambridge Examination for Mental Disorders of the Elderly (Archwiliad Caergrawnt ar gyfer Anhwylder Meddyliol yr Henoed) (CAMCOG-R) | 1 |
| Patient Health Questionnaire-9 (Holiadur Iechyd Cleifion-9) (PHQ-9) | 1 |

- Of the 14 respondents that do not use Welsh measures, 13 gave reasons as to why not. These reasons are listed in Table 7.

Table 7 Respondents' reasons for not using Welsh health measures

| Reason for not using Welsh measure | Frequency |
|--|-----------|
| Measures not available | 7 |
| Do not know where to find them | 3 |
| No welsh speaking researchers | 3 |
| Licence not available | 1 |
| Not trained | 1 |
| I didn't know any were available | 1 |
| Not applicable to our area of research | 1 |
| Not using any at present but if we were and a Welsh version was available, we would use it | 1 |
| None are available for Children and Young people | 1 |

DISCUSSION

- Given the nature of on-line surveys, the population is unknown. Thus, it is not possible to estimate the response rate for this study (Streiner & Norman 2008). However, the 23 respondents represent a range of organisations and clinical / research roles within these organisations. Moreover, a range of clinical trials units and RRGs are also well represented in the sample. Their input into the survey is particularly valuable, given their role in trial design and identification of trial outcome measures.
- Fourteen respondents have some knowledge of Welsh. They are thus likely to have added insight of the needs of bilingual speakers and the implications for language sensitivity in health research (Roberts et al 2007). It is encouraging to note that 9 non-Welsh-speakers have responded to the

survey, thus identifying their interest and commitment towards contributing to language awareness in the research process.

- Over half the sample identified a need for Welsh language health measures. Perhaps this is to be expected given that the sample was self-selecting and that the survey was more likely to attract participants with experience / interest in the field.
- Respondents reported that their greatest priority by far is for a Welsh language version of the SF-12v2. This is not surprising given that the SF-12v2 is reported as the most commonly used measure amongst the survey respondents. It is interesting to note that there are more requests for translation of measures than are actually in use by the sample of respondents. For example, the SF-12v2 is used by 8 respondents but 13 would like to see it translated. This may suggest that more would use the measure if it was available in Welsh or that SF-12v2 is such a widely used measure that there is a perception that it should be translated. This may also be influenced by past use.
- Other health measures highly prioritised for their availability in Welsh are those from the mental health field, particularly dementia care. This ranking is likely to be influenced by the background of the respondents where there is strong representation from OPAN and NEORODEM-Cymru. Nevertheless, this strength of response is also reflected across clinical practice and policy domains, as outlined later.
- Although the HADS and EQ-5D-5L are ranked as a high priority for Welsh translation and adaptation by study respondents, the Welsh version of HADS has already been developed by LLAIS and it is available in Welsh from GL Assessment. Moreover, LLAIS has also recently completed the linguistic validation of a new Welsh language version of the EQ-5D-5L which has received authorisation from EuroQol.
- It is encouraging to note that, of the 7 Welsh language health measures currently in use by these survey respondents, 5 were established by LLAIS. However, it is likely that there is a lack of universal awareness of the availability of Welsh measures. This may account for the fact that one respondent claimed to be using the Geriatric Depression Scale in English but not in Welsh, despite the fact that the measure was developed in Welsh by LLAIS in 2011. Similarly, although the survey identified a need for a Welsh version of the ICECAP, this was also developed by LLAIS in 2011. This suggests that information about the availability of these measures needs to be more readily accessible for researchers if they are to make use of these tools.
- Other factors may also have a bearing on why Welsh language versions of health measures are not being used; and a number of reasons are outlined. The main perception amongst the respondents of this survey is that they are not available. Indeed, one respondent reports that if a Welsh language version of a particular health measure was currently available, they would

use it. This explanation is borne out in the preceding discussion and strengthens the need to move forward with the current LLAIS/NWORTH work programme.

- Access to Welsh language versions of health measures and information about the measures appears problematic amongst some researchers. A web-based information / resource site could provide easy access to information on Welsh health measures, including their availability, authorship, licensing, access and validation data.
- There is a misconception that researchers should be Welsh speaking in order to administer Welsh language health measures. Whilst this may be the case for some cognitive assessments tools, patient-reported outcome measures (PROMs) obviate this requirement. This message needs to be disseminated effectively so that practitioners and researchers offer Welsh and English versions of PROMs to patients, on the basis of equality.
- Another misconception may exist around the availability and status of a Welsh language version of SF-36v2 since two survey respondents report its current usage. We are aware that some Welsh translation / adaptation work has already been undertaken on the SF-36v2 since aspects of the measure are embedded into the Welsh Health Survey. Moreover, discussions with Welsh Government confirm that the translation work was undertaken as far back as the 1990's following the conventional staged approach. Nevertheless, the Welsh version of SF-36v2 has not been subjected to full cognitive testing and thus fails to meet the requirements for full authorisation by Quality Metric. This strengthens the case for prioritising the linguistic validation of a Welsh version of SF-12v2 and SF-36v2 for the research and healthcare community.

Survey Strengths and Limitations

- The administration of the survey during a popular holiday period may have reduced the overall response rate. Nevertheless, the sample represented a wide cross-section of respondents who were able to evaluate current practice and identify priorities.
- Significant representation from OPAN and NEURODEM-Cymru may account for the heavy focus within the survey on measures used in the field of dementia care. Nevertheless, given the challenges of meeting the needs of an ageing population, this focus has shed light on an area which is of particular relevance in current health policy and research.
- This development is particularly timely since the commonly used Mini Mental State Examination (MMSE), which is copyrighted, now incurs a cost for each use, so there is a need to identify alternative assessment tools. The new practical toolkit collated by the DoH and Alzheimer's Society (2013) to assess cognitive function amongst older people offers practical advice for clinicians about a choice of cognitive tests which can be used to assess cognition in clinical settings. All of the suggested tests are available to clinicians free of

charge. Moreover, all are currently used in the research context, with some having been translated into Welsh, although to varying standards.

- LLAIS was approached recently by BCUHB who need a Welsh version of the cognitive assessment toolkit (CAT) to meet the needs of the ageing population across North Wales. This prompted a scoping of the field where the following details were confirmed:
- There is commitment with the new Strategic Framework for Welsh Language Services in Health, Social Services and Social Care (WG 2012b) to 'Develop and issue Welsh language versions of core dementia assessment tools (for non-copyright tools), to the service' (Strategic Objective 2) but this work has not yet commenced.
- There is support for the development of a Welsh language version of this toolkit from the WAMHin PC with endorsement from NISCHR and the Welsh Government.

CONCLUSIONS AND RECOMMENDATIONS

- In light of the findings of this scoping review and survey, the following measures are recommended (in priority order) for Welsh translation and adaptation with a full linguistic validation:
 - ACE-III
 - MOCA
 - GPCOG
 - SF-12v2
 - SF-36v2
- LLAIS/NWORTH to seek permission to undertake the Welsh translation and adaptation of the Cognitive Assessment Toolkit (Alzheimer's Society / DoH 2013)
- LLAIS/NWORTH to explore ways of collating validation data on the measures above.
- LLAIS/NWORTH to proceed with establishing a web resource that provides access to up-to-date information on Welsh health measures, including availability, authorship, licensing, access and validation data.

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