



Gwasanaeth Cefnogi Isadeiledd Iaith (LLAIS)
Language Awareness Infrastructure Support (LLAIS)
NWORTH, Y Wern
Safle'r Normal Site
Prifysgol Bangor University
Bangor, Gwynedd
LL57 2PZ

llais@bangor.ac.uk

01248 38 3171 – Dr Llinos Haf Spencer (Swyddog Ymchwil/Research Officer)

01248 38 3153 – Mrs Beryl Cooledge (Cyfarwyddwr/Director LLAIS)

LLAIS STAKEHOLDER QUESTIONNAIRE 2019

In February 2019, the LLAIS Questionnaire was sent out to n = 141 LLAIS stakeholders (other trials units in Wales, Public Health Wales, Welsh Health Boards and others). Some of the stakeholders could not be reached by e-mail either because they were no longer doing the job, they were away from work for a period (eg maternity or long term illness) or that the email to several people had unable to reach some people for whatever reason to do with IT systems. The original deadline was 28/02/2019, but this was extended to 15/03/2019 as more stakeholders were invited to respond via other sources (Twitter @micymraeg and email from Eleri Hughes- Jones, BCUHB). The number of stakeholders was approximately n = 141.

By 15/03/2019 18 responses were received to the questionnaire giving a response rate of approximately 13%. Although this is a low figure, what is important is raising awareness of LLAIS and obtaining information about the patient outcome measures that need to be verified to Welsh by LLAIS.

The responses were collated by Dr Llinos Haf Spencer (LLAIS Research Officer), and the responses for each question are summarized in this report (see below):

Question 1. Job title

18 respondents gave their job title, from a Statistician to Consultants in Public Health.

Question 2. Name of organisation

18 respondents provided a name for their organisation. Most were from South and North Wales and some were from England.

Question 3. Place of work

18 respondents said they worked in Wales, with one working in England and Wales.

Question 4. Have you heard about LLAIS?

A high percentage (11/18) had heard of the language awareness infrastructure support service (LLAIS).

Question 5. How did you hear about LLAIS?

Some respondents (7/18) said that they had heard of LLAIS by some other means i.e. not a lecture, language awareness session, website or Twitter. Some had worked with Gwerfyl Roberts (former LLAIS director) sometime in the past.

Question 6. Did you know that LLAIS validates patient reported health measures?

Around half (9/18) of respondents knew that LLAIS validates health measures for health services and research.

Question 7. Do you use health measures?

Some (8/18) respondents used health measures in health services or research.

Questions 8 and 9. Health measures and copyright details

Some (8/18) of respondents said that they would like to see the following health measures verified verbally by LLAIS: See Table 1.

Table 1 Responses to Welsh language health measures to be validated (and response to LLAIS comment in brackets).

#	Name of the health measure	Comment from LLAIS
1.	Resource use questionnaire for core primary and secondary services	No specific measure name
2.	Caregiver strain questionnaire	No specific measure name. There are caregiver measures on the micym.org website.
3.	Nottingham Extended Activities of Daily Living Scale (NEADL)	LLAIS has validated this measure in 2016. This is available from the micym.org website.
4.	GESQ	This is a measure of satisfaction and not a patient reported outcome measure (PROM).
5.	Forthcoming measure of resilience in dementia	Not yet created in English. Around 2020.
6.	CAPS-5. Measure for PTSD Copyright: Department of Veterans Affairs, US Government.	Measure given by the doctor, it is not a patient reported outcome measure (PROM).
7.	EQ5D	Validated by LLAIS and Professor Dyfrig Hughes in 2007.
8.	Stroke Impact Scale (Duncan et al 2003)	Potential for validation by LLAIS if researchers / health workers use it in Wales.

Key:

Red – No specific measure name

Grey – The measure is already validated into Welsh.

Green – The measure should be validated into Welsh in the future (not ready yet).

Amber – The measure should be validated into Welsh in the near future if it currently used by health services or researchers in Wales.

Question 10. Time frame

6 respondents said they would like the measures already in place between April 2019 and January 2021.

Question 11. Additional comments

Four additional comments were made.

Comment 1:

Da clywed fod cymorth i'r Gymraeg yn dod.

Good to hear that support for the Welsh language is coming.

Response by LLAIS to comment 1: LLAIS has been supporting research in Wales since 2011.

Comment 2: *I'm not sure which health economics measures have been translated but measures such as the ICECAP-A capabilities measure and CHU-9D (child health utility measure) would also be useful in the long term if not already available. A generic micro-costing diary template would also be a useful Resource.*

Response by LLAIS to comment 2: The ICECAP-A and the CHU-9D have already been verbally verified to Welsh and are available via micym.org. A diary would have to be suitable for a particular project.

Comment 3: *We need more support for translating patient Information sheets and consent forms.*

Response by LLAIS to comment 3: LLAIS is willing to proof read information leaflets that have been translated by other translators, but LLAIS is not a translation service.

Comment 4: (Name) here from the Health Board. We are very interested here about the health measures. I would like to see a library on the web - which lists all the measures but also shows a translation / development timetable. As a Health Board - see that there is an opportunity for the Welsh Government to help with this because of the needs of the whole of Wales. Need to prioritize children and mental health areas extremely important.

Response by LLAIS to comment 4: The micym.org website is a library of Welsh language health measures that can be audited using the 'search' button or 'Control with F' as in a Word document. A special measure can be downloaded, or you can find out who owns the copyright to contact them directly. It is also possible to see what measures are being developed.

As the questionnaire was completed anonymously, it was not possible to communicate directly with some of these respondents, but it was possible for those who had left their name to comment. We tried to respond to others on Twitter (@micymraeg - 474 followers currently) in order to convey the messages that many of the measures are already available in Welsh!

The next steps

1. Llinos and Beryl will be looking for details of the measures mentioned in this activity. Some measures also came via email and contact was made with Sarah Putoni (PROMS) and Kathleen Withers (CEDAR).
2. A meeting to discuss these responses and prioritize for the future will be held in May 2019 at Bangor University. Stakeholders and VOICES will be invited to contribute.
3. Two patient outcome health measures will be prioritized for validation in 2019 by LLAIS.

LLAIS contact details

Language Awareness Infrastructure Support (LLAIS)
NWORTH, Y Wern
Safle'r Normal Site
Prifysgol Bangor University
Bangor, Gwynedd
LL57 2PZ

llais@bangor.ac.uk

01248 38 3171 (Dr Llinos Spencer, Swyddog Ymchwil LLAIS Research Officer)

01248 38 3153 (Mrs Beryl Cooledge, Cyfarwyddwr LLAIS Director)

www.Micym.org (a library of Welsh health measures)

Llais.org (LLAIS website, NWORTH, Prifysgol Bangor University)