**ICECAP-SCM Instrument**

Agreement for use of the ICECAP-SCM (Supportive Care Measure).

The ICECAP-SCM Instrument is a measure of capability well-being for adults, and has been developed for use in an end of life/supportive care setting. It has been initially developed in the UK using in-depth and semi-structured qualitative research. The instrument contains seven attributes (Autonomy, Love, Physical Suffering, Emotional Suffering, Dignity, Support, Preparation), each with four levels.

Development of the instrument is detailed in Sutton & Coast (2013) Development of a supportive care measure for economic evaluation of end of life care using qualitative methods. *Palliative Medicine*. 28(2):151-157.

The developers of ICECAP-SCM are, in principle, happy for the instrument to be used by other researchers. We particularly encourage those wishing to use the measure to include methodological steps aimed at investigating the instrument’s feasibility and psychometric properties. Agreement to use the instrument is on the basis that:

* the instrument is not altered in any way, in terms of the nature of attributes, the wording of attributes, the levels of attributes, or the values provided by the research team.
* Research teams are strongly encouraged to explore the instrument’s psychometric properties, or consider sharing data with the developers of the measure to enable them to explore this.
* Use is registered and is for non-commercial gain.

If you would like to use the instrument for these purposes, please return a signed copy of this agreement, giving details of your study. We will contact you indicating our agreement for you to use the ICECAP-SCM instrument in the named study.

If your needs go beyond those outlined here – for example, if you wish to use the ICECAP-SCM instrument in a country outside the UK and thus are unsure about the applicability of wording in your country, please contact the EconEndLife research team to explore the possibility of conducting further developmental research collaboratively.

**Please complete all sections below:**

|  |  |
| --- | --- |
| **Name of Principal Investigator (PI):** |  |
| **PI’s Institution:** |  |
| **Contact name:** |  |
| **Contact email address:** |  |
| **Postal address:**  (Including country) |  |

|  |  |
| --- | --- |
| **Study name:** |  |
| **Funding source:** |  |
| **Expected start date (month & year):** |  |
| **Expected end date (month & year):** |  |

|  |  |
| --- | --- |
| **Please summarise:**   * **the main study objectives,** * **methodologies (including how ICECAP questionnaires will be administered),** * **patient/participant characteristics,** * **any interventions/comparators:** |  |
| **Please list all countries within which data collection will occur:** |  |

|  |  |  |
| --- | --- | --- |
| **Age demographic of the participant (patient) population** | **< 18 years** |  |
| **18 to 64 years** |  |
| **> 65 years** |  |

|  |  |
| --- | --- |
| **Please outline any methodological steps that you will take to explore feasibility and/or psychometric properties of the measure:** |  |

This section **must** be completed if data collection will take place in non-English language contexts (otherwise please proceed to the next page):

|  |  |  |
| --- | --- | --- |
| **Will you be using an existing translation of ICECAP-SCM?** | NO |  |
| YES  (please specify) |  |
| **Do you wish to translate ICECAP-SCM into a new language?** | NO |  |
| YES (Please specify) |  |
| **I/we have read the document “Using the ICECAP capability measures in non UK/English-speaking contexts”** | Please tick to confirm: |  |
| **I/we will send a copy of the back-translation to** [**p.kinghorn@bham.ac.uk**](mailto:p.kinghorn@bham.ac.uk) **and** [**katie.breheny@bristol.ac.uk**](mailto:katie.breheny@bristol.ac.uk) **for approval, prior to commencing data collection. Approval to use the new translation will not be given until a full-back translation of the final translated version of the measure is received.** | Please tick to confirm: |  |

**Continued overleaf…**

We would like to use the ICECAP-SCM instrument for the purposes outlined in the agreement above and agree to the conditions of use as specified. Completion of this form constitutes agreement to abide by the terms of use outlined in the Agreement for the use of the ICECAP-SCM Instrument.

The contents of this form will be visible to members of the ICECAP research team: a collaboration between the University of Bristol & University of Birmingham. Study details (including the contact name for the study) will be stored in a database on a secure University network. We may contact those who have submitted User Agreement Forms to invite you to attend an ICECAP User Workshops, or to facilitate the sharing of translations of the ICECAP measures.

I am a non-commercial user and use of the instrument will be for academic purposes (please tick) 🗸

|  |  |
| --- | --- |
| **Name of PI or designated contact:** |  |
| **Signature:** |  |
| **Date:** |  |

Submit completed forms to: [katie.breheny@bristol.ac.uk](mailto:katie.breheny@bristol.ac.uk)