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Based on draft by the Pharmaceutical Care Research Group, Petersplatz 14, Postfach 2148, 4001 Basel, Switzerland

Preferred Methods for Translation of the ABC Taxonomy for Medication Adherence

This document describes the methods adopted by the ESPACOMP for the translation of the ABC adherence taxonomy, originally described in English by Vrijens et al. [1], into other languages. A standardised terminology is crucial to enable a reproducible process in different languages to facilitate valid comparisons between studies, and dialogue among scientists. The methods are adapted from Haag & Lehmann et al. [2] who translated the ABC adherence taxonomy into French (Lehmann) and German (Haag). The methods described are recommendations, not instructions; however deviations from these recommendations need to be justified in full.

BACKGROUND

Medication adherence terminology has been an area of confusion and misunderstanding due to use of different terminology and definitions. Terms such as adherence, compliance, persistence and concordance are often used interchangeably [1]. The ABC (Ascertaining Barriers to Compliance) project funded by the European Commission proposed a new medication adherence terminology, which was published in English, adopted by ESPACOMP, and has now been widely adopted internationally.

The ABC adherence taxonomy [1] proposes seven terms and their definitions: 1) medication adherence, 2) initiation, 3) implementation, 4) persistence, 5) discontinuation, 6) management of adherence and 7) adherence-related sciences (Table 1).

English taxonomy	English definition
Adherence to medication	The process by which patients take their medications as prescribed.
Initiation	The process starts with the initiation of the treatment, when the patient takes the first dose of a prescribed medication.
Implementation	The process continues with the implementation of the dosing regimen, defined as the extent to which a patient's actual dosing corresponds to the prescribed dosing regimen, from initiation until the last dose is taken.
Discontinuation	Discontinuation marks the end of therapy, when the next dose to be taken is omitted and no more doses are taken thereafter.
Persistence	Persistence is the length of time between initiation and the last dose, which immediately precedes discontinuation.
Management of adherence	It is the process of monitoring and supporting patients' adherence to medications by health care systems, providers, patient, and their social networks. The objective of management of adherence is to achieve the best

use by patients, of appropriately prescribed medicines, in order to maximise the potential for benefit and minimise the risk of harm.

Adherence-related sciences	This element includes the disciplines that seek understanding of the causes or consequences of differences between the prescribed (i.e. intended) and actual exposures to medicines. The complexity in this field, as well as its richness, results from the fact that it operates across the boundaries between many disciplines, including but not limited to medicine, pharmacy, nursing, behavioural science, sociology, pharmacometrics, biostatistics and health economics.
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Table 1: List of the seven adherence terms and their corresponding definitions in English [1, 2].

Need for ABC taxonomy in different languages

To facilitate international research into medication adherence, transferability between study results, and dialogue among adherence researchers, there is a need for the original English language ABC taxonomy to be translated to other languages. Haag & Lehmann et al. [2] simultaneously translated the taxonomy in French and German, without changing the original meaning with the aim to develop an adherence terminology standard for French- and German-speaking researchers. This preferred methods for translation of the ABC taxonomy for medication adherence applies to instances where translations do not exist, or are deemed unsuitable (or not adequately derived).

METHODS

The Delphi method has been chosen as the preferred methodology to achieve consensus in translated terminology. The methodology described below aims to provide a working practice that will allow for a standardised method of translation of the ABC adherence taxonomy into other languages and result in a harmonised terminology. The French and/or German process is given as an example.

The key steps include: (1) literature search to identify key papers in the target language and to identify key people in the field in the target language; (2) forward translation of terms and definitions; (3) selection of the panellists; (4) Delphi survey (design and administration); (5) supplementary questions; (6) evaluating Delphi rounds. These are each described, in turn, below.

For each language, a protocol should be developed, based on this document, which will be published on the ESPSCOMP website in advance of conducting the research.

1. Literature search

The objectives of the literature search are principally (a) to identify key papers in the target language; and (b) to identify key people in the field in the target language.

A pragmatic approach is acceptable. A search of at least one database (e.g. PubMed) should be undertaken, depending on available resources, to identify medication adherence terms and their corresponding definitions in the target language. Access to language-specific databases should be considered. Searches should use MeSH terms relevant to the ABC taxonomy (e.g. Patient Compliance, Medication Adherence), and supplemented by keyword [All fields] search of known terms in the relevant language, as applicable. Articles published in language-specific journals should be considered. The use of Boolean operators AND, OR and NOT may be necessary to improve the specificity of the search, and syntax varied adapted to different databases. The inclusion and exclusion criteria, methods of data extraction and synthesis should be described in advance. The PRISMA guideline may be consulted for best practice procedures for the reporting of literature reviews.

Example data for extraction include: database, title, authorship, corresponding author, e-mail address of the corresponding author, title and study area of the corresponding author, language, year of publication, location (country of origin of the study), method, terms used, and definition of terms. Identification of e-mail addresses of other authors may be appropriate.

A systematic review is not required; however if resources are available, clearly a systematic review would be the preferred approach. In which case, authors should register their review in PROSPERO, and follow standard guidelines for the conduct and reporting of their review.

2. Forward translation of terms and definitions

A single forward translation by a professional linguist is considered acceptable, with no requirement for backward translation. The reason being that experts involved in the Delphi exercise will make implicit forward/backward translations in expressing their views and opinions.

The same language can contain differences – both in terms of words, and in written form across countries. For example, German in Germany, Switzerland and Austria; French in France, Canada, Switzerland and Belgium. Professional linguists with relevant experience should be therefore consulted, via local institutes or organisations. Their suggestions should be considered in the Delphi survey. Country-specific adaptations is allowable, in view of facilitating the implementation of the terms and definitions into practice in the target language.

3. Selection of the panellists

The panellists should be fluent in the language of interest and in English, dedicated to research or education in medication adherence, and/or be practitioners in order to include vocabulary used in practice. These may be recruited via the ESPACOMP mailing list, personal contacts, and names identified in stage 1. Their consent to participate should be provided, although researchers should ensure adherence to ethical requirements and data protection legislations. They should be invited to participate by e-mail and asked to propose further experts. In case a country(ies) is(are) likely to have very few members at ESPACOMP, another local network or scientific experts/groups working in medication adherence research may be approached. Professional organizations not involved in adherence research should not be approached.

When the same official language is spoken in several countries, some differences in the spoken country-specific language can lead to different meanings or interpretation of terms and definitions. This requires due consideration, both in terms of sampling, and for the potential for variation between agreed versions of translated texts (and therefore requirement for more than one version). Specifically in relation to sampling, it may be necessary to review the number of panellists from each country responding to round one, in order to adjust the sampling / recruitment of experts accordingly.

4. Delphi survey – design and administration

The Delphi survey technique is a method to find consensus in situations where there is contradictory or insufficient information [3]. The opinion of experts is obtained through a series of structured questionnaires (commonly referred to as “rounds”). The responses from each round are fed back in summarised form to panellists, as a part of the process. This enables experts to identify items they may have missed or dismissed and provides opportunity for experts to change their opinions [3]. By using successive rounds, the current status of the group’s collective opinion is fed back, informing the group members of the current status of their collective opinion. Delphi is an iterative multistage process that is continued until consensus is obtained.

a) Piloting

Before starting the first round, the entire survey including the supplementary questions should be pilot tested for clarification and comprehensibility with 6-9 junior researchers or researchers for whom adherence was not their field of expertise. The reason being that participants in the comprehensibility test should not be part of the Delphi rounds and panellists should not be influenced by information from preliminary work.

b) Design

The Delphi process does not provide clear guidelines regarding panel size and the number of iterative rounds. Therefore the methods for determining the number of experts and rounds should be made explicit, and adequate to generate enough answers and reach consensus. This may depend on the number of experts available in a given language context, and the extent to which consensus is reached following each round. Perfect agreement among experts is not required for consensus. Although no clear rules exist concerning the cut-off, these must be defined in advance and set according to the needs of the performed task.

c) Online platform

Google forms is one method which may be used to create online rounds. Other platforms may be used – some offer the advantage of maintaining anonymity and respondent confidentiality. Dissemination of the rounds can be

performed through e-mails containing the active link to the survey without password. Up to two reminders may be sent at the frequency of 2-3 weeks. Usually, all participants remain anonymous. However, the identity of the participants may be known by the people who perform the research, mostly via the participants' e-mail address that frequently contains their first and last name (but this will depend on the platform used). The identity of the participants must not be revealed to the panellists, even after completion of the study.

d) Survey presentation

The survey should present the English term to be translated at the top of the form together with the definitions. The set of synonyms as identified through literature search should be presented underneath, together with a free text field to allow the expert to propose their own term (Fig. 1 upper part). The definition as translated by native experts should also be given for approval or disapproval, and a free text field to allow the expert to propose their own definition (Fig. 1 bottom part). All fields were mandatory (red star) except the free text field.

5. Supplementary questions

Specific questions should be asked to enable demographic characteristics of the experts and placed at the beginning of the survey. These are:

- 1) "What is your e-mail address?" [or some indication, depending on the platform used, to include the participant in the next round]
- 2) "What is your nationality?" [Response options should be restricted to the countries where the target language is spoken, see Fig. 2]
- 3) "What is your profession/occupation?" [Response options included biologist, economist/health management, nurse, pharmacist, physician, psychologist, other....]

6. Evaluating Delphi rounds

In the case of Haag & Lehmann et al. [2], the consensus on the translated items/definitions was defined in advance by acceptance rate as follows: moderate consensus (50-75%), consensus (>75-95%), and strong consensus (>95%).

After the first round, the selected and newly proposed terms were ranked by descending order of acceptance rate [%]. Definitions were collated and similar expressions were captured in a single encompassing statement, with the original words enclosed as variants (Fig. 3). All terms and definitions that were selected with an acceptance rate of $\geq 10\%$ and all newly proposed terms and definitions were included in the second round.

Round two was disseminated to the panellists who completed round one. The acceptance rate (%) of the first round was indicated after each item and visible for panellists. Panellists were asked to select one preferred term or definition (single choice). The analysis of round two discarded items with an acceptance rate $< 10\%$ from the third round. Items reaching a consensus $> 95\%$ (strong) were considered as accepted and discarded from the subsequent round.

Round three was sent to the panellists who completed round two. The procedure was similar to round two and the aim was to reach at least moderate consensus among panellists on each term and definition.

Further details of the results and findings of the French and German ABC translations should be consulted, and are available in Haag & Lehmann et al. [2]

7. Figures

Figure 1: An example of a Google survey form round one in the French and German language for the first term “medication adherence” and its definition.

The image shows two side-by-side screenshots of a Google survey form. The left screenshot is in French, and the right is in German. Both screens show a question about the translation of the term 'adherence to medication' and a definition of the term. The French version asks for the most appropriate translation and whether the user agrees with the definition. The German version asks for a translation suggestion, whether it is appropriate, and whether the user agrees with the definition. The German version also includes a section for 'Meine Antwort' (My answer) and a section for 'Was schlagen Sie vor?' (What do you suggest?) with a text input field.

French version (left):

Traduire en français : adherence to medication (ou medication adherence) *

The process by which patients take their medications as prescribed. (Merci de cocher le terme qui vous semble le plus approprié en Français)

- Adhésion médicamenteuse
- Adhérence médicamenteuse
- Compliance aux médicamentsaption 3
- Observance médicamenteuse
- Adhésion thérapeutique
- Other...

Définition : Ce terme correspond au processus selon lequel les patients prennent les traitements comme prescrit

Etes vous d'accord avec cette traduction de la définition?

- Oui
- Non : que proposeriez vous?
- Other...

German version (right):

1. Adherence to medication (medication adherence)

Zu übersetzen: ADHERENCE TO MEDICATION (medication adherence) - The process by which patients take their medications as prescribed. *

Vorschläge für deutsche Begriffe:

- Adhärenz
- Einnahmetreue
- Einnahmeverlässlichkeit
- Medikamentenadhärenz
- Patientenadhärenz
- Therapieadhärenz
- Therapietreue
- Kein Vorschlag ist passend

Was schlagen Sie vor?

Meine Antwort

Übersetzungsvorschlag: Der Prozess, bei welchem Patienten ihre Medikamente wie verordnet anwenden. *

Sind Sie mit dieser Übersetzung der Definition einverstanden?

- Ja
- Nein

Was schlagen Sie vor?

Der Prozess, in welchem Patienten ihre Medikamente wie verordnet anwenden.

Figure 2: An example of a Google survey form in round one in the French (left) and German (right) language asking about an expert’s nationality with corresponding response options. Note that country-specific adaptations were needed.

The image shows two side-by-side screenshots of a Google survey form. The left screenshot is in French, and the right is in German. Both screens ask for the respondent's nationality. The French version lists Belgium, Germany, Lichtenstein, Luxembourg, Österreich, Schweiz, and Sonstiges. The German version lists Belge, Canadienne, Française, Suisse, and Other....

French version (left):

Was ist Ihre Nationalität? *

- Belgien
- Deutschland
- Lichtenstein
- Luxemburg
- Österreich
- Schweiz
- Sonstiges: _____

German version (right):

De quelle nationalité êtes vous ?

- Belge
- Canadienne
- Française
- Suisse
- Other...

Figure 3: An example of survey form round two in the German language with original words enclosed as variants.

Der Prozess beginnt mit der Initiierung^o der Therapie, <wenn> [1] der Patient die erste Dosis <seiner> [2] <verordneten> [3] <Medikation> [4] <anwendet> [5].

<Ausdruck> [1] ändern:

Auswählen ▾

- sobald (2.4%)
- zum Zeitpunkt zu dem (4.8%)

<Ausdruck> [2] ändern:

Auswählen ▾

- einer (4.8%)

<Ausdruck> [3] ändern:

Auswählen ▾

- verordneten bzw empfohlenen (2.4%)
- untersuchten (2.4%)

<Ausdruck> [4] ändern:

Auswählen ▾

- Medikament (7.3%)
- Arzneimittel (2.4%)

<Ausdruck> [5] ändern:

Auswählen ▾

- einnimmt (4.8%)

REPORTING

In addition to the publication of a systematic review protocol, where applicable (see above):

1. Agreed protocols will be published on the ESPACOMP website at the earliest opportunity (i.e. upon initiation of the translation process) to avoid any duplication of effort in the same language
2. When the process is finalized and approved by the ESPACOMP executive committee, the official translation will be published on the ESPACOMP website. Approval will be on the basis of adhering to the protocol.
3. Authors are encouraged to publish and publicise the final translated taxonomy in peer reviewed and other relevant publications.

REFERENCES

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