An international road map to improve pain assessment in people with impaired cognition: the development of PAIn In Cognitive impairment (PAIC) Toolkit

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Introduction
Pain is common in people with dementia, yet treatment is often ineffective and identification is challenging. A number of pain assessment tools exist, utilizing observation of pain-related behaviours and facial expressions. These often lack sufficient psychometric evaluation, assessment of reliability, face and construct validity, responsiveness and usability and are not internationally implemented. The 15-country EU-COST initiative “Pain in impaired cognition, especially dementia” aims to combine the expertise of clinicians and researchers to address this important issue by identifying existing pain assessment tools for dementia, and developing an evidence-based tool for evaluation and use in research and practice in a wide range of settings. This paper reports the initial phase of this collaboration.

Results
12 eligible assessment tools were identified, and pain items categorised according to behaviour, facial expression and vocalisation according to the AGS guidelines (Domains 1–3). This has been refined to create the new international toolkit for evaluation. A decision was made to create a toolkit to support the core assessment tool to provide specific resources for the assessment of overlapping symptoms in dementia such as behavioural and psychological symptoms.

Conclusions
The PAIC toolkit represents an innovative approach to addressing assessment of pain in dementia on an international scale, based on robust methodological principles. It will now be taken forward for evaluation according to the EU-COST protocol.

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Methods
All existing observational tools were identified and elements categorized according to the American Geriatric Society (AGS) guidelines. Selection and refinement of items for the new international toolkit was achieved through scrutiny of the evidence and consensus of expert opinion. Key considerations informing this consensus process were the need to accommodate the range in duration, localization and severities of pain, in addition to the types and underlying causes of pain to be detected by the toolkit.

Workflow for creation toolkit:
1- Identification of pain assessment tools: systematic review
2- Categorisation and refinement of assessment items: expert consensus
3- Selection of items for inclusion in the Pain in Impaired Cognition (PAIC) toolkit: evidence and expert consensus
4- Creation of preliminary draft of new international toolkit for clinical testing

Theme
Required element of the toolkit

Process
- makes use of the best items from existing instruments, developing a meta-tool with a pool of useful items
- to provide a toolkit, not a single tool, out of which instruments can be created for different contexts of application (type of cognitive impairment, setting etc.)
- provide potential to create specific tools (or additional scales) for specific pain associated conditions (such as oral-facial pain, neuropathic pain)
- includes a guideline-and web-based, multilingual application
- instruments for use in both clinical practice and research
- creation and validation of instruments follows a predefined process, following the COSMIN criteria.

Quality
- practicable and feasible in different settings (home care, long term care, palliative care and acute hospital care) and different countries (with first the focus on the Western world)
- sound psychometric properties, i.e. a reliable and valid instrument
- sensitive to change, i.e. identify new pain and detect changes after successful intervention, for instance with pain medication
- feasible and valid in several important groups of people with cognitive impairment, such as dementias, coma/pvs and people with a mental handicap or learning disability.

The new international PAIC Toolkit for further evaluation