THE OARSI STANDARDISED DEFINITION OF OSTEOARTHRITIS: A LAY VERSION

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Abstract:

Purpose: A standard definition has been produced by OARSI to achieve consensus for defining and classifying for osteoarthritis (OA). The aim is to "facilitate communication about the disease among industry and non-industry researchers, regulatory agencies, funding agencies, third party payers, and patients".

A Research Users Group (RUG) of lay members was asked for views on the OARSI definition and to propose a lay version of the definition if it was needed.

Methods: A meeting of the Research User Group (RUG) was convened. All 13 RUG members (8 female, 5 male) were aged 45 years and over and had a musculoskeletal condition with nine having a diagnosis of OA. RUG members reviewed the definition, either individually or in pairs, and were asked write down the meaning of the definition in their own words. RUG members then shared their own lay definitions. Following the meeting, researchers and RUG members worked in partnership to co-produce a single lay definition of OA.

Results: Initial reactions to OARSI definition were mostly negative. While there was agreement that the definition seemed to be aimed at "medics and biomedical researchers", it was not understandable to the general public ("it's too detailed for a lay audience"; "to a lay person you need a dictionary to read it"). The group felt that the definition was aimed at "top biology scientists and medics" and questioned the usefulness of it to a lay audience. The RUG agreed that a simple lay version of the definition would be useful that included additional concepts important to patients, such as symptoms and impact.

The RUG's suggestions for an alternative version fell into two themes: 1) a literal translation into lay language, and 2) a simplified lay version. There was general consensus that a literal translation would offer greater consistency with the OARSI version and allow inclusion of all concepts agreed as important by OARSI. Extracts of the proposed lay definition of OA are shown in Table 1.

Conclusions: The current OARSI definition for defining and classifying OA should help conversations between researchers, health care professionals and patients. However the current definition requires translation into lay language, therefore a Research User Group has developed a lay definition of OA which is consistent with the OARSI definition. Whether this lay version could be used for public communication and to improve awareness of OA for all stakeholders needs to be tested.

Table 1. Lay definition of osteoarthritis

'Osteoarthritis is a disorder that can affect any moveable joint of the body, for example knees, hips and shoulders. It can show itself as a breakdown of tissues and abnormal changes to cell structures of joints which can be initiated by injury.' AND 'Osteoarthritis first shows itself as a change to the biological processes within a joint, followed by abnormal changes to the joint itself (such as the breakdown of cartilage, bone reshaping, bony lumps, joint inflammation, loss of joint function). This can result in pain, stiffness and loss of movement.'

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