

PUBLIC PRIORITY SETTING FOR RESEARCH IN OSTEOPOROSIS

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Background

Involving members of the public, patients and clinicians in identifying topics for research ensures relevant, impactful research questions and is expected by research funders. This study reports on the first of a two-stage national priority setting exercise to identify the public's views on areas for research in osteoporosis, and osteoporosis related fractures.

Methods

Focus groups were undertaken with members of the National Osteoporosis Society (NOS) (Staffordshire) and a research cohort (Oxford) of individuals who had experienced fracture. A topic guide was co-designed with the Research User Group (RUG) at Keele and Oxford. Each group was audio recorded, and professionally transcribed. Thematic analysis using constant comparison identified research themes and specific research questions. Keele University's Ethics Committee approved the study.

Results

Four focus groups of between four and eight participants were conducted. Of the 23 participants 18 had osteoporosis, 18 were female, 5 male and 14 had osteoporosis related fragility fractures. Three main research themes emerged in relation to osteoporosis 1) living with osteoporosis 2) services for osteoporosis and 3) optimal treatment of fractures in osteoporosis.

Participants described both an illness and treatment burden associated with the condition, manifest by fear of the future (and fracture), feelings of anger, hopelessness and frustration. They highlighted the impact on work, relationships and activities of daily living. Participants highlighted a lack of a systematic approach to long term management of the condition in primary care. Research questions concerned prevention, screening and treatments. Participants demonstrated an interest in both basic science and genetic research. Examples of specific research questions were: "Can you recover bone density with the right amount of activity and intake of calcium?", "Maybe I could have taken something beforehand to prevent this happening"? "Is there any link with a genetic or family history and is there a solution to that"? Why is it that you don't have a bone density check, say when you are 60 or something, as a kind of routine?" "How do you know you are susceptible to a fracture?" Those participants who had experienced a fracture also identified areas relating to the effects of osteoporosis on fracture healing and the impact of prolonged immobilisation following fracture. The findings have been discussed with the Keele

RUG in order to co-design wording of new questions about research priorities for osteoporosis for a national e-survey.

Conclusion

This study has identified research areas of importance to members of the public including prevention, monitoring of established disease and managing impact of the condition on day to day life. These topics will be further investigated in a national survey (December 2015) of NOS members. The overall results will feed into the NOS research strategy (2016-20).

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