

Arthritis Research UK Primary Care Centre

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Public priorities for joint pain: lessons learned

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Overview of presentation

1. Background & introduction
2. Survey of research priorities
 - design,
 - analysis
 - results
3. From consultation to action
4. Lessons learned

Publication in press

Public priorities for joint pain research: results from a general population survey.

Rheumatology (forthcoming)

- Strauss VY, Carter, P, Ong BN, Bedson J, Jordan KP , Jinks C, in collaboration with the Arthritis Research UK Research Users' Group.

Original study aims

1. Investigate the general public's view on priorities for joint pain research
2. Explore differences in priorities by patient characteristics
3. Work collaboratively with PPI (patient and public involvement) groups to identify a research question based upon priorities

Cohort study

- North Staffordshire Osteoarthritis Project (NorStOP)
- General population based cohort survey of joint pain in all adults registered at 3 general practices aged 50 + at baseline.
- In 2008, a new research priorities question was embedded into the survey & mailed to participants who reported joint pain

Designing the question

The new question was developed with Research Users' Group (RUG) at Keele



Tallon et al 2000

Topic	Research Evidence	Patient Preferences
Surgery	26%	36%
Education/Advice	3%	21%
Oral drugs/Tablets	50%	4%

(Tallon D, Chard J and Dieppe P. "Relation between agendas of the research community and the research consumer". Lancet 2000; 355:2037-2040)

New question: Part one

Topic	1 st most important	2 nd most important	3 rd most important
Injections in the joint	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Reduced swelling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tablets	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Diet / weight loss	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Complementary therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Keeping active	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Aids and adaptations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Joint replacement	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Counselling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Removal of fluid/debris	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Improved mobility	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Education and advice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physical therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(Please check that you have only crossed 3 boxes)

Open question

Other (Please write below topics not listed above that you think should be a priority for joint pain research)

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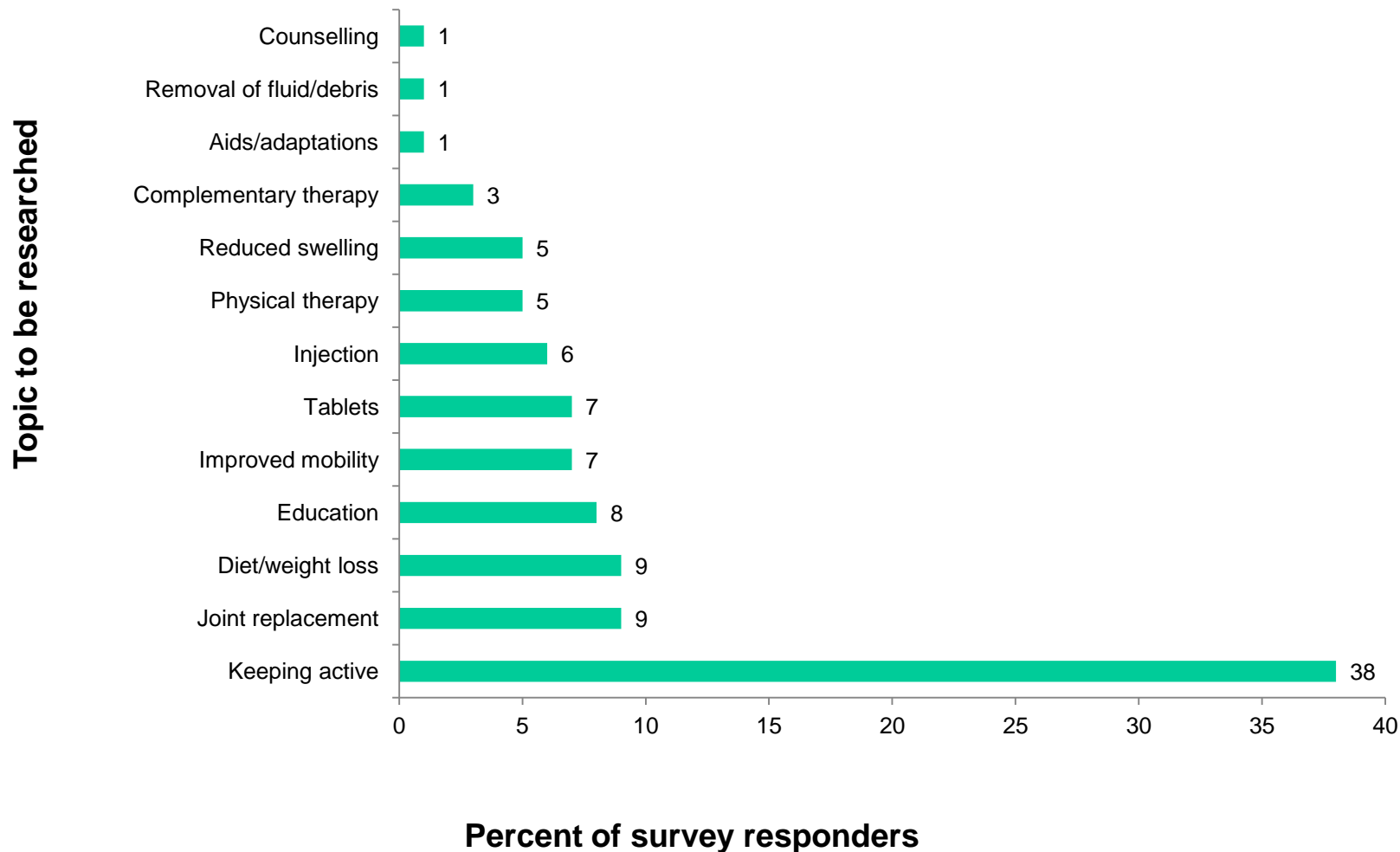
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Results of closed question

- 1756 people responded to the joint pain survey (88%)
- Of these, 1396 (79%) gave a top priority for research and 1356 (77%) gave three priorities for research

First priority for research (n=1396)



3 Priorities for research (n=1356)

- 62% preferred lifestyle/self-management topics
- 38% preferred medical intervention topics
- Respondents who selected medical intervention topics were more likely to
 - be older than 65
 - have foot problems
 - have hip problems

382 free text responses

- Average number of words = 6
- 4 people wrote over 100 words
- Longest response = 209 words
- Some people indicated “no preference”, “don’t know” or “not qualified to say”.

Free text results

- 23 people indicated no preference, nothing to add or don't know.
- 117 responses mapped onto tick box categories
- 5 people indicated not qualified to say

5 responses were questions

1. “The causes? Does certain instance of air conditioning aggravate joint pain?”
2. “Perhaps injections to cushion the foot pads could be researched?”
3. “Do blood pressure tablets contribute to joint pain?”
4. “More research should be done on what effect diabetes has on joint pain”
5. “Would the Alexander technique on the NHS prevent joint problems for most people?”

Narrative responses eg 1

- “please note: I have had an operation on the 28th dec 2007 on my right big toe, a piece of cartilage take from my r knee and harvested into my big toe, op was a success but r knee is still sore because of trapped nerve.”

Narrative responses eg 2

All the doctors say poor circulation and give me paracetamol. The pain is so bad I go back to bed and the pain makes me tired. I have just stopped smoking, this is the 6th day without one.

Lay knowledge

- Thailand 3 years ago I had a Thai massage which rid me of long standing neck pain still free of it best treatment I ever had
- Heat - hot baths hot water bottle. Vitamin - E without gelatine. Natural remedy - cabbage leaves made as a poltice at bed time only. This is definitely a cure

Unable to contribute

- I found this difficult to answer as I don't understand your definition of research in this context
- I don't really know enough about these things to comment on them

“Scientific research”

- “Most of my life I have been a despatch manager. Would you like to know how to get a 40ft container to America instead? Sorry.”
- “I would not presume to offer an opinion on a field of scientific research of which I have no expert knowledge.”

Medical interpretation :

- Aetiology
- Diagnosis
- Pain management



From consultation to action

- Risk of “consultation fatigue” or “dialogue of the deaf”
- Facilitation skills needed
- Currently collaborating with research users
 - PRIMER Manchester University
 - RUG Keele University

Keele RUG workshop

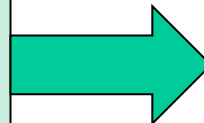
- Specific exercises (swimming, gym, Tai chi)
- Keeping active in daily life : walking, dog walking, cleaning, doing chores, keeping occupied, gardening, working, going up and down stairs
- Three dimensions (bio-psycho-social)

Discussion at RUG workshop

Walking is one of the best ways of keeping active:

- Not age specific
- Cheap
- Get fresh air / look at nature
- Most important is the social side of walking.

Walking in groups is more enjoyable than walking alone



Walking study currently being developed by researchers in our centre

Options for collaboration

Link with existing studies

- Walking trial
- Pain in older people project

Develop new study

- Back to the evidence base

Towards an action plan

- 8 months to develop a funding application
- Scoping exercise for further systematic review
- Link to interests of Research Users, ARUK Centre strategy, capacity of project team.

Lessons learned (a)

1. Voice & choice – combining methods for dialogue & decision making
2. Public or public(s)
3. Utilitarian logic v. equity considerations
4. Top-down, bottom-up, “mesogenic”

Lessons learned (b)

1. Topics or questions?
2. Social or clinical view of health?
3. From consultation to action – planning cycles & decision making
4. Practical issues - time & cost

From users and choosers to makers and shapers

: repositioning participation in social policy
Cornwall and Gaventa (2001)

Institute of Development Studies

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