



ARTHRITIS CARE

*Empowering  
people with arthritis.*

# OA nation

the most comprehensive  
UK report of people  
with osteoarthritis

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# Foreword

Neil Betteridge, Director of Public Affairs, Arthritis Care

## Introduction

Arthritis Care is proud to bring you this important new report. It highlights not only the scale of the problem involved with living with osteoarthritis (OA) in the UK, but many of the things we believe to be part of the solution.

There is no cure for OA.

But there are many ways in which the quality of life of those living with OA can be improved. Some require changes in approach. Change on the part of healthcare professionals, politicians, the general public and especially among the most important group of all – people who live with the pain and associated problems caused by OA.

## Rationale for the Report

One of the reasons we carried out the research was that, despite the enormous numbers affected, OA is so often overlooked.

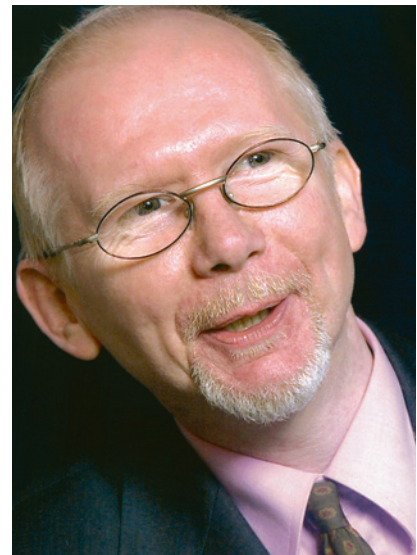
The UK Government's own figures on claimants of disability benefits already show that arthritis is the biggest single cause of physical disability<sup>1</sup>. Yet, where is the political will to address the needs of such large numbers of people? One in five of the population has arthritis<sup>2</sup> – so why is it a largely invisible condition in the mass media?

Arthritis Care commissioned an omnibus survey in 2001<sup>3</sup> to establish the scale of the incidence of arthritis. It revealed that over nine million people are living with the effects of arthritis<sup>2</sup>.

The survey also looked at the impact of arthritis on day-to-day living and results showed that 72 per cent of people with arthritis experienced some adverse effect on their day-to-day activities<sup>4</sup>.

OA is the most prevalent form of arthritis. We have, therefore, commissioned an in-depth study of 1,762 people in the UK<sup>5</sup> who had contacted Arthritis Care for information, to establish the full impact of living with OA.

So why *OA Nation* for our title? Because of the sheer size and scope of the OA problem. Arthritis Care estimates that there are 8.5 million people living with OA in the UK – a population larger than some European countries. With an ageing population, this number is set to increase.



...there is  
no cure for  
OA...

**OA**  
**nation**

...81 per cent  
experience  
constant  
pain or are  
limited in  
their scope  
to perform  
everyday  
tasks<sup>6</sup>...

## Key Findings

One of the most striking of the findings to emerge from our in-depth research, was that a staggering 81 per cent of the sample said they experience constant pain or are limited in their scope to perform everyday tasks<sup>6</sup>.

This could mean that a frightening number of people in the UK are significantly affected by life with OA.

In addition, our in-depth research also shows how, at every stage of the arthritis management pathway, the patient's access to relief appears to be lacking:

- Patient awareness about what can be done to help them is low – 34 per cent of people with OA never visit a doctor<sup>7</sup> and almost 50 per cent would need to have frequently unbearable pain levels before presenting to a doctor<sup>8</sup>.
- Diagnosis of OA is also slow, with 39 per cent of people being diagnosed between 3-11 + visits to their doctor<sup>9</sup>.
- Of those currently taking prescribed medication, a quarter of patients are also buying OTC treatment<sup>10</sup> which could indicate that treatments may not always be effective.

The research also offers some fascinating insights into the attitudes of people towards their own arthritis. The image of OA as something to be borne in silence and without complaint is doing terrible damage to many in society. These are people who might otherwise benefit in all sorts of ways from a prompt diagnosis and appropriate support before joints become too badly affected or before depression kicks in to accompany the physical pain.

Diagnosis is slow. Clearly, we badly need more health professionals themselves to take OA more seriously and develop a 'can-do' approach to the disease. People with a long-term condition like arthritis need not only the most appropriate treatment, but also the skills necessary to self-manage. They will be 'patients' for just a tiny part of their lives, but will need to cope every hour of every day.

## Call to Action

As the largest organisation in the UK representing people with arthritis, we at Arthritis Care passionately believe that this neglect must and will end. Along with delivering high quality services such as information and training, we are also a dynamic campaigning organisation fighting for the rights of all people with arthritis to enjoy full social inclusion.

The voice of the *OA Nation* is still all too often unheard or unheeded. The *OA Nation* report provides a rich seam of evidence to illustrate just why these issues need overdue attention.

In light of these findings Arthritis Care is issuing a twofold call to action:

1. to all people living with OA
2. to policymakers.

We are supporting both of these groups through targeted work which we believe will finally rid arthritis of its 'mustn't grumble' image.

To people with OA we most of all say 'don't put up with it in silence'.

- Speak to your GP about it and explore your options – some of those options might not even have existed at the time you were diagnosed.
- If you have not yet seen your doctor about stiff and painful joints then you should really consider doing so. You won't be wasting the GP's time – and Arthritis Care can help you get the most out of your consultation if you are not sure where to start.
- If you are prescribed treatments then take them as advised; but explore, too, other ways of learning what you can do – the right diet and exercise routines might really help.
- Above all else, manage your arthritis. Don't let it manage you.

To policymakers we simply ask that people with arthritis get a fair deal.

- We must be seen as the sizeable group with real needs, rather than the 'soft touch' group which never asks for attention.

...don't put  
up with it in  
silence...

The logo for 'OA Nation' features the letters 'OA' in a large, bold, pink font. Below 'OA', the word 'nation' is written in a smaller, bold, black font. The 'n' in 'nation' is partially obscured by the bottom of the 'A' in 'OA'.

...people  
with arthritis  
must get a  
fair deal...

In a devolved UK, this approach needs to have several dimensions.

Locally, Arthritis Care will be promoting the involvement of service users in all aspects of their health and social care, whilst also developing a campaigners' network to empower people to access the right services and treatments.

At the four nations level, we will continue to talk to the political assemblies making the decisions that affect people's lives.

At the UK level we are working in partnership with other organisations and health professionals to develop user-focused standards of care on all forms of arthritis. We hope this will lead to a blueprint for a high quality health service for people with OA.

## The Future

People with OA can lead independent and fulfilling lives. But, to do so, things have to change. *OA Nation* paints a picture that, at times, is saddening and frustrating. Yet, as just one person living within this nation, I also welcome it because it sets out exactly where the biggest differences can be made.

Above all, it represents people with OA finally finding their voice. It's a compelling story and one which will not go away.



## References

1. *Disability Living Allowance, Attendance Allowance and Invalid Care Allowance – Disability Care and Mobility Quarterly Statistical Enquiry* Department for Work and Pensions 2002.
2. *Arthritis Care 1 in 5 Report 2002*, p3.
3. *Crossbow/Arthritis Care Capibus Survey, 2001*.
4. *Crossbow/Arthritis Care Capibus Survey 2001*, p28 Q1b06.
5. *TNS/Arthritis Care Survey 2003*, p1,044 Qa.
6. *TNS/Arthritis Care Survey 2003*, p693 Q16.
7. *TNS/Arthritis Care Survey 2003*, p77 Q5 & p78 Q5.
8. *TNS/Arthritis Care Survey 2003*, p706-707 Q17.
9. *TNS/Arthritis Care Survey 2003*, p63-64 Q4.
10. *TNS/Arthritis Care Survey 2003*, p222-236 Q11.

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# Arthritis Care's call to action

## What we want policy makers to do

Arthritis Care campaigns for a set of minimum standards of care for people with OA that will apply regardless of address. But because health is devolved, these standards will have to be adapted by individual national governments. In the meantime, the UK needs to acknowledge millions of people who have OA, the fact that often they get a raw deal and to accord the issue greater priority.

To ensure best practice, OA needs to be a health priority throughout the UK.

**Locally** – real change for people living with OA, so that they get access to the most appropriate treatment and service for them. They should also have a say in the development and running of local services.

**Across the UK** – recognition that Scotland, Wales and Northern Ireland have health devolved to them, understandably so, to ensure the treatments and services are appropriate to each nation. For example, the Welsh Assembly, working closely with Arthritis Care, is developing a national strategy for arthritis in Wales.

**UK-Wide** – certain standards of care need to be met for people with OA, wherever they are. There needs to be UK-wide standards set. This could build upon work that Arthritis Care is involved in to develop criteria for how musculoskeletal conditions are managed clinically, including OA and rheumatoid arthritis.

...there  
needs to  
be UK-wide  
standards  
of care...



'The invisibility of the pain of osteoarthritis is most frustrating for me. Nothing is more annoying than when someone says; "But you look so well".'

...manage  
your OA.  
Don't let it  
manage you...

## What we want people with OA to do

- Act – if you are in pain, instigate a discussion at your next appointment with your GP. And, if you haven't been for ages, make an appointment. Most people find their visits to their GP helpful and informative.
- Plan how to use your time with your GP wisely once you've got your appointment. Get a copy of Arthritis Care's factsheet on *Things to Discuss* with health professionals.
- Don't be afraid to ask GPs, nurses and pharmacists about any new treatments for OA. A newer treatment might be much better for you than the one you've been prescribed or buying for yourself for years.
- Don't put off going to the GP if you think you might be getting OA – earlier action can help manage symptoms and their impact.
- Take your treatment as prescribed by your health professional – it is designed to help you.
- Manage your OA. Don't let it manage you. Use exercise and diet as ways to help you manage. To find out more, get a copy of Arthritis Care's booklet *Osteoarthritis – a guide*.
- Use the help and treatment widely available across the UK. Recognise OA is not just 'old age' and that you don't have to put up with unnecessary pain or immobility just because you are older than you were.
- To order a copy of Arthritis Care's *Things to Discuss* leaflet and *Osteoarthritis – a guide*:  
Tel: 0845 600 6868  
Email: [OANation@arthritiscare.org.uk](mailto:OANation@arthritiscare.org.uk)  
[www.arthritiscare.org.uk/OANation](http://www.arthritiscare.org.uk/OANation)  
Write to:  
OA Nation, Arthritis Care,  
18 Stephenson Way, London NW1 2HD

# Report Structure

## Objective

- To establish the impact of OA on the people living with the condition.

The research was conducted from the patient perspective only, with the specific objective of measuring the impact OA has on day-to-day living. It is not intended to be an in-depth medical study nor does it go into the economic impact of OA in the UK.

...measuring  
the impact  
OA has on  
day-to-day  
living...



'I had to give up gardening – I used to have an allotment. However, I still grow tomatoes and have very good neighbours who help to pick them for me. There are ways round things – it's a lot to do with your own attitude.'

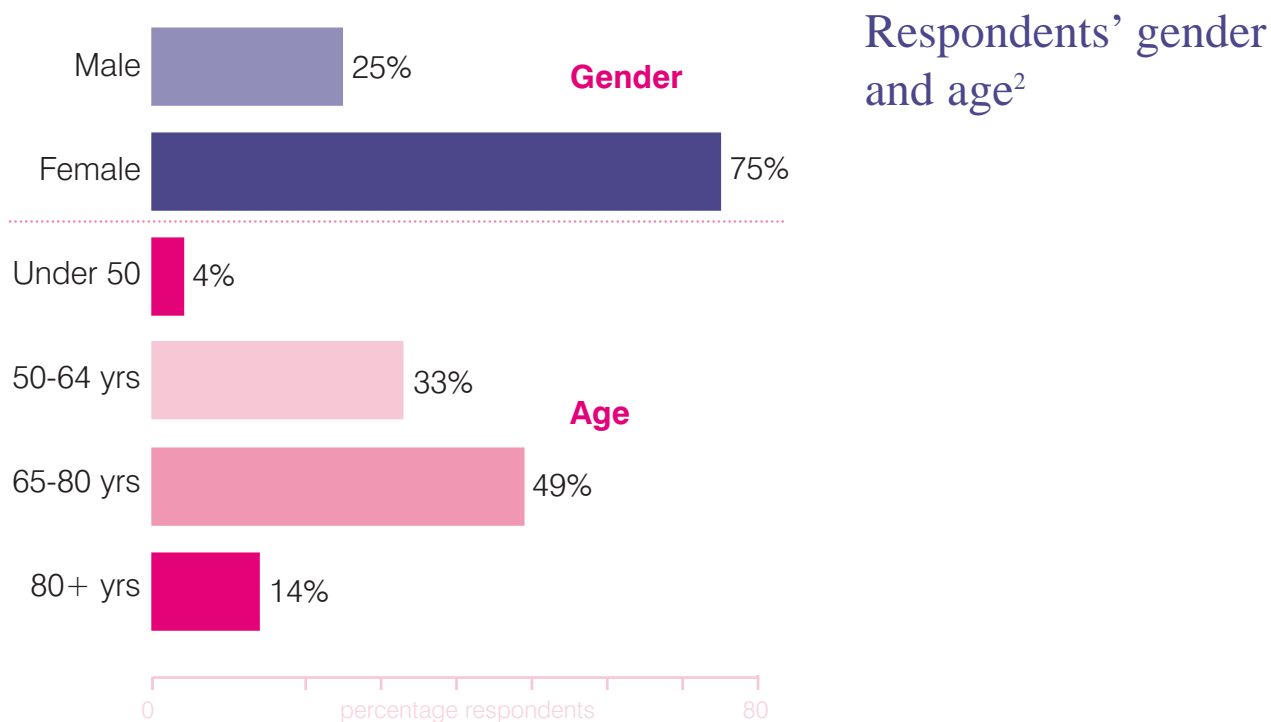
**OA**  
**nation**

the most comprehensive  
UK report of people  
with osteoarthritis

## Methodology

- The research was carried out by TNS Healthcare.
- It was conducted with people who had contacted Arthritis Care for information.
- Respondents were screened to include only those with OA.
- 1,762 telephone interviews were conducted on a one-to-one basis in November and December 2003 and took an average of 20 minutes.
- The sample was split across the UK as follows<sup>1</sup>

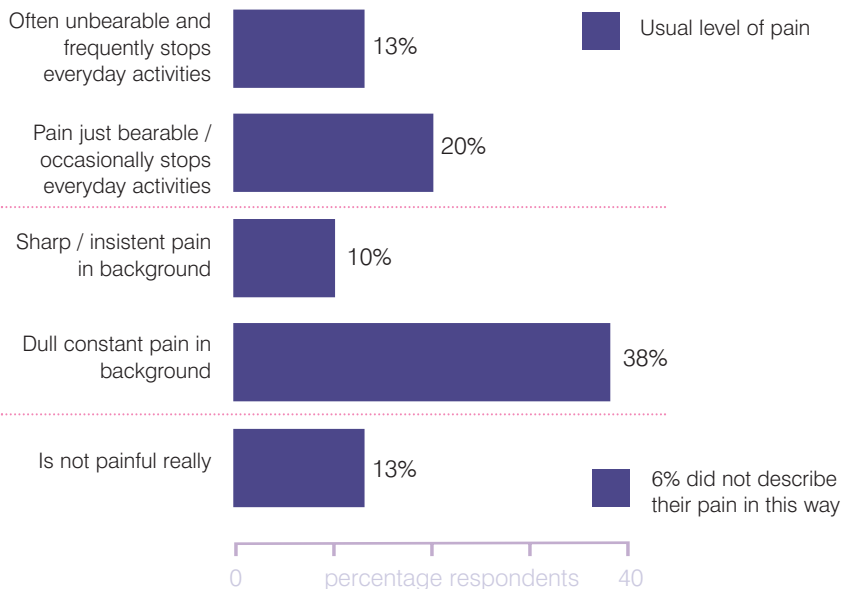
|                  |         |
|------------------|---------|
| England          | n=1,000 |
| Scotland         | n=254   |
| Wales            | n=255   |
| Northern Ireland | n=253   |
- The sample of 1,762 is robust, and allows comparison across the UK as well as stand alone data from each area.



Base: All respondents (1,762)

## Living with OA

- 1,762 patients interviewed across the UK<sup>1</sup>.
- 81 per cent of respondents have constant pain or are limited in their scope to perform everyday tasks<sup>3</sup>.
- When their OA is bad, 69 per cent of those interviewed have difficulty carrying out daily household tasks and 53 per cent even struggle to get out of bed<sup>4</sup>.
- Almost half of the sample would need to have frequently unbearable pain levels before presenting to a doctor<sup>5</sup>.
- Some respondents have had symptoms of OA for more than 25 years, with an average of 12 years<sup>6</sup>.
- Typically, diagnosis was made c18 months after symptoms first appeared<sup>7</sup>.
- Many respondents had visited their doctor three or four times before OA was diagnosed<sup>8</sup>.



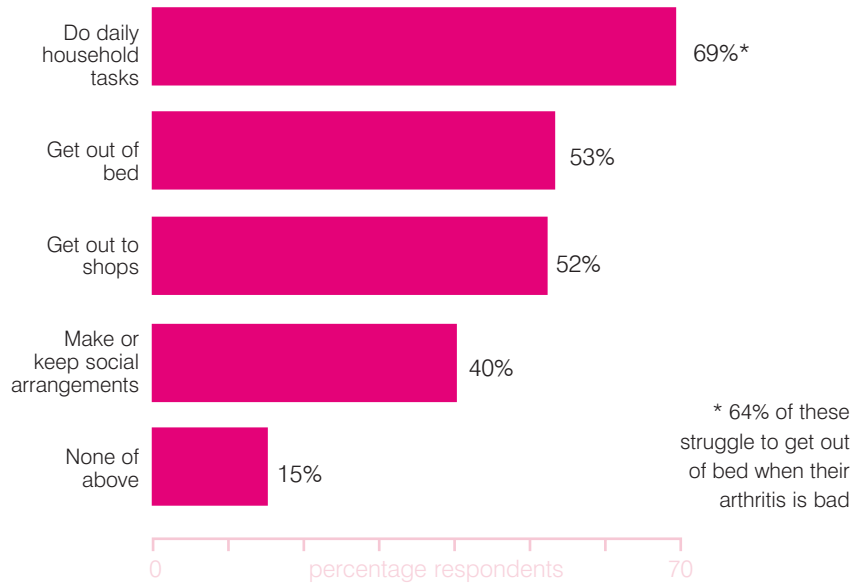
**81% of the respondents have constant pain or are limited in their scope to perform everyday tasks<sup>3</sup>**

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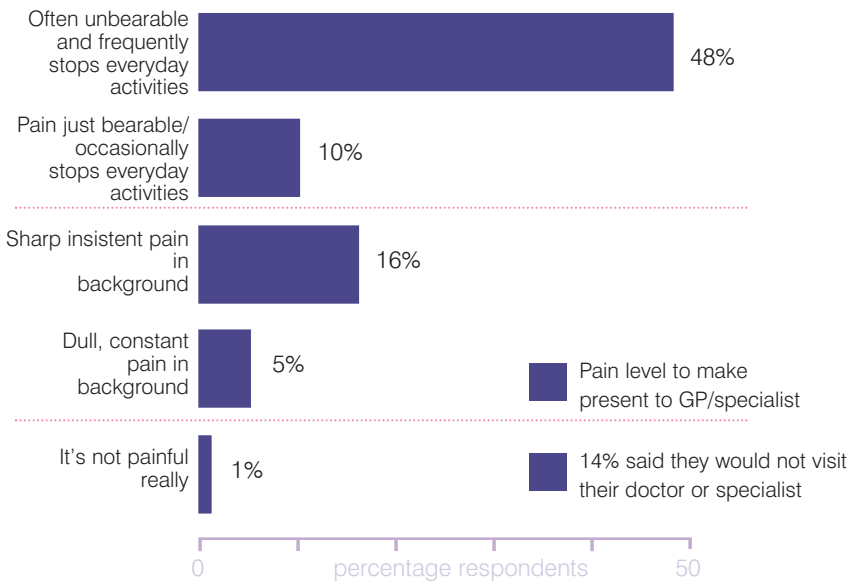
Question 16

Base: All respondents (1,762)

When their OA is bad, 69% of those interviewed have difficulty carrying out daily household tasks and 53% even struggle to get out of bed<sup>4</sup>



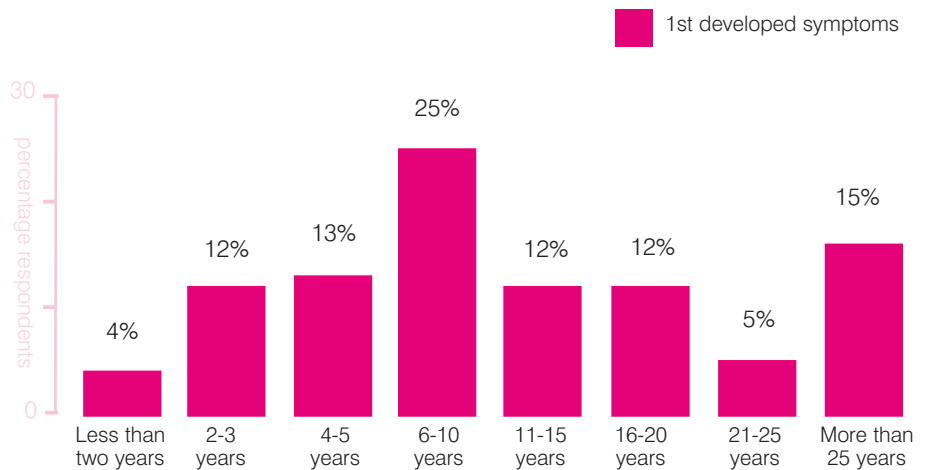
Question 18 Base: All respondents (1,762)



Question 17 Base: All respondents (1,762)

Almost half the sample would need to have frequently unbearable pain levels before presenting to a doctor<sup>5</sup>

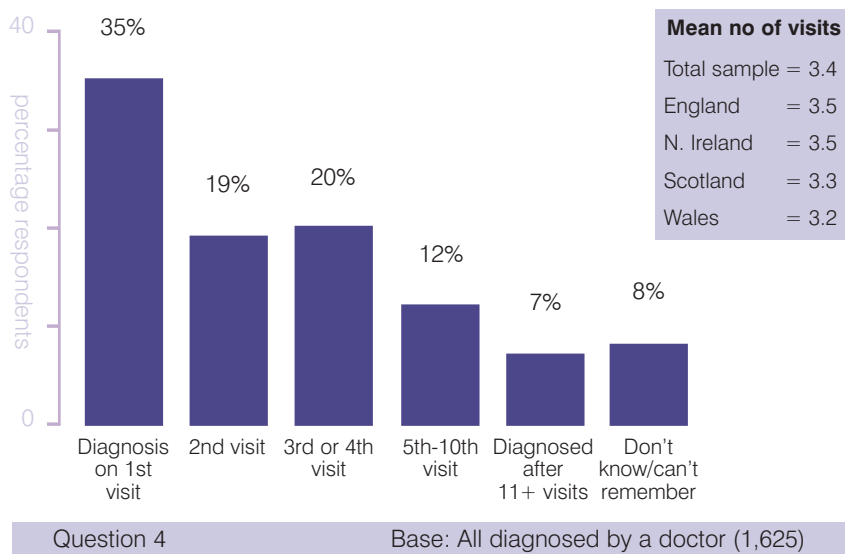
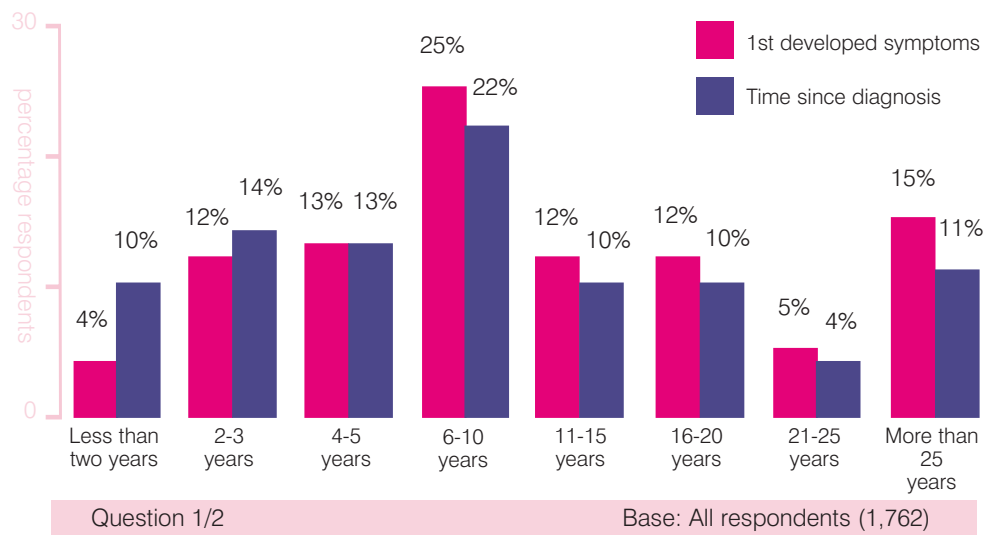
Some respondents have had symptoms of OA for more than 25 years, with an average of 12 years<sup>6</sup>



Question 1 Base: All respondents (1,762)

Typically diagnosis was made c18 months after symptoms first appeared<sup>7</sup>

On average, respondents experienced initial onset of symptoms 12 years ago whilst the typical respondent was diagnosed with OA 10.5 years ago



Many respondents had visited their doctor three or four times before OA was diagnosed<sup>8</sup>



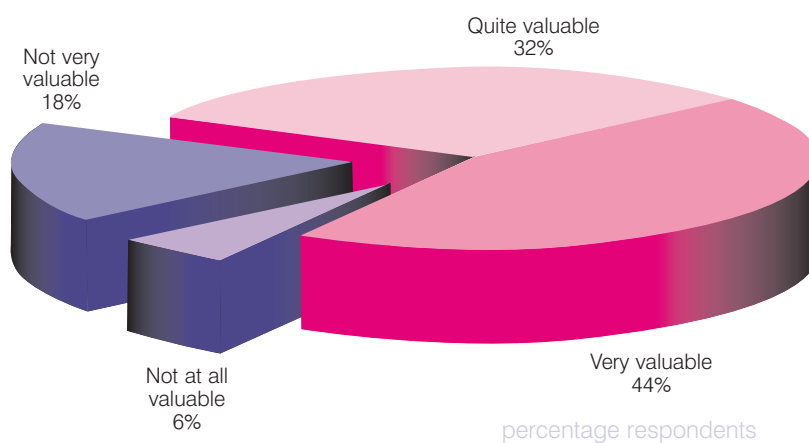
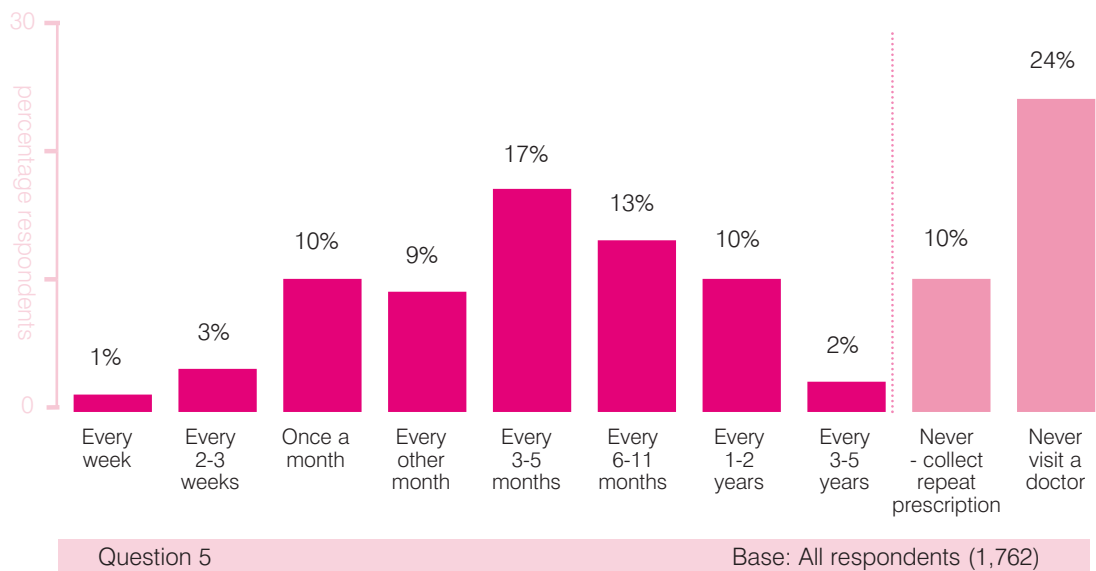
'No doctor's a mind reader. You've got to speak out, say what's worrying you. Say what you feel you need. Nobody else can do it for you.'

**OA**  
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## Role of the health professional

- On average, respondents visit their doctor every five months about their OA, but a third never visit<sup>9</sup>.
- 76 per cent of respondents find doctor visits valuable<sup>10</sup>.
- Press articles and GPs are the most useful sources of information for our sample, with leaflets also featuring strongly<sup>11</sup>.
- More than half the sample find their doctor responds positively to any acquired knowledge/information the patient brings<sup>12</sup>.

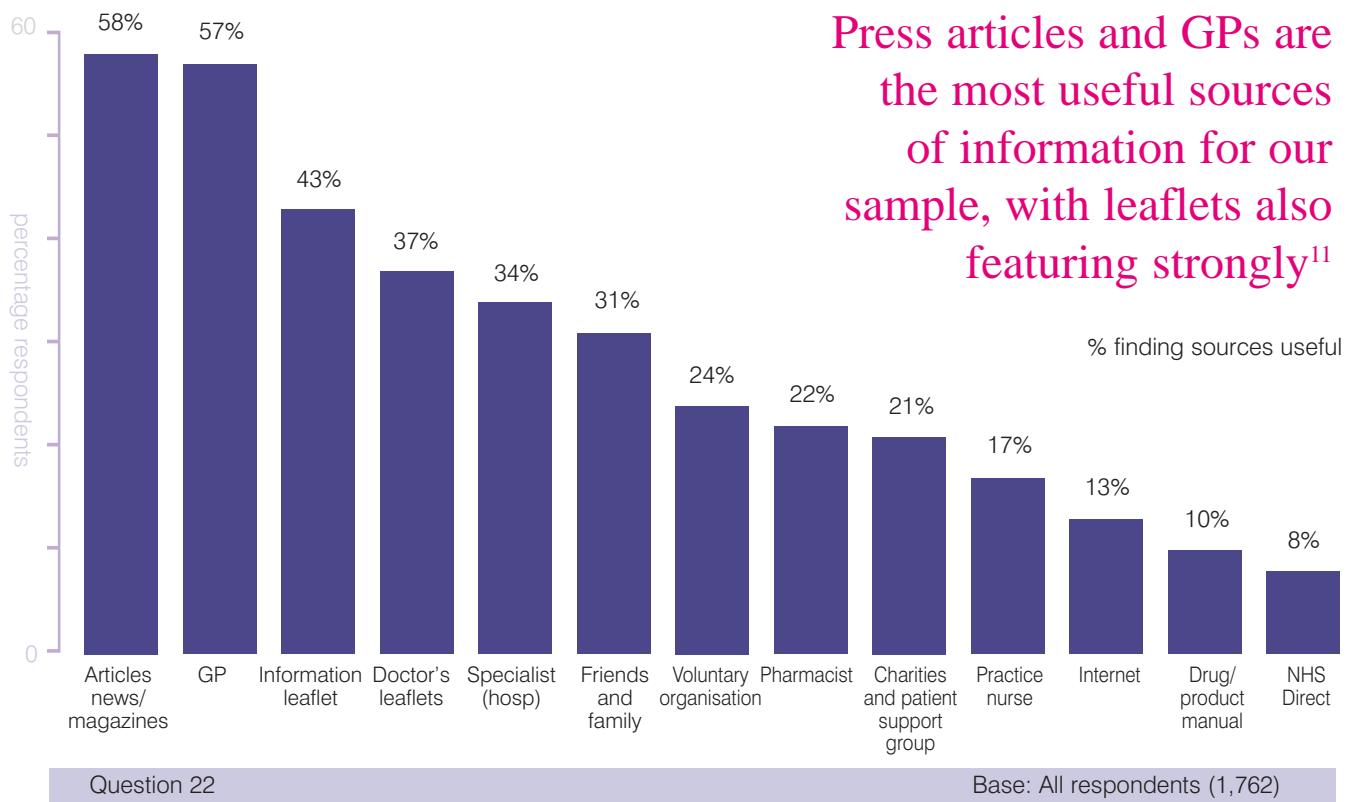
### On average, respondents visit their doctor every five months about their OA, but a third never visit<sup>9</sup>



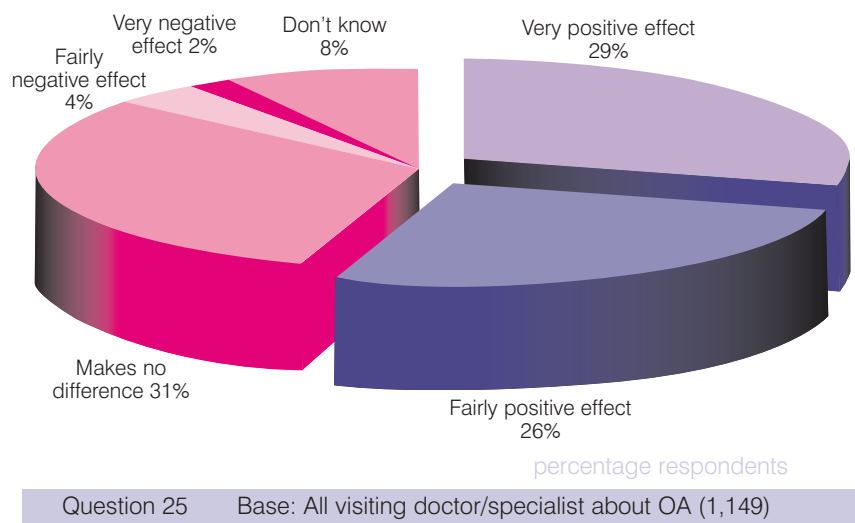
76% of respondents find doctor visits valuable<sup>10</sup>

Question 6

Base: All respondents (1,762)



More than half the sample find their doctor responds positively to any acquired knowledge/information the patient brings<sup>12</sup>

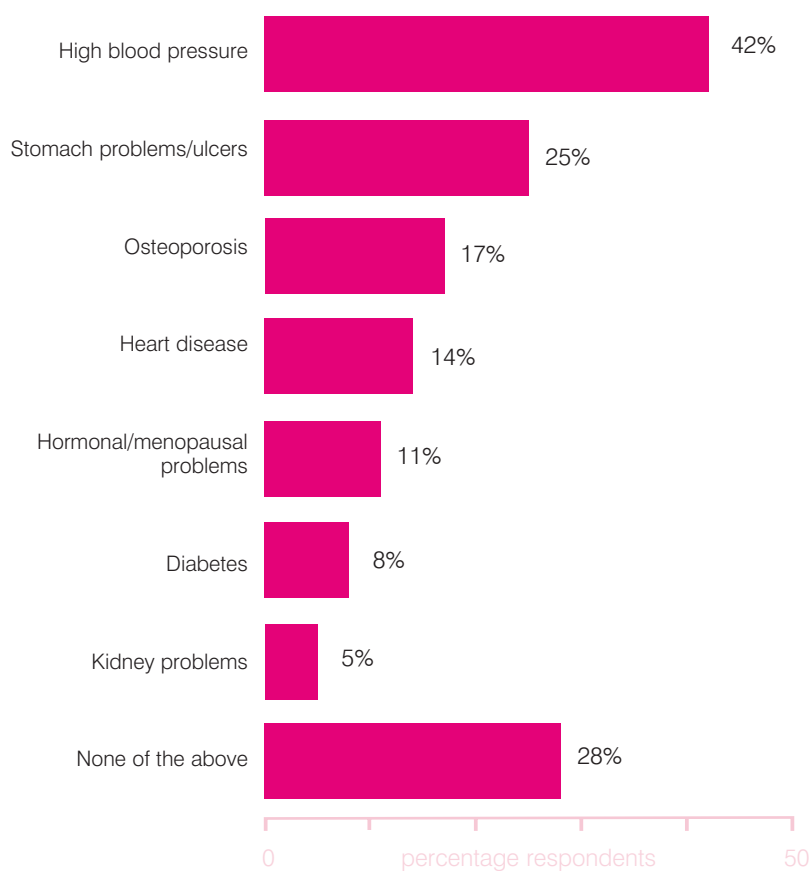


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## Treatments for OA

- 72 per cent of those interviewed have concomitant conditions<sup>13</sup>.
- Their medication for OA is usually NSAIDs, Cox-2s, painkillers or combinations thereof<sup>14</sup>.
- Evidence of self-medication with or without doctor involvement<sup>15</sup>.
- A quarter of respondents have proactively asked about medication and the majority received it<sup>16</sup>.
- Respondents want medicines offering more pain relief and help with mobility<sup>17</sup>.
- For our sample, 'easy to understand' is the most important factor in patient information<sup>18</sup>.
- 57 per cent of respondents use exercise to help manage their OA<sup>19</sup>.

72% of those interviewed have a concomitant medical condition<sup>13</sup>

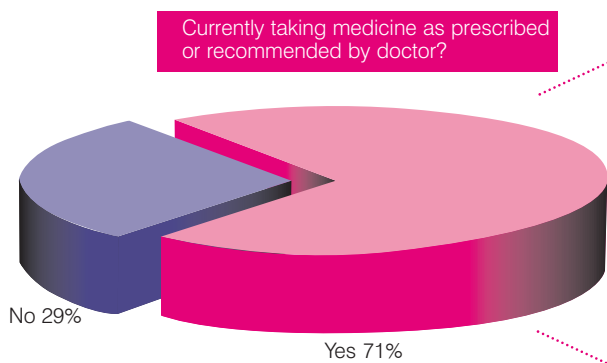


Question 20a

Base: All respondents (1,762)

**OA**  
nation

# Medication for OA is usually NSAIDs, Cox-2s, painkillers or combinations thereof<sup>14</sup>



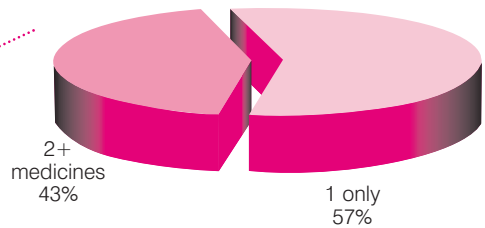
percentage respondents

Base: All currently visiting their doctor about arthritis (1,149)

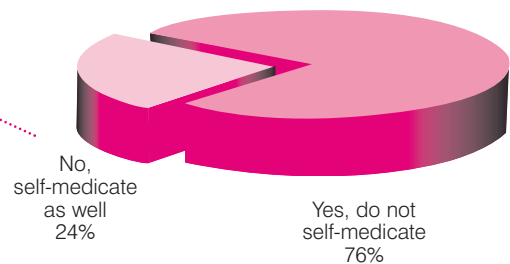
### Drug types used:

- NSAIDs (non-steroidal anti-inflammatories) (32%)
- Selective Cox-2 inhibitors (18%)
- Paracetamol (15%)

### Number of prescribed/GP recommended medicines taken?



### Is this the only type of medicine taken?

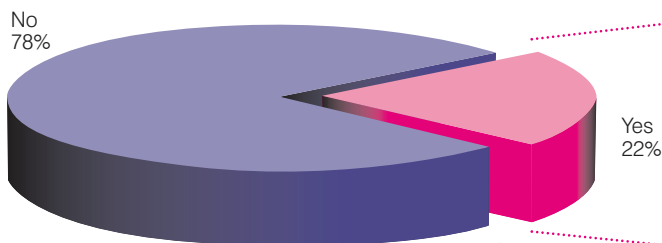


percentage respondents

Base: All receiving a prescription or doctor recommended medicine (812)

## Evidence of self-medication with or without doctor involvement<sup>15</sup>

### Other medicines used that are not prescribed or recommended by a doctor?

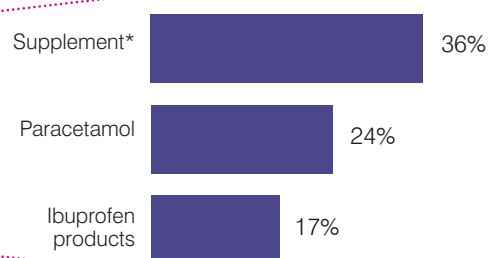


percentage respondents

Base: All respondents (1,762)

Of those taking one or more medicines neither prescribed nor recommended by a doctor, four in ten take no other remedy (40%)

### Type of self-selected medicine used ?



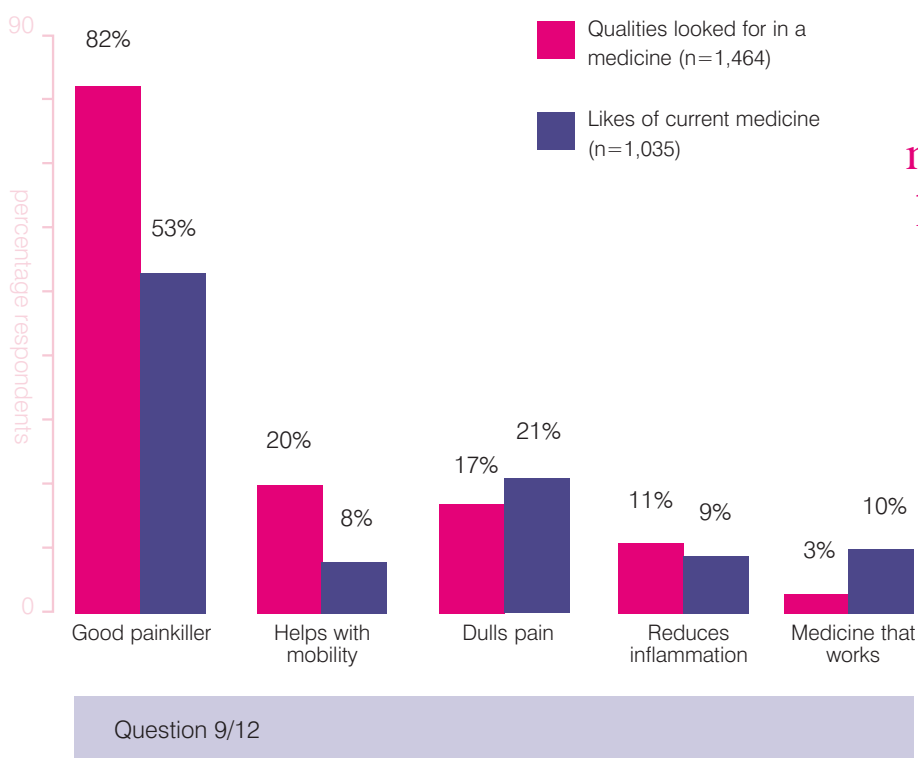
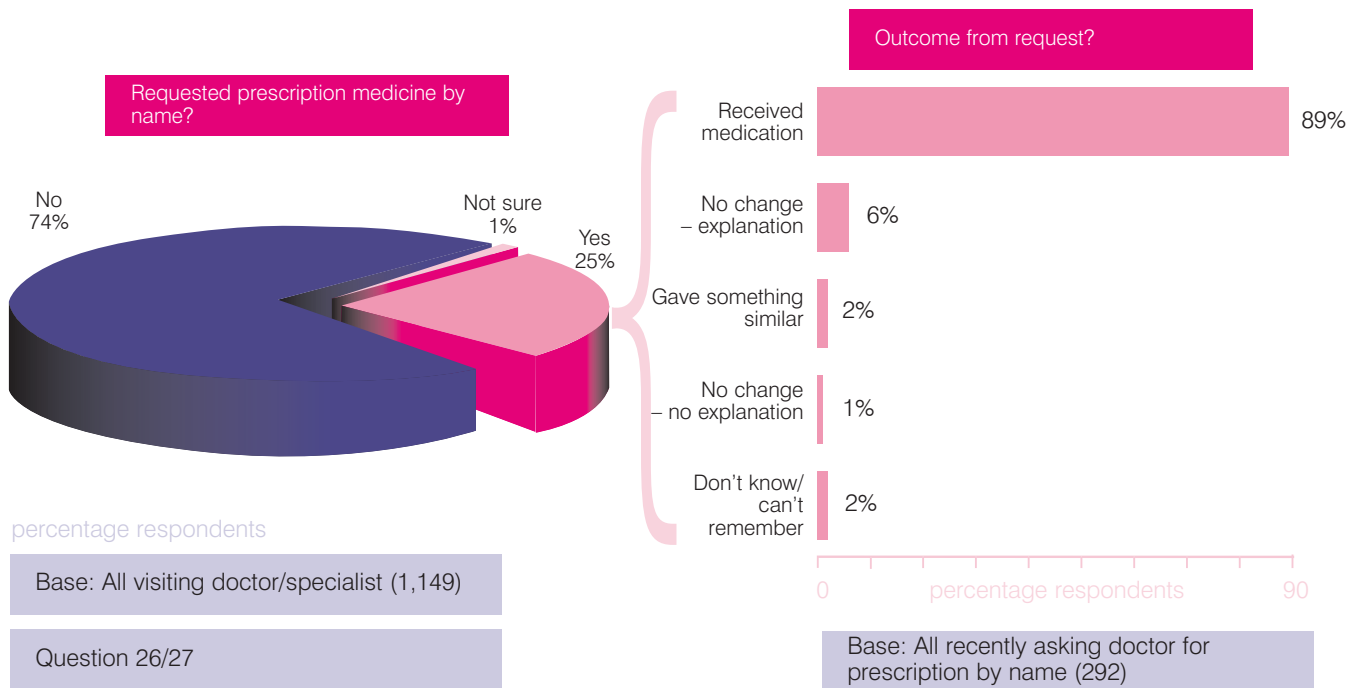
0 percentage respondents 40

All mentions > 10%

Base: All using other medicines to help control their arthritis (379)

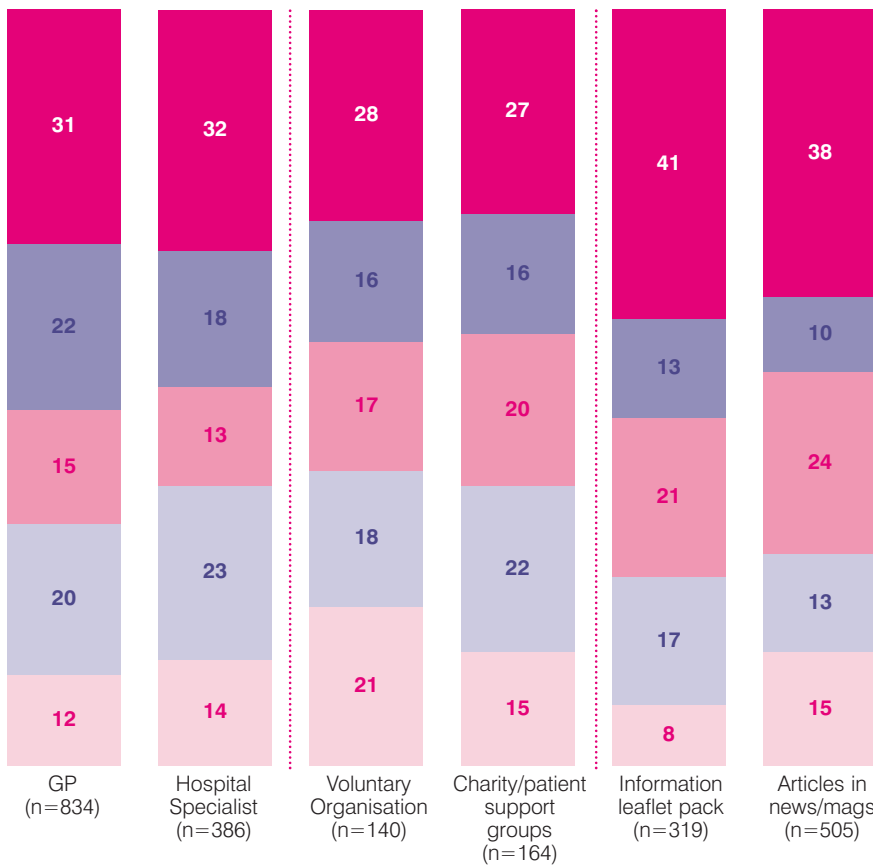
\* Includes Glucosamine Chondroitin, Cod Liver Oil and Fish Oils

# A quarter of respondents have proactively asked about medication and the majority received it<sup>16</sup>



## Respondents want medicines offering more pain relief and help with mobility<sup>17</sup>

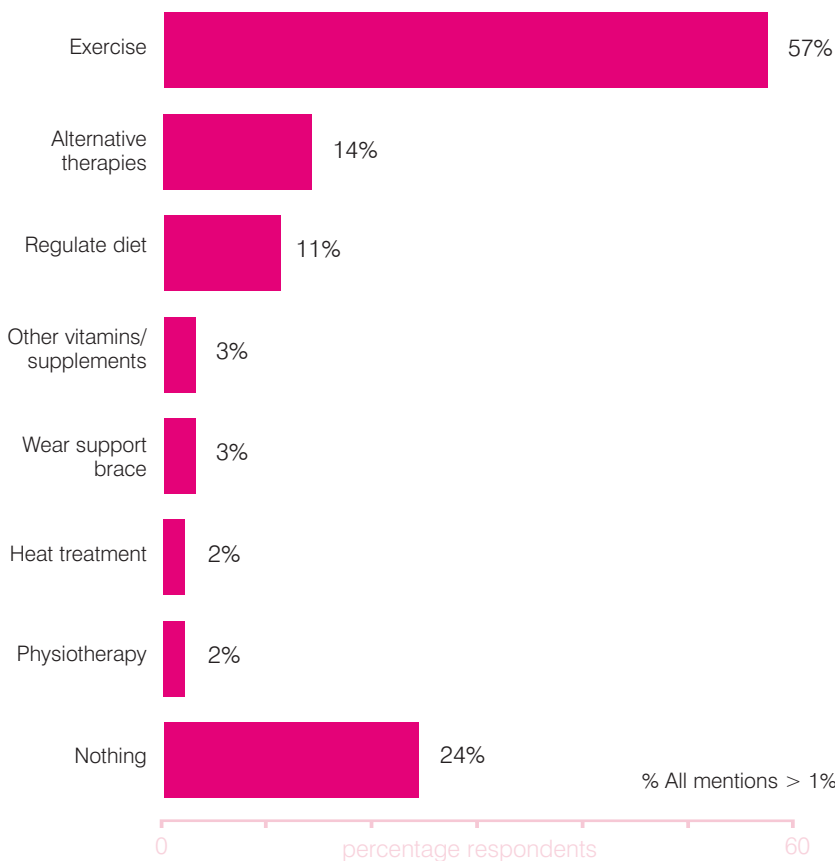
Respondents were asked to spontaneously name the qualities looked for in a medicine and were subsequently asked to state what they like about their current medication



For our sample, 'easy to understand' is the most important factor in patient information<sup>18</sup>



Question 24a-c (Total mentions) Base: All finding each source of information useful



57% of respondents use exercise to help manage their OA<sup>19</sup>

Question 10 Base: All respondents (1,762)



## Differences across the UK<sup>20a-i</sup>

|  | UK                    | England               | Scotland              | Wales                 | N Ireland             |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| a) <b>Condition onset</b><br><i>(mean number of years)</i>   | 12 years              | 12yr 11mth            | 11yr 2mth             | 10yr 1mth             | 10yr 11mth            |
| b) <b>Doctor visits</b><br><i>(mean visits per year)</i>   | 5 times/yr            | 5 times/yr            | 5 times/yr            | 4 times/yr            | 4 times/yr            |
| c) <b>Medication</b><br><i>(mean number of days medication used per week)</i>  | Most days<br>(5 in 7) | Most days<br>(5 in 7) | Most days<br>(5 in 7) | Most days<br>(5 in 7) | Most days<br>(5 in 7) |
| d) <b>Prescription and GP recommendation</b><br><i>(percentage of those visiting GP that take a valid OA medicine)</i> | 71%                   | 69%                   | 69%                   | 75%                   | 75%                   |
| e) <b>Self-medication</b><br><i>(percentage per country)</i>   | 22%                   | 23%                   | 20%                   | 19%                   | 20%                   |
| f) <b>Concomitant condition experienced and corresponding treatment</b><br><i>(percentage per country)</i>             | 72%                   | 73%                   | 71%                   | 68%                   | 77%                   |
| g) <b>Pain levels</b><br><i>(percentage in constant pain or prevented from doing everyday tasks)</i>                   | 81%                   | 81%                   | 82%                   | 79%                   | 79%                   |
| h) <b>Information sources</b><br><i>(percentage finding one or more information source useful)</i>                     | 93%                   | 95%                   | 91%                   | 90%                   | 90%                   |
| i) <b>Patient proactivity</b><br><i>(percentage asking doctor for prescription by name)</i>                            | 25%                   | 25%                   | 21%                   | 25%                   | 31%                   |

'Pain is invisible. It doesn't show up on X-rays or in blood tests, and even if you have swollen joints you can only hope to get across to others just how much pain arthritis can cause. Even relatives and friends sometimes can't comprehend that someone can be in varying degrees of pain all the time. And GPs often underestimate the effect of long-term pain on a person's quality of life.'



## References

- 1 TNS/Arthritis Care Survey 2003, p1,044 Qa.
- 2 TNS/Arthritis Care Survey 2003, p1,051 Qb & p1,044 Qa.
- 3 TNS/Arthritis Care Survey 2003, p693 Q16.
- 4 TNS/Arthritis Care Survey 2003, p720 Q18.
- 5 TNS/Arthritis Care Survey 2003, p706-707 Q17.
- 6 TNS/Arthritis Care Survey 2003, p1-3 Q1.  
TNS/Arthritis Care Survey 2003, p28 Q2.
- 7 TNS/Arthritis Care Survey 2003, p3 Q1 & p28 Q2.
- 8 TNS/Arthritis Care Survey 2003, p63-64 Q4.
- 9 TNS/Arthritis Care Survey 2003, p77 Q5 & p78 Q5.
- 10 TNS/Arthritis Care Survey 2003, p95 Q6.
- 11 TNS/Arthritis Care Survey 2003, p929-930 Q22.
- 12 TNS/Arthritis Care Survey 2003, p1,015 Q25.
- 13 TNS/Arthritis Care Survey 2003, p833-834 Q20a.
- 14 TNS/Arthritis Care Survey 2003, p222-236 Q11.
- 15 TNS/Arthritis Care Survey 2003, p728/737-738 Q19a/Q19b.
- 16 TNS/Arthritis Care Survey 2003, p1,022 Q26 & p1,030 Q27.
- 17 TNS/Arthritis Care Survey 2003, p116 Q9 & p390 Q12.
- 18 TNS/Arthritis Care Survey 2003, p1,013-1,014 Q24a-c.
- 19 TNS/Arthritis Care Survey 2003, p176-177 Q10.
- 20
  - a TNS/Arthritis Care Survey 2003, p3 Q1.
  - b TNS/Arthritis Care Survey 2003, p78 Q5.
  - c TNS/Arthritis Care Survey 2003, p109 Q8.
  - d TNS/Arthritis Care Survey 2003, p315 Q11 & p205 Q11.
  - e TNS/Arthritis Care Survey 2003, p728 Q19a.
  - f TNS/Arthritis Care Survey 2003, p834 Q20a.
  - g TNS/Arthritis Care Survey 2003, p693 Q16.
  - h TNS/Arthritis Care Survey 2003, p931 Q22.
  - i TNS/Arthritis Care Survey 2003, p1,022 Q26.



# Information about Arthritis Care



- Arthritis Care is the UK's largest voluntary organisation working with and for all people with arthritis.
- We campaign for greater awareness of the needs of everyone with arthritis, improved services for people with arthritis and an end to discrimination.
- We provide clear and accurate information about arthritis. A confidential helpline offers information and support to people backed up by a wealth of useful publications, including the bi-monthly magazine *Arthritis News*. Arthritis Care aims to give all people with arthritis the information they need to make informed decisions about how they manage their arthritis and their lives.
- We run a range of self-management and personal development courses, giving people the confidence and skills to manage their arthritis and improve their quality of life.
- We work at a national and local level, with eight offices throughout the UK and a network of local groups and volunteers.
- We run four accessible hotels in the UK.
- We work closely with health professionals and other arthritis organisations in the UK and internationally to get a better deal for people with arthritis.



# OANation

the most comprehensive  
UK report of people  
with osteoarthritis



**ARTHRITIS CARE**

*Empowering  
people with arthritis.*

18 Stephenson Way, London NW1 2HD  
Tel: 020 7380 6500 Fax: 020 7380 6505  
Email: OANation@arthritiscare.org.uk

[www.arthritiscare.org.uk/OANation](http://www.arthritiscare.org.uk/OANation)

Registered charity no: 206563

This research was carried out by TNS Healthcare.  
They interviewed 1,762 people by telephone in an interview  
lasting 20 minutes. Respondents had previously requested  
information from Arthritis Care. Respondents were screened to  
include, as far as possible, only those persons with osteoarthritis.  
The research was carried out in November/December, 2003.



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**PAIN MANAGEMENT**

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