

Arthritis, joint replacements and patients'
rights under the NHS Constitution

POLICY SPOTLIGHT



ARTHRITIS RESEARCH UK

Arthritis Research UK is the leading authority on arthritis in the UK, conducting scientific and medical research into all types of arthritis and other musculoskeletal conditions. It is the UK's fourth largest medical research charity and the only charity solely committed to funding high quality research into the cause, treatment and cure of arthritis.

Our remit includes arthritis and musculoskeletal conditions, which are disorders of the joints, bones and muscles – including back pain – along with rarer systemic autoimmune diseases such as lupus. Together, these conditions affect around ten million people across the UK and account for the fourth largest NHS programme budget spend of £5 billion in England.

Arthritis is the biggest cause of pain and disability in the UK, and each year 1 in 5 of the general population consults a GP about a musculoskeletal condition. As a charity we fund research, provide information to patients and educational resources for health professionals.

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This policy spotlight focuses on people with arthritis' awareness of their rights in the NHS Constitution when having a joint replacement operation. It outlines their awareness, their need for information and support, and their experiences of living with the pain of severe arthritis. It also examines what they would like to see done differently.

1. INTRODUCTION

Severe osteoarthritis is a painful condition which can have a substantial impact on people's lives: 93% of initial hip replacements and 98% of initial knee replacements occur because of osteoarthritis.¹ People often live in pain for many years before they approach their general practitioner about their condition. If a joint replacement operation is needed, the referral to treatment waiting times encountered in orthopaedics (the specialty in which joint replacement surgery is undertaken) are longer than in many other specialities.²

Under the NHS Constitution a person referred for an operation, including for a joint replacement, has a number of rights about the treatment they can expect to receive: a right to be treated within an agreed waiting time of 18 weeks from referral; and a right to request an alternative provider* if their current provider is unable to treat them within the specified time frame.

A workshop was jointly held by the Department of Health and Arthritis Research UK to learn more about people with arthritis' awareness of their rights within the NHS. The workshop was facilitated by a market research agency, Research Works Ltd. This policy spotlight focuses on the main observations from the perspectives of people with arthritis, a longer report of the workshop is available via the Department of Health website.



* An alternative provider can be another NHS hospital or an independent provider of services to the NHS.

2. ARTHRITIS AND JOINT REPLACEMENTS

Osteoarthritis is a painful condition which affects 8 million people nationwide.³ The main symptoms are pain and loss of movement, which are usually caused by damage to joints and surrounding tissues. Almost any joint can develop osteoarthritis but the knees, hips, hands, spine and big toes are most often affected. When osteoarthritis occurs in the hip and knee joints it can reduce mobility. The risk of developing osteoarthritis can increase with age and obesity.

The main treatment options are physical activity and pain management. In the most severe cases, osteoarthritis can cause debilitating pain and a joint replacement is required to give people back their quality of life and allow them to undertake normal daily activities. A joint replacement is a substantial operation which can take up to nine months to fully recover from.

Rheumatoid arthritis and other inflammatory conditions are a second group of conditions that cause painful joints, stiffness and swelling. These inflammatory conditions can occur at any age, can affect the whole body and usually require lifelong specialist treatment. In rheumatoid arthritis, the elbow, ankle and shoulder are often affected, and replacement of these joints can be necessary in the most severe cases.

Joint replacement surgery

Over 80,000 people had a hip replacement and over 84,000 had a knee replacement in England and Wales in 2011 alone.⁴ The numbers of joint replacements continue to increase: there was an increase of 5% and 3.3% respectively in the numbers of hip and knee replacements from 2010.⁵ As both age and obesity are risk factors for the development of osteoarthritis, it is envisaged that demand for joint replacements will continue to grow.

In comparison to other surgical specialities, trauma and orthopaedics were among a small number of specialities which were below the inpatient referral to treatment waiting times standard, that 90% of patients should start treatment within 18 weeks of referral, in 2011 and 2012.^{6,7}

The delays in treatment mean that people with severe arthritis are living in pain and experiencing disability for longer. It also means that despite the pledges within the NHS Constitution, not all treatments are occurring within the timeframes committed to. There may be instances where people are comfortable to wait longer than 18 weeks or when it is clinically appropriate for someone to wait longer than 18 weeks. At the same time, the presence of pain means that treatment delays can have an impact across an individual's entire life.

Ensuring high quality and safe treatment of people needing a joint replacement is of primary concern. Joint replacement surgery is now a common operation and can be done in most hospitals in the country. However, some people have complex joint problems, so they need to have their surgery in a specialist centre. For these people, an alternative provider may not always be appropriate.

3. PATIENTS' RIGHTS

The introduction of the NHS Constitution was a result of the NHS paying greater attention to the needs of the people who use its services. The NHS Constitution articulated for the first time a number of commitments and pledges to people.

The NHS Constitution was first published (in draft form for consultation) in 2008 to give people a clear picture of what to expect in terms of their treatment, safety and quality of care in the NHS. In 2009, the NHS Constitution included the pledge to provide 'access to within the waiting times':⁸ a commitment which continues to feature in later versions. From March 2010, the NHS Constitution revised the pledge to a new legal right* for patients to start consultant-led non-emergency treatment within a maximum of 18 weeks from referral, or for the NHS to take all reasonable steps to offer you a range of alternative providers if this is not possible.⁹

The primacy of patients' rights was reaffirmed as recently as November 2012, when the Government published its Mandate to the NHS Commissioning Board (now NHS England). In this, the Government stated that: 'The Board's **objective** is to uphold these rights and commitments, and where possible to improve the levels of performance in access to care.'¹⁰ NHS England also reflected these sentiments in its planning guidance to clinical commissioning groups (CCGs), alongside providing a financial incentive via a Quality Premium for those CCGs who are able to deliver on the NHS Constitution pledges on waiting times.¹¹

Much progress has been made over the last decade to reduce waiting times for operations. But NHS England continues to recognise that 'there remains a small number of patients who are waiting too long. It is unfair to provide patients with a right and then not deliver against it.'¹² The feedback from this workshop provides insights about what can be done *differently* when planning services for people requiring a joint replacement.

Involving individuals in decisions about their care

A person's right to request a transfer to an alternative provider is among many decisions a person may make in relation to joint replacement surgery. From the initial decision to approach their GP to discuss their joint pain, to orthopaedic 'physio triage', to the decision to have surgery, where and when, people make a series of important choices within the unique context of their lives. Some choices along the patient journey are explicitly set out within NHS systems, for example, the NHS Choose and Book system enables people to select a place, date and time for their first outpatient appointment in a hospital or clinic.**

In a wider sense, there has been increasing recognition of the importance of involving people in decisions about their care. Shared decision making is an approach which centres on people being fully engaged in managing their health status and healthcare, and involved in making decisions about their treatment and care. It has been described as 'both a philosophy and a process',¹³ in which people and health professionals work in partnership and contribute equally at every stage of the health and care journey. For effective shared decisions to be reached, individuals must be sufficiently empowered, and have adequate information to contribute to decision making.

* The legislation establishes this right is the National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012 available at: http://www.legislation.gov.uk/uksi/2012/2996/pdfs/uksi_20122996_en.pdf.

** Choose and Book allows people to choose a place, date and time for their first outpatient appointment in a hospital or clinic: www.chooseandbook.nhs.uk.

4. THE WORKSHOP

In collaboration with the Department of Health, Arthritis Research UK conducted a workshop in October 2012 with sixteen people with arthritis and other musculoskeletal conditions. Fourteen people had osteoarthritis and two people had rheumatoid arthritis: in this group seven were waiting for a joint to be replaced; seven had had either one or several joints replaced; and two people had had a joint replaced and were waiting for another to be replaced.

The purpose of the workshop was to explore people with arthritis' awareness and understanding of the 18 week waiting time limit, their right to request an alternative provider, and their information and support needs. The workshop also explored what participants would like to see done differently. More details of sample and methodology may be found in Appendix I. At the same time, an individual with severe osteoarthritis who had had several joint replacement operations in the NHS was supported by Arthritis Research UK to join a Department of Health working group.

in England and Wales in 2011 there were over



80,000
HIP REPLACEMENTS



84,000
KNEE REPLACEMENTS

98%

of initial knee replacements
are due to osteoarthritis

93%

of initial hip replacements are
due to osteoarthritis

The NHS Constitution was first published in **2008**.

Your waiting time right is to start consultant-led treatment within **18 weeks** from referral.

A workshop participant said "You sometimes struggle for a long time before you go to the GP."

5. EMERGING THEMES

5.1 Awareness

'I just thought you just got referred and sat back and waited. I knew I would not wait say, four years, but they would get to me as soon as they could.' – **comment from participant in workshop**

The workshop participants' awareness of their right to be treated within 18 weeks was low. They were either unaware of the 18 week limit or were confused about what it actually meant. No one was clear that the clock starts ticking once the hospital receives the referral from the patient's GP and that it keeps on ticking until treatment starts.*

Only one person was broadly aware of the NHS Constitution and their awareness of the waiting limit for operations was gained via personal experience. Understandably, people felt that the NHS should do much more to communicate the right to treatment within 18 weeks and to explain the process involved.

There was some confusion amongst participants between the right to choose a hospital at the beginning of the process via the NHS Choose and Book system, and the right to request an alternative hospital if their current provider was unable to make the 18 week treatment commitment. Around half the group had heard of Choose and Book; those that were unaware had not been introduced to the concept by their GP. Interestingly, a key driver for using Choose and Book was the opportunity to request a specific surgeon, which was sometimes based on previous experience or a recommendation by friends or relatives.

'I knew someone who had had a good experience with a surgeon so I asked about where he was and then requested if I could be under him.' – **comment from participant in workshop**

If their operation could not take place as planned, the group discussed what could be done differently. They recommended that people should be notified about the time limit when the referral to see a specialist was **first** made. This might be best communicated in the initial appointment letter, or the news could come from their GP. There was a largely negative response to the prospect of being informed they could go elsewhere for treatment at the point when the hospital realised it could not deliver the 18 week treatment commitment.

'If their 18 weeks is more like 26, tell us.' – **comment from participant in workshop**

Participants also suggested that hospitals should alert patients after 9-12 weeks (i.e. roughly at the halfway stage) if it appeared that they might not be able to meet the 18 week commitment. This would then be the time to inform or remind people what action to take if they wished to consider different options.

Although a minority of patients had heard of the right to request an alternative provider, they were unclear that it was up to them to make a request before this new process could start. The procedure was opaque.

* In specific circumstances, there may be instances where the treatment pathway can be paused if, for example the patient requests a delay or makes themselves unavailable for treatment.

5.2 Pain

'You sometimes struggle for a long time before you go to the GP.' – comment from participant in workshop

Pain is one of the most common symptoms of musculoskeletal conditions, along with joint stiffness, limitations in movement and fluctuations in severity over time. At the workshop, it was clear that people had been living in pain for years before they approached their GP. The last 18 weeks from referral to treatment was merely the tip of the iceberg.

The impact and burden of pain being experienced was prominent in the minds of those waiting for an operation, especially those due for knee replacements. Consequently, the date of the operation, once fixed, was a red letter day in the calendar. People needing a joint replacement operation were planning their lives around when this would take place.

'We know. Your whole life revolves around that countdown.' – comment from participant in workshop

The presence of pain had an impact on people's perceptions of their vulnerability and their desire for support. Making comparisons and taking decisions about their treatment options was challenging because of pain. Some people might require substantial support to aid their decision-making about possibly changing their treatment plans. There was a strong appetite for mutual support and empathy for the pain of arthritis – especially as symptoms are often not visible.

There can be instances when a person with arthritis is recommended to wait for a joint replacement operation owing to their age and the expected life span of a joint replacement. In eight out of ten people, a hip replacement should last twenty years.* Medication to reduce pain can be effective for many people with arthritis. Like all medication there can be side effects, particularly with long term use. One individual highlighted her experience of living in pain and in turn the side effects caused by long term medication use. Being able to stop painkilling medication is an important goal for people having joint replacement surgery.

'I was told at 52 I would have to wait until I was 60 before they would do anything, so the clock is not ticking then – however you still have to live with the pain. I was on Tramadol and cortisone injections which have led to other complications.' – comment from participant in workshop



* In more active people the joints may wear out more quickly.

5.3 Information and support

*It is the pain in the end that drives you to it, but you are actually comparing two very different things in a difficult situation and you are very vulnerable and you actually don't have the expertise to make those comparisons. It's based on, essentially, other emotive factors like: when do I want to get it done, will it be convenient, how much pain can I stand, what other support can I get in the interim? Will I get some exercises and some drugs to help me manage? There are lots of other variables.' – **comment from participant in workshop***

The workshop discussed in detail participants' perceptions and expectations of next steps if they could not be treated within the 18 week timeframe.

They first considered how they would like to be informed that their operation would not occur as planned. People agreed that the initial news should come in a phone call from the hospital, ideally from the secretary to their consultant. This should be followed by a formal letter of confirmation providing more detail about the options available. Crucially, such a letter should explain who to contact about organising an alternative.

There was also an interest in being able to speak to someone to help in the decision-making process. But a balance must be struck: people were concerned about being overwhelmed with information.

The right to request an alternative provider when the maximum waiting time was at risk was viewed positively. People felt that such a decision would be determined by two main factors:

- » The opportunity to be treated more swiftly: the pain was a driving force.
- » Their level of confidence in the alternative surgeon performing the operation.

*I would need to know about the consultant/surgeon if I was going to ask for an alternative, what his procedure involved and what kind of prosthesis he used because they vary as well, what the post-operative treatment is in the particular hospital – would I get physio? How many times would they see me subsequently? Trying to compare.' – **comment from participant in workshop***

A decision to change to an alternative surgical team would not be taken lightly: especially owing to the presence of pain. People awaiting a joint replacement operation really wanted to understand the risks and benefits of making a change. Foremost in the majority of participants' minds was the impact of a change of consultant on their operation. The relationship established with the consultant over time was important, particularly if he or she had conducted a joint replacement operation for the person previously.

Most people suggested that, in the first instance, they would probably prefer to stay with their original surgeon and would therefore be prepared to tolerate a reasonably extended waiting time – or move hospitals if they could have the same team. When researching alternatives, information about the surgeon was the priority, followed by details about the care provided by the hospital.

There was a strong appetite to find out about the new surgeon performing the operation including where the surgeon had trained, their experience and success rates. The majority of participants also wished to meet the new surgical team before the actual operation occurred (but not on the same day as the operation).

As far as the hospital was concerned, people said they would want to know its record on matters such as safety and length of stay, and its standards for post-operative support and follow-up, such as the amount of physiotherapy provided. The quality of care and safety were key.

People recognised that all this information might be difficult to find, and therefore wanted to be directed to the most useful sources. Given the complexity of the decision-making process and the pain that people could be experiencing, information would need to be accompanied by support. Many participants spoke favourably of preoperative talks given by nurses, supported by a DVD and booklet. Specialist arthritis nurses and GPs were generally trusted and highly rated in these circumstances.

There were different levels of confidence amongst participants about obtaining information: some were comfortable using the internet, while others preferred the option of a discussion with their GP or using a telephone helpline.

*‘Talking to people who have had it done is a benefit. It’s what to expect. And they are honest with you.’ – **comment from participant in workshop***

Peer-to-peer support was regarded as valuable if it could be found: people appreciated hearing what others in their position had experienced. Some had used online forums and rated them highly for information about arthritis and joint replacements. Testimonials from peers who had undergone treatment at particular hospitals were suggested as a way of offering a patient perspective on treatment.

Arthritis charities provide information about joint replacement operations and can offer support. People could see the value of charities providing these services, but there was generally low awareness of what was available. Further work needs to be undertaken to ensure that people are aware of the information and support that is available to them.

6. LOOKING AHEAD

The findings from this workshop have shed new light on the perspectives and information needs of people with arthritis requiring a joint replacement. Since it was held these observations have contributed to the development of NHS planning guidance, which now recommends:

- » *The NHS Standard Contract will make it a requirement for all letters for first outpatient appointments to include standard information on the right to a treatment within a maximum waiting time and what patients can do if they are concerned that they are or will be waiting longer than 18 weeks.*
- » *We will explore how providers can inform patients of their estimated waiting time, as early as possible in their pathway, including whether they are at risk of waiting longer than 18 weeks.*
- » *We will explore how Choose and Book can be used to raise patients' awareness of their right to treatment within 18 weeks and their expected waiting times and to support them in choosing alternative providers.*

Arthritis Research UK is glad to have had the opportunity to ensure that the voice of people with arthritis and other musculoskeletal conditions is heard as policy evolves. Looking ahead, the discussions held at this workshop suggest that when caring for people with severe arthritis who are waiting for a joint replacement, services should:

- » routinely make people aware of their right to NHS treatment within 18 weeks, and their right to request treatment from an alternative provider if this cannot be achieved.*
- » give people easy access to information about proposed alternative providers, including surgeon-level outcomes data.
- » create the opportunity for people to meet their surgical team from the alternative provider before finalising their decision.
- » identify clear mechanisms to ensure people have personal support in making a decision about treatment from an alternative provider.
- » direct people towards patient charities that can offer individual support, including through peer-to-peer networks.

* Participants suggested the ideal time to be notified that the 18 week timeframe could not be met was 9-12 weeks.

APPENDIX I: WORKSHOP SAMPLE AND METHODOLOGY

Sample

A total of sixteen people took part in a workshop conducted by Research Works Ltd in Birmingham on Thursday 4 October 2012. Representatives from the Department of Health (DH) and Arthritis Research UK attended, as well as an individual who had participated in a DH working group for the project (and had experienced hip, knee and both shoulder replacement operations).

The sample included:

- » A mix of male and female respondents (5 male and 11 female)
- » A range of ages from 52-74 years old
- » A mix of socioeconomic groups B, C1, C2 and D
- » Respondents came from central Birmingham, Birmingham suburbs and Warwickshire
- » Ethnic minority representation (South Asian and Black Caribbean)
- » Two respondents with rheumatoid arthritis and fourteen with osteoarthritis
- » A mix of joint replacement experience:
 - » Seven people waiting for a joint to be replaced
 - » Seven people who had had either one or several joints replaced
 - » Two people who had had a joint replaced and were waiting for another to be replaced

Respondents with hips and/or knees and shoulders that had either been replaced or were waiting to be replaced, as follows:

	Have been replaced	To be replaced
Hip	4	1
Knee	9	9
Shoulder	0	1

Respondents were asked about the level of impact their condition had on their lives. A range of mild, moderate and severe was recorded, as follows:

- » Mild – two respondents
- » Moderate – seven respondents
- » Severe – seven respondents

Those who described their condition as severe typically had other long term health conditions including: migraine, depression, type 2 diabetes, rheumatoid arthritis, heart disease, chronic obstructive pulmonary disease (COPD), asthma and thyroid problems.

Methodology

The agenda for the workshop is provided below. Copies of the questionnaires used and a full report on the research are available on request.

Welcome	Short self-completion questionnaire: individual experiences of joint replacements.
Convene whole group	Introduction and explanations from Research Works, DH and Arthritis Research UK.
Whole group discussion	Preliminary discussion led by Research Works focusing on spontaneous awareness of 18 weeks and right to request alternative provision.
Presentation to whole group	DH presentation of 18 weeks alternative provision. Any questions?
Convene two groups of 8 participants	Research Works lead discussion of 18 weeks and the right to request alternative provision.
Break	
Reconvene two groups of 8 participants	Research Works lead discussion of information and support needed on 18 weeks and alternative provision.
Summing up of session	Representatives from each focus group, Research Works, Arthritis Research UK and DH to summarise what they have learned.
Thanks and close	

APPENDIX II: EXTRACT FROM THE HANDBOOK TO THE NHS CONSTITUTION

Handbook to the NHS Constitution: revised March 2013

What this right means for patients

You have the right to:

- » start your consultant-led treatment within a maximum of 18 weeks from referral for non-urgent conditions.

If this is not possible, the clinical commissioning group or the NHS Commissioning Board (now NHS England), which commissions and funds your treatment, must take all reasonable steps to offer a suitable alternative provider, or if there is more than one, a range of suitable alternative providers, that would be able to see or treat you more quickly than the provider to which you were referred. A suitable alternative provider is one that can provide clinically appropriate treatment and is commissioned by a clinical commissioning group or the NHS Commissioning Board (now NHS England). You will need to contact either the provider you have been referred to or your local clinical commissioning group before alternatives can be investigated for you. Your clinical commissioning group or the NHS Commissioning Board (now NHS England) must take all reasonable steps to meet your request.

Your right to start treatment within 18 weeks from referral will include treatments where a consultant retains overall clinical responsibility for the service or team, or for your treatment. This means the consultant will not necessarily be physically present for each appointment, but will take overall responsibility for your care. The setting of your consultant-led treatment, for example whether hospital based or in a GP-based clinic, will not affect your right to start treatment within 18 weeks.

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The individual views in this report are those of workshop participants and should not be taken as representing the views of Research Works Ltd., Arthritis Research UK or the Department of Health.

Arthritis Research UK produces information for people with arthritis, including leaflets on:

- » Hip replacement
- » Knee replacement
- » Shoulder and elbow joint replacement
- » Hand and wrist surgery (including knuckle and wrist joint replacement)
- » Foot and ankle surgery (including ankle joint replacement)

These can be accessed at www.arthritisresearchuk.org/arthritis-information/surgery.aspx

Arthritis Research UK
Copeman House, St Mary's Gate
Chesterfield, S41 7TD

www.arthritisresearchuk.org