



Never Stand Still

Faculty of Arts and Social Sciences

# Arthritis and disability

## Research plan

Prepared for Arthritis Australia

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## Abbreviations

AIHW	Australian Institute of Health and Welfare
HREC	Human Research Ethics Committee
NDIS	National Disability Insurance Scheme
NHMRC	National Health and Medical Research Council
SPRC	Social Policy Research Centre
UNSW	University of New South Wales

# 1 Introduction

Arthritis Australia is commissioning research on disability impacts caused by arthritis. The project examines the lived experience of people with arthritis and the impact of arthritis on their quality of life. In particular, the investigation includes the prevalence of disability caused by arthritis; the nature and extent of the disability; age at onset of the disability; impact of the disability on mobility and independence; impact on income and employment; impact on additional costs such as medical care, home maintenance and modifications as well as aids, equipment and transport; impact on management of co-morbid conditions; impact on lifestyle, social inclusion, family and carers; mental health and impact on entry into aged care facilities. Additionally, the research will also identify the potential effects of the National Disability Insurance Scheme (NDIS), now known as DisabilityCare. This study will increase recognition of the disability impacts of arthritis and understanding of the service and support needs of people with arthritis.

Arthritis Australia is the peak body providing leadership in arthritis, as well as advocacy and resources for community awareness and understanding. They also encourage and participate in research initiatives. Their services are for people living with arthritis and related conditions.

Arthritis is a significant contributor to disability in Australia and is the second leading cause of disability after mental health (Australian Institute of Health and Welfare, 2010, ABS 2010). In 2011-12, arthritis was the leading long-term health condition experienced in Australia where it affected over 3 million people or about 15 per cent of the population (ABS, 2012).

Arthritis and other musculoskeletal conditions are the leading causes of chronic pain and disability in Australia. People with arthritic and related disorders reported having 11 per cent profound core activity limitation and 14.5 per cent severe core activity limitation (ABS, 2010). There are more than 100 forms of arthritis; however, the most common types include osteoarthritis and rheumatoid arthritis. Other than the severe pain caused by these conditions, people with arthritis have lower quality of life, reduced productivity and significant costs associated with ongoing care and management (NAMSCAG, 2004).

Arthritis is more prevalent in women than in men and the onset of arthritis usually occurs between the ages of 15 and 64. The prevalence of arthritis increases with age where half of all Australians over the age of 80 have some form of arthritis (Deloitte Access Economics, 2007). There is also evidence that socioeconomic factors affect and influence the prevalence of arthritis - the proportion of Indigenous people with arthritis is higher than non-Indigenous people and the proportion of arthritis and related disorders is higher among low socioeconomic groups (Australian Institute of Health and Welfare, 2010).

The economic impacts from arthritis are also detrimental. In a report by Deloitte Access Economics, it was estimated that in 2007, the allocated health system expenditure associated with arthritis was \$4.2 billion (Deloitte Access Economics, 2007). In addition, approximately \$4 billion was spent in 2011 on disability support pension recipients with musculo-skeletal and connective tissue medical conditions (FaHCSIA, 2011).

Because of their impact on the Australian community, arthritis and musculoskeletal conditions were declared a National Health Priority Area in 2002. The National Centre for Monitoring Arthritis and Musculoskeletal Conditions was established at the Australian Institute of Health and Welfare (AIHW) in 2005 to undertake surveillance and monitoring of arthritis and other musculoskeletal conditions in Australia (Australian Institute of Health and Welfare, <http://www.aihw.gov.au/>). A National Action Plan for Osteoarthritis, Rheumatoid Arthritis and Osteoporosis has been prepared by the National Arthritis and Musculoskeletal Conditions Advisory Group with the goal "...to decrease the burden of disease and disability associated with osteoarthritis, rheumatoid arthritis and osteoporosis within Australia and improve health related quality of life." (NAMSCAG, 2004)

The research project will inform future Arthritis Australia decisions about priorities, responsibilities and roles for the organisation to address these gaps through promoting policy change, partnering with other organisations or providing new support programs.

This is the research plan for the project. It outlines the methodology and project management.

## 2 Methodology

The methodology is designed to provide a comprehensive account of the disability impact on the lives of people with arthritis and their families and carers. The focus will be on what support people need to maximise their quality of life and participation.

The key data collection methods are:

- *Qualitative data collection* – face-to-face and telephone interviews with people with arthritis
- *Quantitative data collection* – a survey of people with arthritis and their families and carers.

The research will be conducted in three phases – 1) Project plan and review of the literature; 2) Fieldwork data collection; 3) Analysis and reporting about the implication of the research findings. The phases align with the project schedule and are outlined below.

### 2.1 Phase 1: Project plan and review of the literature

We will refine research questions and methodology with Arthritis Australia and the Advisory Group. Ethics approval has been granted by UNSW Human Research Ethics Committee.

We will conduct a review of the literature to collate information about current programs and national and international conceptualisation and practice relating to quality of life, disability service and support needs, experience of good support and gaps in support and service models. This information will be used to inform the scope and focus of the research questions and objectives and to design the fieldwork methods and instruments.

We will finalise and pilot the fieldwork instruments in this phase in response to the literature review findings, in order to fill the gaps and to collect specific information.

### 2.2 Phase 2: Fieldwork data collection

The purpose of the fieldwork is to understand the lived experience of people with arthritis in terms of functional change, quality of life, life choices, service and support needs, barriers to access of services, experience of good support and gaps in support, as well as the service and support responses to their experiences including good practice examples.

The methods will seek information about support to improve their quality of life and participation in three timeframes:

- what support would people prefer to assist them now
- what support helped or could have helped earlier in their experience of arthritis (early intervention or prevention of disability)
- what support would they want in the future.

The fieldwork includes roundtables with key informants; in-depth interviews; and a survey of people with arthritis and their families and carers (Table 2.1). Each method is described below. A progress report will be delivered during this phase.

**Table 2.1: Sampling framework**

Method	Sample	Framework
Roundtable 1	1	Arthritis Australia Advisory Group; Consumer Group
Roundtable 2	1	Arthritis Australia Advisory Group; Consumer Group
Interviews	20	Range by gender, age, cultural background, location, arthritis type and time since onset, support needs
Survey	>100	National distribution through Arthritis Australia, disability groups and other internet communication

### 2.2.1 Key informant roundtables

The roundtables will be with key informants who are people with arthritis and families and carers who have expertise in and knowledge of the policy context as well as lived experience. A first roundtable will be held at the commencement of the research in order to inform the research design (Phase 1). A second roundtable at the completion of fieldwork will confirm research findings and explore its implications.

The first roundtable will include people with arthritis and their families and carers who can provide an informed (both policy knowledgeable and personal) perspective on the disability impact of arthritis on life experiences and the barriers to maintaining good quality of life. Information from this roundtable and the literature review will inform the questions for the face-to-face interviews and the survey.

A second roundtable will be used to reflect on preliminary findings at the end of the fieldwork phase and will include members of the Advisory Group, Consumer Group and Arthritis Australia.

### 2.2.2 In-depth interviews

With the assistance of Arthritis Australia, we will recruit a sample of people to be interviewed, including: people with arthritis; their families; and carers of children and other people unable to directly participate. This will include men and women, people of diverse age and cultural background, location, length of time since diagnosis with

arthritis, type of arthritis, support needs and any other variables identified as significant in the literature review.

The sample includes 10 in-depth face-to-face interviews in Sydney metropolitan region and 10 national telephone interviews. The focus of the interviews will be identifying each person's opportunities to full participation and the barriers to meeting these goals. Semi-structured interviews will be used to gain in-depth knowledge about these issues. The methodology can be adapted by adjusting the timing, frequency and number of interviews. The researchers are experienced in inclusive interviewing of people with cognitive needs, families, carers and providers. Methods will be adjusted according to the capacity of the respondents.

### 2.2.3 Survey of people with arthritis

Following the in-depth interviews a brief survey of people with arthritis sampled from Arthritis Australia's networks will be conducted. The survey will provide quantitative data and be used to confirm the extent to which the findings (including the identified needs, gaps and barriers) from the in-depth interviews are applicable to the broader networks and, if relevant, to explore and clarify specific findings. The researchers are experienced in inclusive survey design, including modifying written language, alternative formats, telephone or face to face administration or proxy completion.

## 2.3 Phase 3: Analysis and reporting

The qualitative and quantitative fieldwork data will be analysed against the project objectives and thematically analysed by the research team and synthesized with literature review. A draft final report of the results will be submitted. Feedback from the Advisory Group will be used to prepare a final report.

The project will conclude with a presentation of the research findings and exploration of the potential directions to address the gaps and unmet needs identified in the research through promoting policy change, partnering with other organisations or providing new support programs and service models to facilitate quality of life, community living and access to NDIS support. The aim of this phase would be to maximise the utility of the deliverables for Arthritis Australia, service providers and the government as part of its strategic directions.

## 3 Program management

### 3.1 Project schedule

The research will be completed by October 2013 (Table 3.1). All deliverables will be presented in draft to receive comment and make amendments and a final version agreed. With the agreement and permission of Arthritis Australia, the results will be submitted for national and international publication to contribute to the evidence base on support for people with arthritis and their families and carers.

**Table 3.1: Research activities and timeframe**

Phase and deliverable	Activity	Date due
1: Project plan	Sign contract	Apr
	Meet with Arthritis Australia to refine design	Apr
	Ethics approval UNSW	Apr
	Literature review	May
	Advisory group	May
	Draft instrument development	May
	Submit Project Plan	June
2: Fieldwork	Roundtable 1	June
	Conduct and analyse in depth interviews	July
	Progress report	July
	Survey design, pilot and distribution	Jul
	Survey analysis	Sept
	Roundtable 2	Sept
3: Final report	Draft report	Sept
	Advisory group	Sept
	Final report	Sept
	Propose academic outputs	Sept
	Presentation	Oct

### 3.2 Governance

The project is conducted by SPRC researchers (Table 3.2).

**Table 3.2: Research team**

Responsibility	Researcher
Chief Investigator	Rosemary Kayess
Research design, literature review, fieldwork, analysis, survey management, reporting	Shona Bates, Charlotte Smedley, Anna Jones and Trish Hill
Adviser	Karen Fisher

The Advisory Group comprises of representatives from a consumer group, Arthritis NSW, AIHW (Musculoskeletal Monitoring Centre), a rheumatologist, the CEO of Arthritis Australia, the National Policy and Government Relations Manager for Arthritis Australia, and potential representatives from NDIS or FaCHSIA.

The Consumer Group will comprise of members of an existing Arthritis Australia consumer reference group.

### 3.3 Ethics

UNSW Human Research Ethics Committee (HREC), which is registered with the National Health and Medical Research Council (NHMRC) has granted ethics approval (HC13115). UNSW is committed to the highest standard of integrity in research. All human research activities are governed by the principles outlined in The National Statement on Ethical Conduct in Research Involving Humans. The University's Code of Conduct for the Responsible Practice of Research sets out the obligations by which all University researchers must abide, including confidentiality, freedom to withdraw, privacy and voluntary participation.

Prior to participation in the research, all participants will be provided with clear, accessible information about participating in the research, voluntary consent to participate (with continuous opportunities to withdraw from the research), respect for individuals' rights and dignity, reimbursement for participation expenses and confidentiality. Participants will also be informed that they can decide at any time to withdraw from the study by revoking their consent.

An Easy English version of the information statements and consent forms has been developed. A protocol for developing an ethical research environment and responding to participant risk will be designed before fieldwork begins. If participants agree, responses will be recorded for accuracy and transcription. All identifiable data will be de-identified in any publications resulting from this research. Data from this research will be kept in secure storage at the SPRC, viewed only by the research team for the purpose of the research and destroyed after seven years.

The research team has extensive experience in conducting research with people with physical and intellectual disability. Researchers responsible for carrying out the fieldwork component of the study have undertaken research with people with disabilities, families and service providers.

## 3.4 Communication plan

**Table 3.3: Communication strategy**

Communication to	Form	Frequency
Project manager, governance groups	Written reports, meetings, phone, email, presentations	Start and finish of each Phase and as required
People with arthritis and families	Written summaries of plan and progress inviting input distributed through Arthritis Australia	Start and finish of each Phase and as required, after approval
Other interested persons or organisations	Written summaries of plan and progress inviting input on SPRC website and elsewhere as agreed with Arthritis Australia	After each Phase after approval

At critical stages of engagement and collaboration we will confirm the research methods and tools with Arthritis Australia. There will be meetings with the Project Manager to discuss an overview of the project, the context, and schedule further meetings with the Project Manager and Advisory Group, to ensure a common understanding of the requirements of the project, co-ordinate the project design and discuss the draft methodology. Throughout the project, we will liaise regularly with the Project Manager to design a methodology and analysis that addresses the needs of Arthritis Australia.

## 3.5 Risk management

Potential risks that may impact on the management of the research and collection of data are summarised in Table 3.3, drawing on the expertise and experience of the research team.

**Table 3.4: Preliminary risk management strategy**

Risk	Likelihood	Severity	Solution
Failure to recruit diverse samples	Low	High	Work actively with Arthritis Australia to maximise participatory methodology across interest groups Recompense participants and families Trained researchers will facilitate participation
Poor quality data collection (inter-rater reliability)	Low	High	Training for researchers and good quality assurance systems
Psychological distress or other harm caused to participants and families	Low	High	Stringently designed recruitment and interview procedures. Trained interviewers. Follow up and referral where necessary.
Poor communication between researchers and Arthritis Australia	Low	High	Rosemary Kayess and the team have worked very closely with organisations commissioning research
Research does not adhere to budget	Low	High	Budget is based on previous experience of many projects, all of which have reported on time and within budget
Research design does not meet the needs of Arthritis Australia	Low	High	Design, detailed objectives and dissemination strategy will be developed in collaboration with Arthritis Australia and can be amended during the project
Data gaps to address the research objectives	Low	Med	Triangulate data sources. Work with the governance groups and Arthritis Australia to maximise triangulated data sources.
Research compromised due to lack of capacity	Low	Med	The research centre has a wide range of skills which could be drawn on if needed to enhance capacity of team
Research team fails to work effectively	Low	Low	Build on history of collaboration and protocols for accountability and communication
Research team member unavailable	Low	Low	Succession plan within the research team for continuity

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