

•*, *!,!+3Ï& 3 !+Ï + ï* 3(\$ï&

- * (Ï * 3• *',* 3* !, ! + ***ä**\$! Ï+3,

- \$ 1 3 B @ A C 3

3 ('*, 3ù?AC3



Contents

1	Int	troduction1		
2	Me	ethodology3		
	2.2	Phase 1: Project plan and review of the literature		
3	Pr	ogram manage-3(mn45m [(D6a30.002 WTJ EMC 5m <2i)6(n9 12 12>	4 >>BDC	12001

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 con1(m)-6(pl)3(oy)94i /Foot -1.3ne and modiare oB and r

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,

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 mako rs and a rinal version agreed. With the agreew 9 07 and rw 9 0 ission of Arthr 9 0 its Australia, rhe resultbewill subm 9 0 itted for national a7 rnterna rional publication to rontr 9 0 ibuteo rhe ridence base on sup rt ror peop re with ar 9 0 thr 9 0 its a7d rheir 9 0 ram 9 0 ilies a7d carers.

Phase a7d deliverable	Activity	Date due
1: Pro rect pla7]TJ ET C		Apr
	Meet with Arthritis Austra ria8to refine design8	Apr
	Ethics approval UNSW	Apr
	Literature review	Мау
	A 2(i)14roupew	

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 pin mo Ifn Eas anearch), is a combined of the statements agree.

3.4 Communication plan

tegy
)

	•	
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: Pre	eliminary risk m	anagement strategy
		anagomon onatogy

Risk	Likelihood	Severity	Solution
Failure to recruit			
diverse samples			

Social Policy Research Centre The University of New South Wales

sprc@unsw.edu.au +612 9385 78 00