



Arthritis Foundation of Australia
Level 2, 255 Broadway, Glebe NSW 2037
PO Box 550, Broadway NSW 2007
p: +61 2 9518 4441 f: +61 2 9518 4011
e: info@arthritisaustralia.com.au
w: www.arthritisaustralia.com.au

Arthritis Australia submission on the refresh of the Chronic Disease Framework

ABOUT US

Arthritis Australia is the peak arthritis organisation in Australia and is supported by affiliate organisations in ACT, New South Wales, Northern Territory, Queensland, South Australia, Tasmania and Western Australia.

Arthritis Australia provides support and information to people with arthritis as well as their family and friends. It promotes awareness of the challenges facing people with arthritis across the community, and advocates on behalf of consumers to leaders in business, industry and government.

In addition, Arthritis Australia funds research into potential causes and possible cures as well as better ways to live with the disease.

For further information on this submission contact:

Louise Hardy, Director of Policy and Advocacy

m- 0424 055 149

e- lhardy@arthritisaustralia.com.au



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| Demographic Questions | | |
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| 1. Which stakeholder group best describes you? Please tick all that apply. | <ul style="list-style-type: none"> • Federal Government • State Government • Local Government • National private non-government organisation • National not for profit non-government organisation • Jurisdictional private non-government organisation • Jurisdictional not for profit non-government organisation • Academic or researcher • Health professional/clinician • Consumer/person living with a chronic condition • Family member or carer of a person living with a chronic condition • Interested member of the public • Prefer not to say | <ul style="list-style-type: none"> • Tick all that apply |
| Part 1: Overview of the Framework | | |
| 2. Have you engaged with and used the Framework, and if so, how? Please tick all that apply. | <ul style="list-style-type: none"> • To improve my understanding of the healthcare system • An organisation that I am engaged with shared the document with me • I have discussed it with a healthcare professional • I am a health professional who has used the Framework to inform my clinical practice • I read it out of personal interest | <ul style="list-style-type: none"> • Tick all that apply • Option for free text 'other' |

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| | <p>There is also the option to include any other information about your engagement with the Framework in the 'Other' open-text response box.</p> | <ul style="list-style-type: none"> • To guide the development of policies, programs and/or projects for the organisation I represent • My organisation has shared this document with our members/consumers • To guide our organisation's funding models and initiatives • I, or the organisation I represent, have not utilised the Framework in any capacity • I, or the organisation I represent, did not know about the Framework prior to this consultation • Other: | |
| <p>3.</p> | <p>The Vision of the Framework (Vision) is: "All Australians live healthier lives through effective prevention and management of chronic conditions."</p> <p>To what extent do you agree the Vision is still relevant?</p> <p>(Optional): Please provide further comments</p> | <ul style="list-style-type: none"> • Agree • Somewhat agree • Neither agree nor disagree • Somewhat disagree • Disagree • Not applicable | <ul style="list-style-type: none"> • Sliding scale • Open text response <p>We agree that the vision statement as it is currently written is appropriate.</p> |

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| | <p>about your response, including any suggested amendments to the Vision.</p> | | |
| <p>4.</p> | <p>There are 7 enablers to achieving the Vision included in the Framework. Each of these enablers are shown below.</p> <p>Please provide a score from 0-10 to demonstrate how important you think each of the enablers are (with 0 being not at all important and 10 being very important).</p> <p>(Optional): Are there any other enablers you think should be</p> | <ul style="list-style-type: none"> • Governance and leadership — supports evidence-based shared decision-making and encourages collaboration to enhance health system performance. • Health workforce — a suitably trained, resourced and distributed workforce is supported to work to its full scope of practice and is responsive to change. • Health literacy — people are supported to understand information about health and health care and appropriate health care settings, to apply that information to their lives and to use it to make decisions and take actions relating to their health. • Research — quality health research accompanied by the translation of research into practice and knowledge exchange strengthens the evidence base and improves health outcomes. • Data and information — the use of consistent, quality data and real-time data sharing enables monitoring and quality improvement to achieve better health outcomes. • Technology — supports more effective and accessible prevention and management strategies and offers avenues for new and improved technologically driven initiatives. • Resources — adequate allocation, appropriate distribution and efficient use of resources, including funding, to address identified health needs over the long-term. | <ul style="list-style-type: none"> • 0-10 score • Open text response <p>Health workforce: this section should place more emphasis on primarily having the appropriate numbers of suitably trained, resourced and distributed health professionals.</p> <p>Expanding scopes of practice can and will play a role in addressing workforce shortages – but it should not be seen as the primary solution.</p> <p>Research: Research funding and support needs to more closely reflect the burden of disease across the community. Diseases such as arthritis currently receive less research funding than would be indicated if funding more closely reflected the burden of disease.</p> <p>Resources: the distribution of resources needs to more appropriately reflect the burden of disease. There is an ongoing need for disease-specific investment strategies, particularly for conditions which have been historically overlooked such as arthritis and musculoskeletal conditions. The Arthritis Action Plan implementation funding has been a key enabler for initiatives such as development of health professional education modules.</p> |

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| | included in the Framework? | | |
| Part 2: Objectives of the Framework | | | |
| Objective 1: Focus on prevention for a healthier Australia | | | |
| 5. | The Framework identifies determinants of health that influence the prevention, treatment and management of chronic conditions. Several are listed below. These are commonly referred to as the social, cultural, environmental and economic or commercial determinants of health. | <ul style="list-style-type: none"> • Employment | Arthritis disproportionately impacts people from socio-economically disadvantaged groups, people living in rural and remote locations, and Aboriginal and Torres Strait Islanders. Each of these groups also face greater barriers to accessing services. People with arthritis and musculoskeletal conditions also have a particular need for affordable support to remain active and mobile and manage pain, and support to achieve a healthy weight. People with arthritis face weight related stigma, and challenges maintaining a healthy weight, from the side effects of medicines, to disability and mobility issues impacting physical activity. As policy responsibility for these determinants ranges across the tiers of government and across different portfolios, effective prevention needs to incorporate a health in all policies approach. This needs to have buy-in and support not only from specific policy departments but also from first ministers, treasurers and finance ministers and their departments. |
| | | <ul style="list-style-type: none"> • Income level | |
| | | <ul style="list-style-type: none"> • Living in a rural/ regional/remote location | |
| | | <ul style="list-style-type: none"> • Education | |
| | | <ul style="list-style-type: none"> • Language and writing skills | |
| | | <ul style="list-style-type: none"> • Refugee or migration status | |
| | | <ul style="list-style-type: none"> • Housing | |
| | | <ul style="list-style-type: none"> • Living with a disability | |
| | | <ul style="list-style-type: none"> • Promotion of unhealthy products | |
| | | <ul style="list-style-type: none"> • Social connection | |
| | | <ul style="list-style-type: none"> • Racism and discrimination | |
| | | <ul style="list-style-type: none"> • Air and water quality | |
| | | <ul style="list-style-type: none"> • Climate change | |
| | | <ul style="list-style-type: none"> • Opportunities to take part in physical activity | |
| <ul style="list-style-type: none"> • Weight related stigma | | | |
| <ul style="list-style-type: none"> • Access to safe, nutritious and culturally appropriate food | | | |
| Please discuss which, if any, of the above determinants of health impact have most significantly impacted you or the work of your organisation. | | | |
| Additionally, are there any other determinants of health that you think the Framework should focus on? If yes, please note them. | | | |
| Objective 2: Provide efficient, effective and appropriate care to support people with chronic conditions to optimise quality of life | | | |

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| <p>6.</p> | <p>One of the aspirational outcomes of Objective 2 of the Framework is that people with chronic conditions have equitable access to quality health care. Pages 35-36 of the Framework discuss this in further detail.</p> | <ul style="list-style-type: none"> • Agree • Somewhat agree • Neither agree nor disagree • Somewhat disagree • Disagree • Not applicable <p>To what extent do you agree with the following statements?</p> <p>a. Australians with chronic conditions can easily access primary care services, including regular care with a GP and/or allied health providers.</p> <p>b. Australians with chronic conditions can easily access specialty healthcare services when required.</p> <p>(Optional): Please provide further comments about any of your responses to the previous statements.</p> | <ul style="list-style-type: none"> • Sliding scale • Open text response <p>Comment:</p> <p>It is widely acknowledged, including by governments, that there are currently significant challenges for many Australians in being able to access in a timely way primary and specialist care, with unacceptably long waiting lists for some specialties and geographic regions. There is a workforce crisis in rheumatology, with about half the required workforce in adult rheumatology, long waits for appointments well exceeding care standards.</p> <p>In Arthritis Australia’s consumer research and surveys over many years, lack of affordable access to allied healthcare is consistently a top concerns.</p> <p>Whilst initiatives to reduce the cost of medicines have been welcome and the recent budget measures to increase GP bulk billing rates appear to have stabilised bulk billing rates, out of pocket costs for non-bulk billing GPs continue to climb.</p> <p>Out of pocket charges for specialists continue to increase from an already high base. A high proportion of adult rheumatology takes place in the private system.</p> <ul style="list-style-type: none"> • |
| <p>7.</p> | <p>Another of the aspirational outcomes of</p> | <ul style="list-style-type: none"> • Agree • Somewhat agree • Neither agree nor disagree | <ul style="list-style-type: none"> • Sliding scale • Open text response |

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| | <p>Objective 2 of the Framework is effective sharing of information and data. Pages 37-38 of the Framework discuss this in further detail.</p> | <ul style="list-style-type: none"> • Somewhat disagree • Disagree • Not applicable <p>To what extent do you agree with the following statement?</p> <p>I have access to health information and data, and use this to help make decisions regarding the prevention, diagnosis, treatment and management of chronic conditions.</p> <p>(Optional): Please provide further comments about your response, and if appropriate, provide examples of ways you have or have not used information and data.</p> | <p>Comment:</p> <p>This will depend on individual circumstances and their particular contexts.</p> <p>Many Australians with chronic conditions find navigating the health system difficult and confusing – particularly where they may have multiple and complex co-morbidities.</p> <p>The roles of navigation and co-ordination – particularly at a primary care level are crucial.</p> <p>Equity in access to information is also important – particularly for those who may not have access to, or literacy in, IT and communications devices.</p> |
| Objective 3: Target priority populations | | | |
| <p>8.</p> | <p>The Framework aims to act as a broad overarching guidance document that is inclusive of the full spectrum of chronic conditions.</p> <p>To what extent do you agree with the</p> | <ul style="list-style-type: none"> • Agree • Somewhat agree • Neither agree nor disagree • Somewhat disagree • Disagree • Not applicable <ol style="list-style-type: none"> 1. Australians living with chronic conditions, including myself, friends/family, patients, or members of the organisation I represent if applicable, are recognised in the Framework. 2. The Framework is representative of the diversity of population groups in Australia. 3. The Framework recognises the individual needs of the many different groups in Australia. | <ul style="list-style-type: none"> • Sliding scale • Open text response |

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| | following statements? | <p>4. The Framework provides guidance about how the prevention and management of chronic conditions can be tailored to the needs of different population groups.</p> <p>(Optional): Please provide further comments about any of your responses to the previous statements.</p> | |
| 9. | The Framework includes the following list of priority populations, but notes this list is not exhaustive. | <ul style="list-style-type: none"> • Aboriginal and Torres Strait Islander people • People from culturally and linguistically diverse backgrounds • Older Australians • Carers of people with chronic conditions • People experiencing socio-economic disadvantage • People living in remote, or rural and regional locations • People with disability • People with mental illness • People who are, or have been incarcerated <p>Please provide information known to you on the experiences of people with chronic conditions in the above, or additional, priority population groups including any challenges and barriers in accessing prevention and/or treatment services that you think may be of relevance to the refresh of the Framework.</p> | <ul style="list-style-type: none"> • Open text response • We would suggest adding people from the LGBTIQ community, as well as older women with limited financial assets, a group recognised in the Women’s Health Strategy, which is a key group impacted by arthritis. |
| Part 3: Focus on the Future | | | |
| 10. | Potential barriers for people with chronic conditions are shown below. | <ul style="list-style-type: none"> • Difficulty in finding an appropriate healthcare provider or facility • Long wait lists • Lack of coordinated care and communication between health professionals • Lack of information sharing and exchange between healthcare providers • Financial cost of healthcare | <ul style="list-style-type: none"> • Select all that apply • Open-text response <p>particularly relevant for arthritis are:</p> <ul style="list-style-type: none"> • long wait lists both for joint replacement surgery and rheumatology appointments • out of pocket healthcare costs |

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| | <p>Which of these barriers do you believe significantly impact Australians living with chronic conditions (including yourself if applicable)? Please select all that apply.</p> <p>(Optional): Are there any other barriers that you would like to draw attention to?</p> | <ul style="list-style-type: none"> • Limited awareness and understanding of chronic conditions and/or prevention by patients and/or carers • Limited understanding of the healthcare system by patients and/or carers • Limited knowledge of some chronic conditions by healthcare professionals • Stigma associated with chronic conditions and risk factors • Stigma of accessing healthcare <ul style="list-style-type: none"> • Not being able to attend appointments due to geographical location/transport • Difficulty using technology to receive or navigate healthcare services • Lack of health promotion education and prevention activities • Low English proficiency and other language challenges • Limited availability of publicly funded health programs • Lack of access to research and data • Lack of culturally safe healthcare | <ul style="list-style-type: none"> • the need for co-ordinated affordable multidisciplinary care and the lack of access to this • Lack of recognition of arthritis from health professionals, often leading to delayed diagnoses • Health professionals' limited understanding of care pathways and best practice management of arthritis, for example people with osteoarthritis are often not referred to allied health or encouraged to keep active – in fact they are sometimes told to stop physical activity they were previously undertaking. • Stigma around people with chronic pain and 'invisible' disabilities such as arthritis. People report being perceived as malingering, or stigmatised as opioid seeking. There is also a general trivialisation and misunderstanding of arthritis as a normal part of ageing for which nothing can be done. |
| <p>11.</p> | <p>As part of the refresh of the Framework, condition-</p> | <ul style="list-style-type: none"> • Yes • No • Not applicable • (Optional): Please elaborate on your response. | <p>Yes/No answer with optional open text response</p> <p>Arthritis Australia supports this approach. It is important that disease specific action plans continue to be utilised to</p> |

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| | <p>specific Action Plans and Strategies will be reviewed to ensure that the documents are complementary to, and build on, the Framework.</p> | <p>Do you support this description of the inter-relationship between the Framework and condition specific Action Plans and Strategies?</p> | <p>address issues that cannot be covered by cross-disease approaches.</p> <p>Reviews and any revisions of condition specific action plans should be done in full consultation with the relevant condition specific stakeholder groups.</p> |
| <p>12.</p> | <p>The condition-specific Action Plans and Strategies include a number of commonalities in priorities and actions.</p> | <ul style="list-style-type: none"> • Yes • No • Not applicable <p>(Optional): Please elaborate on your response.</p> <p>It is proposed to embed these common priorities and actions in the refreshed Framework. Therefore, any condition-specific guidance would be focussed on tailored actions for that condition, where the need exists.</p> <p>Do you support this approach?</p> | <p>Yes/No answer with optional open text response</p> <p>Whilst Arthritis Australia can understand the logic of embedding common priorities and actions within the framework, it is vitally important to ensure that important disease specific initiatives from specific action plans are not lost in this process.</p> <p>Experience in Australia and overseas is that in the absence of specific guidance, most resources and attention tends to flow to the following conditions:</p> <ul style="list-style-type: none"> • Cancer • Diabetes • Respiratory illness • Cardio-vascular disease <p>Whilst the above conditions constitute a significant burden of disease, other conditions that impose significant morbidity such as musculoskeletal conditions can be overlooked unless they are specifically addressed within framework documents.</p> |

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| | | | <p>If the individual condition specific action plans are going to rolled up into an overall framework, consideration should be given to adding an appendix that sets out the priorities and actions for specific conditions that are currently included in the existing action plans.</p> |
| <p>13.</p> | <p>Many common issues and challenges can be found in the prevention, treatment and management of different chronic conditions. Several of these issues are listed below.</p> | <ul style="list-style-type: none"> • Yes • No • Not applicable <ul style="list-style-type: none"> • Multi-disciplinary care • Managing multimorbidity • Continuity of care across life stages • Transitions of care as a patient moves across and through the health system • Enhanced and targeted support for priority populations • Health promotion and education • Self-management • Life stage transitions • Embedding prevention in the continuum of care <p>Do you believe a focus on these common issues is relevant, accurate and appropriate for Australians living with a chronic condition?</p> <p>(Optional): Please elaborate on your response and/or include any other common issues across chronic conditions that you would like to note.</p> | <ul style="list-style-type: none"> • Yes/No answer with optional open text response • Open text response <ul style="list-style-type: none"> • There needs to be a greater focus on multi-disciplinary care in the community, including access to community -based medical specialists as part of multi-disciplinary teams. • There needs to be greater recognition of multi-morbidity and the interaction of different conditions. Arthritis is one of the most commonly comorbid conditions, with about three quarters of people with arthritis impacted, including high proportions of people with COPD, diabetes and cardiovascular disease. Arthritis symptoms, as well as medications used to treat arthritis, may lead to or exacerbate other disease conditions. • Effective models of care developed to manage arthritis and musculoskeletal conditions could be applied to manage other chronic conditions and multimorbidity. • Greater emphasis on prevention at all stages of a chronic is also critical - too often the early stages of chronic conditions are allowed to progress to the point where they become a significant burden. |

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| <p>14.</p> | <p>A large number of resources, training modules, tools and guidelines have been developed to support the prevention, treatment and management of chronic conditions.</p> | <p>There is an opportunity for digitisation to reduce duplication, improve effectiveness of support and enhance impact. Use of emerging digital technologies provide opportunities for enhanced chronic conditions management into the future.</p> <p>This will be a key consideration for the refresh of the Framework.</p> <p>(Optional): Please provide information on any opportunities for digitisation to enhance the prevention, treatment and management of chronic conditions.</p> | <ul style="list-style-type: none"> • Open text response <p>The rapid development of digital technologies has huge potential to enhance prevention, diagnosis, treatment and management of chronic conditions going forward – particularly as AI deployment gathers pace. The arthritis and musculoskeletal space has some excellent examples of innovation that could be drawn upon and learnt from including pioneering living clinical guidelines, health professional education modules on arthritis, and Arthritis Australia’s suite of condition specific web platforms.</p> <p>This potential needs to be qualified by the experiences and lessons from the deployment of new technologies up to now. In particular the actual reality of the deployment of new technology – eg the digital health record - has often not lived up to its promise.</p> <p>It is also important that unique elements of disease specific resources, often codesigned with consumers, are not lost in a drive to reduce duplication.</p> |
| <p>15.</p> | <p>COVID-19 has had significant impacts on the Australian healthcare system, including the prevention, treatment and management of</p> | | <ul style="list-style-type: none"> • Open text response <p>As recognised in the discussion paper, the pandemic and the response to it have had a significant impact on the health system. On the positive side, the pandemic has prompted the wider adoption of innovative models of service delivery such as telehealth, and have resulted in increased access to health services for many individuals and groups.</p> <p>Negative impacts include:</p> |

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| | <p>chronic conditions.</p> <p>Please describe any impacts (positive or negative) of COVID-19 that you would like to highlight.</p> | | <ul style="list-style-type: none"> • Long covid and exacerbation of other chronic conditions as a result of Covid infections • delayed diagnoses and treatment • Workforce shortages – Joint replacement surgery has been a particular issue as it is deprioritised under current clinical urgency coding, and as a result many people with arthritis who cannot afford surgery in the private system have been left waiting with significant pain and disability for well over a year for surgery • Exacerbation of many existing inequities |
| <p>16.</p> | <p>Which of the following statements are most important to you in terms of how the Australian Government enhances and uses the Framework in the future? Please select up to 5 options.</p> | <ul style="list-style-type: none"> • Greater promotion of the Framework to peak bodies to increase awareness • Greater promotion of the Framework to health professionals and researchers to increase awareness • Greater promotion of the Framework to consumers and the general public to increase awareness • Increased focus on how organisations can work together to improve the management of chronic conditions • Improve the collaboration between state and territory governments and the federal government • Refresh the content of the Framework to be better aligned with other state and territory, national and international policies, strategies and plans • Refresh the content of the Framework to focus on emerging risks and issues (e.g., the use of e-cigarettes) • Refresh the content of the Framework so it reflects the post COVID-19 health landscape | <ul style="list-style-type: none"> • Select up to five (5) options <p>The government should also plan for how it intends to monitor and evaluate the impact of the framework, including how it will report against the performance indicators in the framework.</p> |

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| | | <ul style="list-style-type: none"> Increased focus on the importance of lived experience in the Framework | |
| | | <ul style="list-style-type: none"> Greater emphasis on the needs of priority populations | |
| Part 4: Summary | | | |
| 17. | (Optional): In 1000 words (6000 characters) or less, please provide any additional feedback on the Framework including any other opportunities to improve the Framework. | | <ul style="list-style-type: none"> Open-text response Limit of 1000 words <p>The framework is an important document to guide governments and non-government organisations in their work.</p> <p>It is however important that the document, once refreshed, is not left to sit on the shelf until the next refresh occurs. It is not clear whether implementation steering groups that were proposed in disease specific action plans were actually convened, but the refresh of this Framework provides an opportunity to involve stakeholders in advising and overseeing implementation.</p> <p>Ultimately, governments at both the Commonwealth and State/Territory level have responsibility for setting the policy framework that will enable the outcomes set out in the framework to be achieved.</p> <p>Governments should also hold themselves accountable for the achievement of the outcomes.</p> <p>The framework covers a range of portfolios beyond health and also cuts across the responsibilities of the different tiers of government and jurisdictions.</p> |

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| | | | <p>Effective implementation of the framework will require sustained effort across the whole of government at both the Commonwealth and State levels.</p> <p>Arthritis Australia therefore proposes that the Prime Minister and the Chief Minister of each jurisdiction make an annual statement to Parliament outlining the progress to achieving the outcomes in the framework over the past year, the barriers encountered and actions proposed to overcome them.</p> |
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