



Submission on the consultation draft of *The Whole Journey Guide*

Introduction

Arthritis Australia welcomes the opportunity to provide feedback on the consultation draft of *The Whole Journey: A guide for thinking beyond compliance to create accessible public transport journeys*.

We represent nearly seven million Australians living with arthritis and musculoskeletal conditions. These conditions are the leading cause of disability in Australia.¹

Contrary to popular perceptions, arthritis related disability does not just affect older people. Around half of all people with disability associated with arthritis and musculoskeletal conditions are aged less than 65 years.

Many people living with these conditions experience great difficulty in accessing public transport. For example, more than one million people with arthritis and osteoporosis report that they are restricted in their ability to use public transport.² Two out of three people with arthritis related impairment report difficulties in accessing and using public transport.³

Difficulties with transport in general, including public transport, reduce social participation and affect people's ability to undertake everyday activities such as working, shopping or attending health services. Many people with arthritis and musculoskeletal conditions report that difficulties with travelling to and from work are an important factor in their decision to reduce or cease employment. This is significant because these conditions are the leading cause of early retirement due to illness in Australia.⁴

Arthritis and musculoskeletal conditions are often referred to as a 'hidden disability.' A person struggling with arthritis may not have a visible disability but may endure constant pain, joint restriction, chronic fatigue, and associated functional and mobility issues. Many find it difficult to stand or walk for any length of time, climb up or down stairs or grip things.

Because of the often invisible nature of their condition, people with arthritis report that they do not get the assistance and consideration they need either from drivers of public transport or from fellow passengers, in terms of boarding or disembarking assistance, access to seats and rails, and patience when additional time is required to get on and off public transport.

For people with mobility devices, such as walkers, getting on and off public transport is very difficult. People with mobility scooters cannot access trams or buses at all.

Comments on the consultation draft

Addressing issues relating to whole of journey accessibility is critical to enable people with disability to access and use public transport with confidence and to support social, economic and cultural inclusion. Consequently, we strongly commend the development of *The Whole Journey Guide* and generally support the principles and guidelines it outlines.

We note that the Guide includes specific guidelines for transport interchanges. We recommend that more detailed guidelines should also be provided for other complex facilities such as airport terminals and larger train or bus stations. These more complex facilities are more difficult to negotiate for people with disability and often require people to move substantial distances to access boarding points or facilities such as lifts, ramps or escalators.

2. Influencing Factors

Varied needs of users

It is important to recognise that many impairments such as arthritis, are not visible and that this can create specific problems when using public transport.

For example, people with arthritis, especially younger people, are unlikely to be offered priority seating on public transport or they are maligned for using it, because they do not look disabled. Many are loath to have to constantly explain their condition to strangers in order to use these facilities, so they endure the pain of standing or avoid public transport altogether. Of particular concern, people with arthritis commonly report that they are abused for using disabled parking spots, despite having a permit, an embarrassing and sometimes scary situation.

Including signage reminding other community members that not all impairments and conditions are visible could encourage increased courtesy and understanding from fellow travellers in these situations (see 'Public transport service' below).

Drivers of change, urban design and liveability

Increasing rates of chronic disease are an important factor that is likely to influence urban and public transport design in the future.

Higher rates of chronic disease, in addition to the ageing population will increase the number of people with impairments using public transport. For example the number of people with arthritis is projected to increase from 3.9 million in 2015 to 5.5 million by 2030.

In addition, the impact of urban design on health and well-being is increasingly being recognised in strategies to address Australia's increasing rates of obesity and chronic disease. Well connected, integrated and accessible public transport systems can help to support better health and wellbeing and healthy ageing. Public transport use increases incidental physical activity which may help prevent the onset of chronic illness and may delay many of the functional losses that may lead to dependency.⁵

3. Parts of a journey

This section gives considerable emphasis to the use of online tools and apps in relation to journey planning. While this approach has great potential to meet the needs of people with disability, apps and online planning tools are unlikely to be widely used by older clients who are disabled. Access to an alternative, such as a customer service telephone hotline, especially for pre-journey planning, could be of great assistance for these users.

Pre journey planning tools

In addition to the information listed, we recommend that information regarding seating availability at stops and the location of disability parking spaces is included. In the real-time information to be included in tools, the number of disability parking spaces could be included. As noted above, a telephone hotline to assist people with planning their travel, and which does not rely on access to

technology or on people being physically present at a stop/station to see the information, would be helpful.

Journey start and end

Information about accessing stops/stations/terminals should also include information regarding availability of disabled car parking spaces and lifts and availability of nearby taxi ranks.

Public transport stop, station or terminal

We recommend that two additional aspirations be added to this section.

Firstly, that larger stops/stations/terminals should be easy to move around, with conveniently placed lifts, ramps and travelators and seats allowing opportunities for rest. Moving between floors or boarding access points, especially in a large station or interchange can entail walking long distances to access lifts or escalators, a major challenge for people with mobility impairment. When planning services, consideration needs to be given to placement of lifts, escalators and travelators to minimise the distance that people need to walk to access public transport vehicles.

Secondly, any additional equipment and procedures required to support accessibility are deployed sensitively and unobtrusively and with respect for an individual's dignity. Many people with mobility impairment are reluctant or embarrassed about drawing attention to themselves by using services such as wheelchairs or special lifts like those used to access aircraft where no aerobridge is available.

Airport terminals in particular can offer major challenges for people with arthritis in relation to the distances they need to move to access boarding, challenges of managing luggage and mobility aids, passing through security checks and boarding aircraft where no aerobridge is available. A number of people with arthritis have highlighted issues with airport terminals including:

- The need to travel significant distances to access boarding gates
- Difficulties associated with security procedures including:
 - standing in queue during busy times
 - lack of a convenient chair to allow people to remove and replace their shoes without needing to walk significant distances in bare feet, a particular problem for people with balance issues;
 - the need to lift carry-on items on to the scanner belt
 - the difficulties of navigating these processes while juggling mobility aids and carry-on items
 - inconsiderate staff.
- Difficulties in managing stairs to access the tarmac and the aircraft when an aerobridge is not available. This is a significant issue in rural areas which are predominantly serviced by smaller aircraft. One traveller with arthritis reports being embarrassed by the lift and procedures used to help her access small aircraft without an aerobridge, highlighting the discomfort of the lift itself and the fact that it is deployed after all other passengers are on board. In her words, this requires a *'walk of shame past every single person who just witnessed you on your journey to the door...It is bad enough travelling when you have a disability, but humiliation on top is just not the way I want to go. I need to keep some modicum of dignity and I will fight to retain that as long as I can even if I have to crawl up those damn plane steps.'*

- Lack of consideration and patience from other commuters when additional time is required to board aircraft using stairs or to stow carry-on luggage.

Design and procedures which support independent movement and boarding, minimise the distance people need to walk to access boarding points and offer frequent opportunities for rest, as well as procedures that respect an individual's dignity are required.

In particular, customer service or concierge style services to help people to access services should be available in airports or large transport stations or interchanges.

For smaller stops/stations, lack of adequate seating and shelter and the need to navigate stairs without a lift (eg for railway stations) are common issues that need to be addressed.

Signage heights at stops/station should take into account the needs of all users eg those in a wheelchair.

Public transport service

Boarding and disembarking

As highlighted above, boarding and disembarking from public transport vehicles for people with mobility impairment or joint stiffness can be problematic and often requires additional time. For people with mobility devices such as walkers, getting on and off public transport is especially difficult, while people with mobility scooters cannot access trams or buses at all.

People with arthritis often complain about lack of willingness from drivers and other public transport staff to assist them with boarding or disembarking, or impatience or rudeness from staff as well as fellow passengers, because of the extra time required.

Driver and staff training, and education and awareness campaigns for commuters could assist.

Access to seating

People with arthritis and musculoskeletal conditions experience pain and fatigue that can make standing on public transport journeys difficult. However the invisible nature of their condition, especially for younger people, means they are unlikely to be offered priority seating on public transport or they are maligned for using it. Many are loath to have to constantly explain their condition to strangers in order to use these facilities.

One solution would be to offer a 'Please offer me a seat' badge and card, as recently implemented by Transport for London. This program has been introduced to recognise customers with invisible impairments who have difficulty standing but struggle to get a seat on public transport because their impairment is not immediately apparent.⁶

The badge was tested in a six-week trial with 1,200 users. Participants reported increased confidence in using public transport, with more than 72% reporting journeys were easier as a result of the badge and 98% saying they would recommend the badge to others who needed it.

Seats and hand rails

Seats should be designed to be comfortable to minimise pain for people with conditions such as arthritis, especially during lengthy or rough travel.

There should be a number of handrail and grip options for traveling including for boarding, sitting down and getting up from their seat, during the journey and disembarking. The shape, finish and location of these points, should consider the needs of all customers (eg people with shoulder problems are unable to use overhead hand grips) and be comfortable to hold.

Consumer feedback

Negative experiences can create anxiety for consumers which cause them to avoid public transport in future. Not all consumers, especially older consumers, will be able to provide feedback through online avenues or apps, so alternatives processes for providing feedback should be made available and promoted eg a telephone hotline or written process for feedback and complaints.

4. What does this mean for us?

Consumers with a range of disabilities should be involved in planning and design processes. Consumer testing is the most reliable way to identify problems with current systems.

Having designers and other stakeholder undergo empathy tasks can also help to shift perspective and foster empathy. For example at Arthritis Australia, we have arthritis simulation gloves which allow users to develop a greater understanding of how limited dexterity and grip strength can affect an individual's activities.

Conclusion

We welcome the development of the *Whole of Journey Guide* and support the principles and guidelines it outlines. We would however like to see more specific guidelines included for more complex facilities such as larger train and bus stations and, in particular, airport terminals.

We would also like to see the needs of commuters with invisible disabilities addressed in the Guide. In particular we support the introduction of a 'Please offer me a seat' program, like that recently introduced by Transport for London to recognise customers with invisible impairments who have difficulty standing but struggle to get a seat on public transport because their impairment is not immediately apparent.

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23/6/2017

¹ Australian Bureau of Statistics 2016. *2015 Disability, Ageing and Carers Australia: Summary of Findings 2015*

² Australian Institute of Health and Welfare: Rahman N & Bhatia K 2007. Impairments and disability associated with arthritis and osteoporosis. Arthritis series no. 4. Cat. no. PHE 90. Canberra: AIHW.

³ Bates, S., Smedley, C., Wong, M., Kayess, R. & Fisher, K. R. (2014). *Arthritis and disability* (SPRCReport 26/2014). Sydney: Social Policy Research Centre, UNSW Australia

⁴ Schofield DJ, Shrestha RN, Cunich M 2016. *Counting the cost: the current and future burden of arthritis. Part 2 Economic Costs*. Arthritis Australia 2016

⁵ Australian Chronic Disease Prevention Alliance 2010: *Submission to Our Cities – Building a productive sustainable future*

⁶<https://tfl.gov.uk/campaign/please-offer-me-a-seat>