

Medical Imaging and Women's Health Services in NSW
Final report

SCIA Policy & Advocacy Team
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Executive Summary

In partnership with the Physical Disability Council of NSW, Paraquad NSW, Muscular Dystrophy NSW and the Cerebral Palsy Alliance, Spinal Cord Injuries Australia commissioned a survey to investigate the experiences of people with physical disability when accessing medical imaging and women's health services in NSW. **The survey received 112 responses and of 118 specific services described, challenges and barriers were identified in 57% of experiences.** Specifically, the following challenges and barriers to universal accessibility and their respective impact was identified:

- Lack of assistive technology or other accessible features on the premises of the medical facility;
- Lack of wheelchair manoeuvrability for power wheelchairs;
- Lack of disability awareness across staff and health professionals;
- Undue burden on people with disability to find alternative solutions when medical imaging or women's health services of their choice are inaccessible (which includes additional costs, travel or risks to health due to alternative procedures sought);
- Increased wait times or delays obtaining diagnoses or abandonment of health screening altogether; and
- Emotional impact of poor experiences and treatment by health professionals.

The survey's findings clearly indicate the inequitable experiences faced by people with physical disability accessing medical imaging and women's health services in NSW. It suggests that policy-makers need to take urgent action to address the above barriers and further research should be conducted across other states and territories to determine the extent of these issues across other jurisdictions.

1 Background

Greg Killeen, Senior Policy Officer at Spinal Cord Injuries Australia (**SCIA**), is the Consumer Representative of the NSW Health Agency for Clinical Innovation Clinical Development Committee (**CDC**) for Spinal. The role requires him to report on access barriers to NSW Health services and facilities to the CDC. It is impossible to report all barriers experienced by all people with spinal cord injury across NSW, and often the issues are identified through word-of-mouth, social media or personal experience.

Greg has quadriplegia and personally encountered access barriers when attempting to use medical imaging services either due to the lack of hoist and sling facilities or due to the Prince of Wales Hospital's (**POW Hospital**) policy in their Medical Imaging Department of not accepting GP referrals for ultrasounds. He recently attempted to get a Doppler ultrasound on his leg at the Vascular Lab, POW Hospital, which is a privately operated service within the public hospital system. The Vascular Lab does not have a hoist and sling, and although the Vascular Lab is located next to the Outpatients Clinic, the POW Hospital administration would not allow the Vascular Lab to use its lifting equipment or Surgical Dressers (Wardsmen) to assist.

In 2017 the Federal Government's Senate Inquiry into the Accessibility of Medical Imaging services throughout Australia had Terms of Reference that focused on the 'accessibility' of medical imaging services throughout Australia, relating specifically to the location of such facilities. SCIA made a submission that highlighted the lack of physical access to medical imaging services at private medical imaging services and public hospitals. The submission also mentioned the problems for women accessing women's health services including mammograms.

The Senate Inquiry's report recommended that states and territories provide hoists and slings to transfer people with disability, however, the recommendations were not made mandatory.

Subsequently, Greg and SCIA have tried to address the lack of access to medical imaging and women's health services through the CDC. One meeting with the CDC (Spinal) management resulted in SCIA being asked to do a survey of its members to find out the extent of the problems. SCIA's Policy and Advocacy Team created and distributed a survey in collaboration with the Physical Disability Council of NSW (**PDCN**), Muscular Dystrophy NSW (**MDNSW**), Cerebral Palsy Alliance (**CPA**) and Paraquaid NSW.

2 Research objective and questions

The research objective of this project is to better understand the extent of barriers experienced by people with physical disability in NSW when accessing medical imaging and women's health services. The primary audience for this study is individuals with physical disabilities, wheelchair users and others requiring assistive technology (**AT**) to facilitate mobility. The secondary audience includes these individuals' families and carers. Another subsidiary objective of the project is to collect de-identified case studies that could potentially inform any future advocacy or campaign activities associated with this issue.

In order to achieve this objective, the following research questions have been developed:

1. *What are the basic demographics of individuals with physical disabilities in NSW?*
2. *What types of medical imaging and women's health services are people with physical disability attempting to access in NSW?*
3. *Have people with physical disability in NSW encountered barriers to these services and what specific barriers have arisen?*

3 Methodology

The project was conducted using an anonymised, online survey. Quantitative data from the survey's closed questions provided results to respond to all three research questions. Further conclusions to address the second and third research questions were derived from other open and closed questions from the survey.

Survey questions were divided into three parts: demographics, experiences accessing medical imaging and women's health services in NSW, and, if relevant, access to mobile imaging services. Additional questions were included to provide opportunities for respondents to identify facilities with best practice approaches to accessibility.

The survey was designed using templates from SurveyMonkey and questions were drafted by SCIA's Policy and Advocacy Team, with input and endorsement from representatives of SCIA's partner organisations: PDCN, MDNSW, CPA and Paraquad NSW. The survey was open for a period of three weeks from 3 August 2021 to 24 August 2021. Invitations to complete the survey were sent out via electronic direct mail to SCIA's members and partner organisations, and invitations posted on SCIA and partner organisations' social media platforms, including Facebook, Twitter and LinkedIn.

The survey logic was devised such that respondents could provide detailed insight into their most recent experience with a medical imaging or women's health service in NSW. They could also provide detailed insight into a second service of their choosing and then provide general open text response to their overall experiences accessing their experiences. This provided scope for data to capture multiple encounters of different service types.

The accumulated data from the survey was analysed using basic statistical examination and content analysis. The following sections outline the results and conclusions drawn from the survey and data.

4 Survey results

There was a **total of 112 responses to the survey** with a completion rate of 64% (71). The typical length of time spent completing the survey was 6 minutes and 57 seconds. For complete responses, the typical time spent was 10 minutes 11 seconds. Within the first 24 hours of the survey opening, 42.0% (47) responses were collected.

4.1 Demographics ¹

The survey recorded four demographic factors: gender identification; age; geographical residence area type; identification as Aboriginal and/or Torres Strait Islander (**ATSI**) and/or coming from a culturally and linguistically diverse background (**CALD**).

The gender split across respondents skewed female, with 60% identifying as female, 39% male and 1% identifying as gender diverse or non-binary.

The age breakdown skewed toward older age brackets with 52% of respondents aged over 55, while only 5% were aged between 18 to 24. In terms of the geographical area people resided in, there were a significant number of responses from people living in regional and rural areas, making up almost 46% of total responses. As will be shown in the following sections, findings reveal that many of the difficulties associated with accessing services are increased for those living in these areas. While the vast majority (approximately 97%) did not identify as either ATSI or CALD, almost 3% of respondents identify as First Nations, however no respondents identified as coming from a CALD background.

¹ See Appendix A for full survey results in response to demographics questions.

4.2 Experiences accessing medical imaging and women's health services in NSW ²

Almost 86% of respondents had accessed medical imaging or women's health services in NSW in the past and answered questions in this section relating to their experiences. With the survey logic outlined in the Methodology section, the survey provided **detailed insight into 118 experiences with different medical imaging and women's health services across NSW** as respondents provided feedback on multiple service encounters.

The most prevalent service sought by respondents was for an ultrasound (27), followed by x-rays or mammography (22), bone density scans (19) and magnetic resonance imaging (17). Some of the feedback for 'other' services included orthopantomagrams, videofluoroscopy swallow studies and pap smears.

Significantly, across all respondents, 57% reported encountering challenges to accessing medical imaging and women's health services in NSW.

Of the services accessed by respondents, 49% were through a private facility, 46% via a public health facility, and 2% via 'other' (which included an in-home service).

According to the survey's findings, the availability of some accessibility features was very variable depending on the type of feature. For example, accessible parking, height adjustable tables and accessible toilets were present in the majority of facilities (57.8%, 54.6% and 66.7% respectively).³ However, scales to measure patients' weight and patient lifting hoists to enable safe transfers were absent in the vast majority of facilities (11.1% and 25.9% respectively). The issue of access to hoists was prevalent across many open text responses and in some cases, people indicated that they would actually take their own personal hoist to ensure that could access services in their local area.

While 82 of 108 of the services (75.9%) had wheelchair access and 58% reported sufficient wheelchair manoeuvrability, it is important to specify that many respondents highlighted in their open-text responses that while there was sufficient access for a manual wheelchair, they felt it was very tight access and believed that power wheelchair users would have difficulty accessing the service at all. A collateral impact of this outlined by respondents was the lengthier appointment times required to facilitate access.

Another issue we were aware of prior to launching the survey was anecdotal instances of people being denied access to services as the referral had to be made by a specialist rather than a GP. As such, it was interesting to note that 54% of the services were accessed via a GP referral as compared with 42% from specialists. People in the 'other' category included those who self-referred to services like BreastScreen NSW.

When asked to cite examples of best practice in accessibility across medical imaging and women's health services, 52.9% of responses could not cite a suitable service or noted that they had always encountered barriers. One respondent noted that due to accessibility barriers in NSW, they sought these services interstate. Of best practice services, they varied in type and location, but most cited examples of private facilities or large public hospitals in Sydney.

² See Appendix B for full survey results in response to experiences accessing medical imaging and women's health services in NSW.

³ It should be noted that the question of availability of 'accessible toilets' did not specify whether the toilet was categorised as 'ambulant', 'accessible' or an 'accessible adult change facility'. This obviously has a bearing on the experiences of different users and requires further investigation.

4.3 Mobile imaging services use ⁴

The vast majority of respondents, 88%, had not used mobile imaging services, so we received limited feedback on this experience. However, of those that did, **only 46% of respondents had had no difficulties relating to accessing mobile imaging services.** For example, in one instance a motorised lifting ramp did not meet the curb of the street safely, so various materials had to be cobbled together to create a makeshift bridge to cover the gap of the gutter to ensure the respondent's safety before mounting the ramp.

To facilitate access to mobile imaging services, respondents noted that they required assistive technology, in either the form of hoists or ramps, or physical assistance from support workers or additional technicians operating the service.

5 Discussion

The quantitative data from the survey reflected the significant challenges and barriers faced by people with physical disability accessing medical imaging and women's health services in NSW. The seriousness of these barriers was reflected in the experiences expanded on in open-text responses. This section will outline some of the common themes discussed by respondents and provide insight into specific experiences.

5.1 Availability of assistive technology and inaccessible premises

The primary barrier for most respondents was a lack of assistive technology to facilitate access to the medical imaging or women's health service. This either resulted in a complete inability to proceed with the service or the necessity to bring additional support persons to facilitate safe transfer. This places an unnecessary burden on a person with disability to facilitate access to a service, which may involve additional costs associated with accessing facilities further afield with transport or with hiring support workers. This does not even account for the emotional impact and increased safety risks of these experiences, which will be detailed in an upcoming sub-section.

The follow responses illustrate the practical barriers of lack of assistive technology or inaccessible premises that were most commonly cited by respondents:

"Clinic was not wheelchair friendly, small rooms, no hoist and scan had to be in my chair."

"Whilst pregnant I received wonderful care though the public hospital however, the treatment rooms when getting an ultrasound were tight to manoeuvre in, they didn't have a hoist and the beds didn't really move up and down."

"Toilets were not in the same building as any of the xray, ultrasound rooms etc. They were in a building across the car park (exposed to the weather) in a private hospital facility."

5.2 Lack of disability awareness across staff and health professionals

Another aspect that complicated respondents' experiences accessing medical imaging and women's health services. While some respondents were complimentary of 'professional' and 'competent' staff, many more had had poor experiences with staff who either had a significant lack of knowledge about disability or accessibility or were either inconsiderate or rude. Some attributed this to an individual lack of awareness as many staff may not have encountered patients using wheelchairs, while more respondents suggested this was a systemic issue. Some of the difficulties experienced by respondents are outlined below:

⁴ See Appendix C for full survey results in response to experiences using mobile imaging services.

“Despite being informed that I was a T4 paraplegic paralysed from chest down, doctor constantly asked me to do things that I cannot do independently or have no control over (e.g. relax my legs (when they are spasming), move my hips forward, ‘pop’ myself up on the high bed). [They] brought in trainees without consulting me...and kept talking about how difficult it was to perform because my body sits different to someone without SCI. [The doctor] kept sighing because my legs had a mind of their own and he had to get two people to hold a leg each (no stirrups were there).”

“I stayed sitting in my electric wheelchair whilst the very unobliging female technician half-heartedly did the test.”

“Unfortunately, every experience I have had is a frustrating, anxiety driven emotional one. Staff are not empathetic or understanding at all, they just want you to hurry up so they can see the next patient.”

5.3 Impact of accessibility barriers

Analysing the open-text responses provided an opportunity to begin to appreciate the impacts of a lack of accessible services, which are practical, emotional and potentially long-term.

5.3.1 Finding alternative services

For those patients unable to access the initial service of their choice due to accessibility barriers, it was often an onerous process to find an alternative solution. Alternative solutions ranged from seeking a service further afield, which impacts travel time and cost, to undergoing other procedures that may pose other risks to patients’ health or may be more financially burdensome. Ultimately, in all the scenarios outlined below, the onus rests on the person with disability to determine an alternative solution or to compromise by undergoing an alternative scan or service that poses other safety risks to their health:

“My GP attempted a pelvic exam. Because of my spasticity she was unable to complete it, and referred me to a gyno, who completed it under general.”

“For my next annual BDS [Bone Density Scan] I was told that this examination room has been relocated to another section within the hospital and there is no longer any space for a patient in a power wheelchair to transfer at all due to lack of space.”

“I have found that most private imaging centres didn’t have an adjustable height bed. This means I have often had to wait for access to the public hospital facilities which can take a long time. I have had scans in a private hospital to speed things up. They also did not have an adjustable height bed but they had more staff and more experience staff than the little private imaging centres so they could lift me onto their bed.”

“I phoned numerous imaging facilities until I found one able to assist. Not in my local area. I had to travel. My local hospital would not even consider an ultrasound.”

“Mammograms are really awkward for me as a manual wheelchair user, so much so I have stopped them and opt for an ultrasound instead.”

5.3.2 Increased wait times or delays accessing screening

One of the suspected effects of a lack of accessible services was a delay in receiving diagnoses and/or postponing screening checks altogether. The survey’s findings unfortunately confirmed this. The collateral effects of this cannot be understated. First, a delayed diagnosis prevents the possibility of benefitting from early treatment and result in poorer future health outcomes. Second, a lack of diagnosis can have an impact on people’s ability to apply for funding for supports and services via schemes including, among others, the National Disability Insurance Scheme, Disability Support Pension. As seen below, many people have either forgone using a medical imaging or women’s health service altogether or experienced significant delays:

"I have been waiting almost three years to see a Dentist at the Westmead Dental Hospital because they are the only place I'm aware of with a 'Tilt Platform' on which you park your wheelchair and it tilts and rises to simulate a reclined sitting position."

"My GP was unable to conduct the Pap smear as the medical practice did not have an adjustable bed."

"The OPG was unable to be attended as the OPG machine was not able to navigate around the backrest of my wheelchair."

"It's like no-one thinks of this and just assumes that it is a service that women in wheelchairs don't require which in itself is ludicrous."

5.3.3 Safety, dignity and emotional impact

The survey also highlighted the dangerous situations people with physical disability experienced when using inaccessible services as well as devastating emotional and social impact that these encounters have on their sense of independence and dignity:

"Horrific and humiliating first experience of this procedure...which results now in high anxiety when it comes to these appointments."

"[The] table had curved sides and did not go low enough for my feet to touch the ground. Needed to hurl myself onto my walker then into the wheelchair but nearly fell..."

"It is always very stressful to use the services because it involves a lot of planning and physical assistance with people who are not used to it."

"The bed for the MRI was not height adjustable and it was extremely narrow/dangerous. I had to bring 2 carers with me to assist with transferring."

"To have [a] pap smear done...it was very hard for me to get into a position for my GP to get the instrument into a position to be able to take a sample to be tested. It took the help of the 2 nurses from the practice and the GP and myself holding my legs and abdominal [sic] in a suitable position for the procedure to be completed. It shouldn't have to be this hard or embarrassing (for all involved)."

6 Conclusion

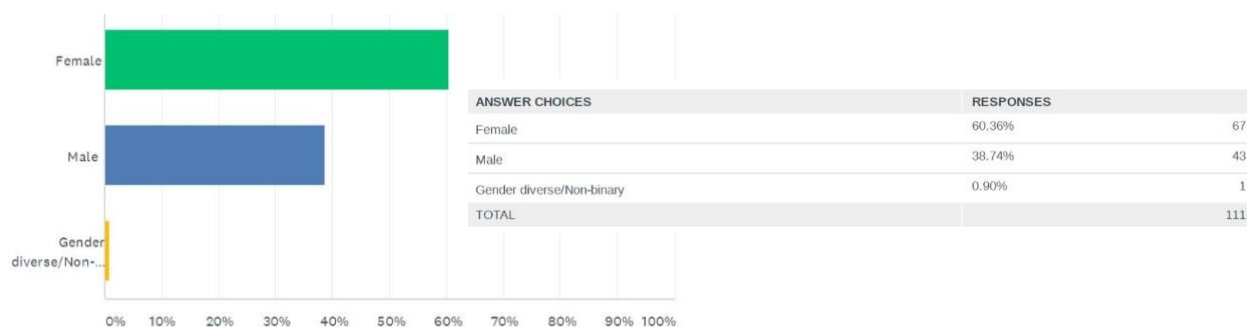
This survey has shown that the majority of people with physical disability that rely on assistive technology or other accessible features encounter barriers when accessing medical imaging and women's health services in NSW. The impact of these barriers and the emotional toll of navigating an inherently inaccessible system, evident as these issues persist across medical facilities of all types, effectively results in inequitable access and is fundamentally a non-fulfilment of governments' human rights obligations. Policy makers in NSW and in other states and territories that may have a similar inequitable system, as well as the Australian Government need to take proactive actions and set targets and timeframes to address these issues. As one respondent best summarised:

"It is vitally important to all patients that all medical facilities are fully [accessible] for all medical procedures no matter where they attend."

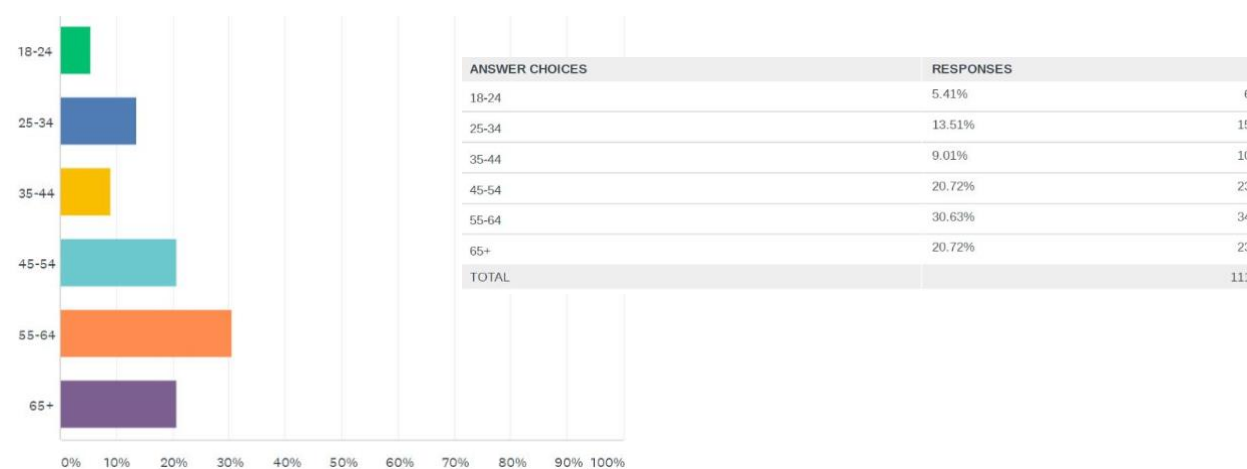
Appendices

Appendix A: Demographics results

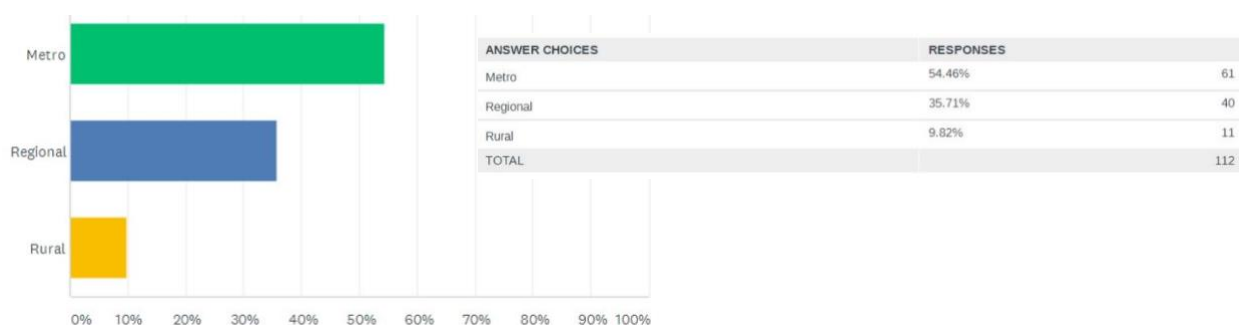
Gender distribution



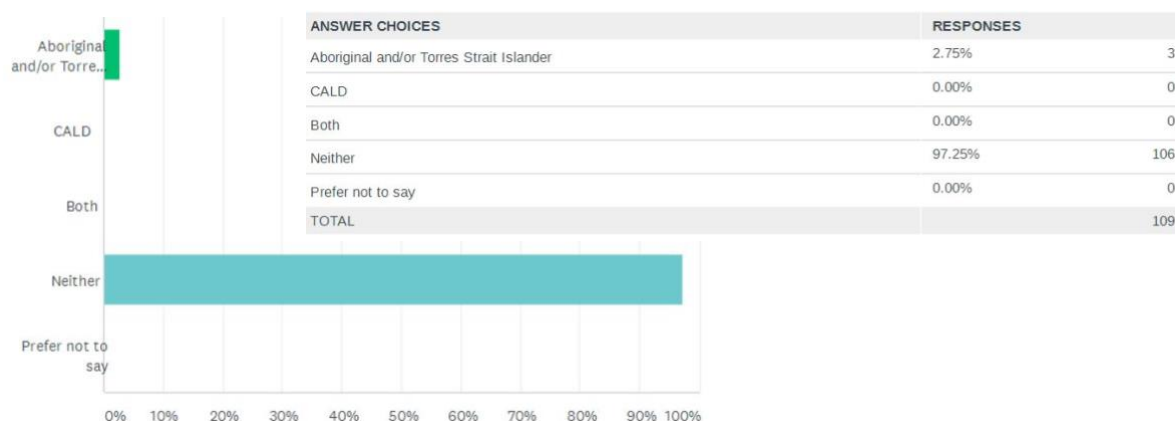
Age distribution



Residence (type of area)



Identification as ATSI and/or CALD

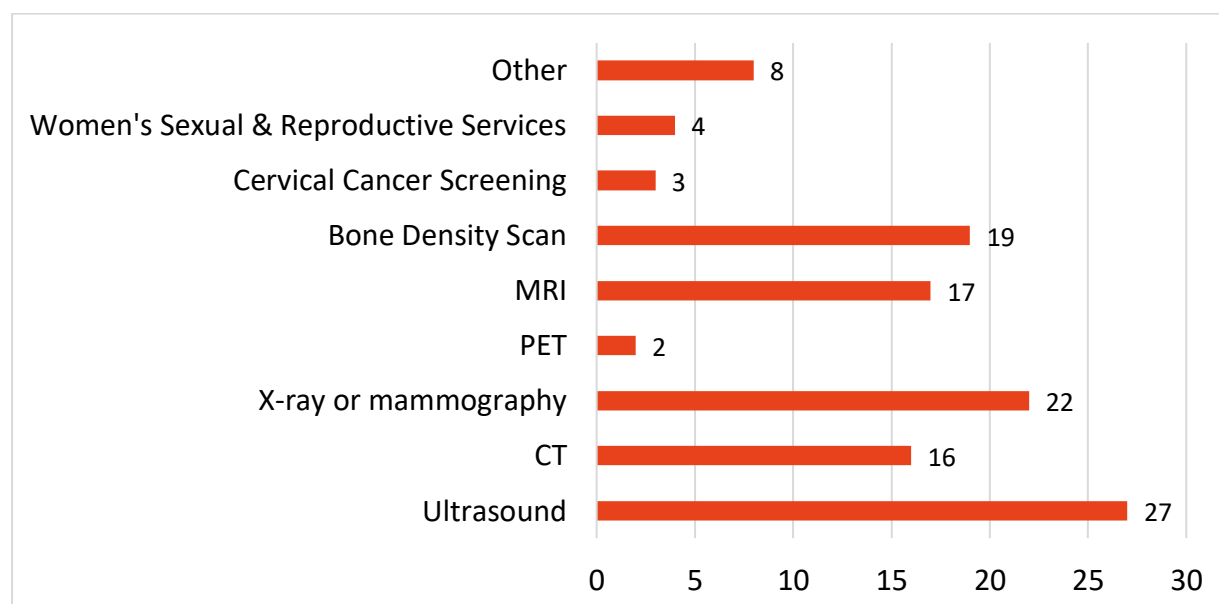


Appendix B: Experiences accessing medical imaging and women's health services in NSW

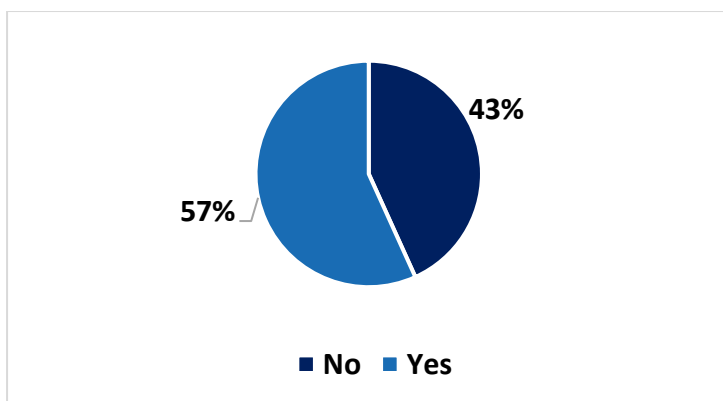
Have you accessed medical imaging or women's health services in NSW?



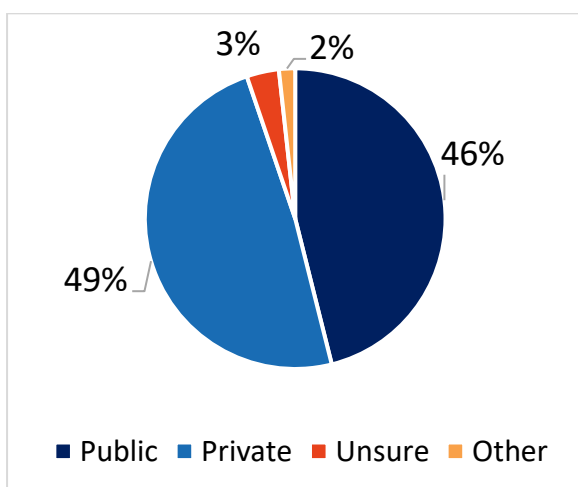
Medical imaging and/or women's health service accessed



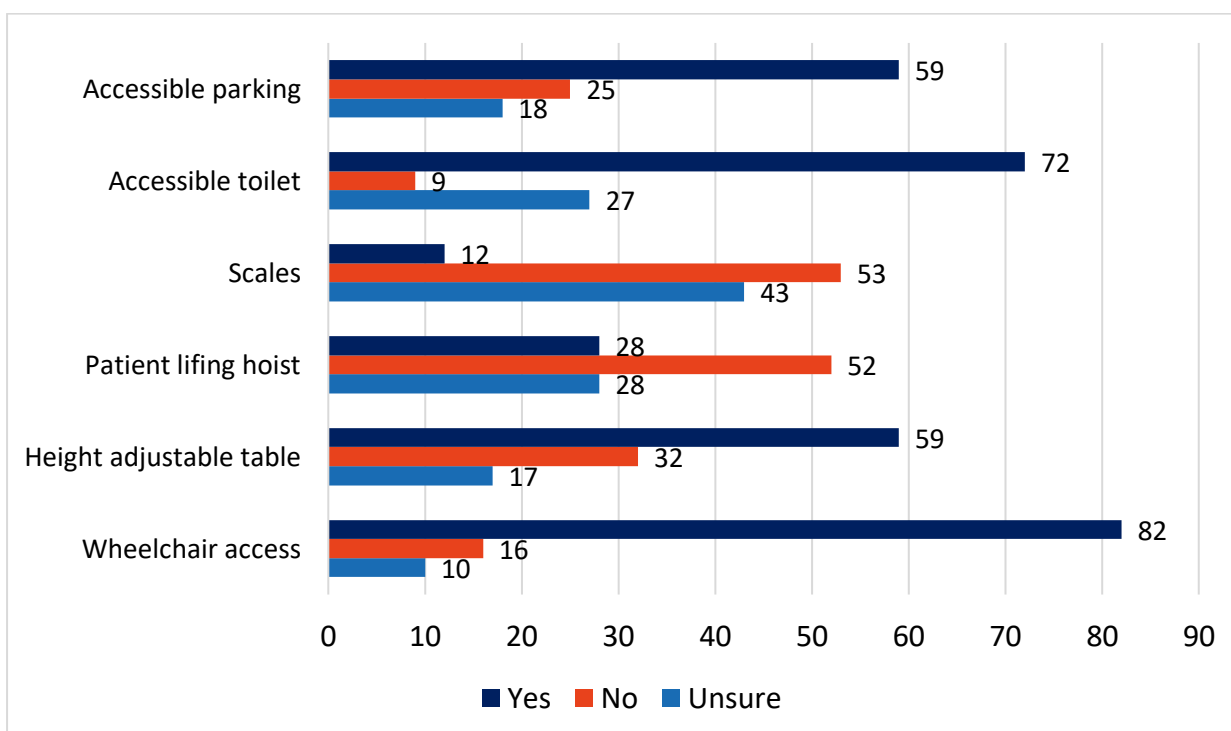
Did you encounter any challenges or barriers?



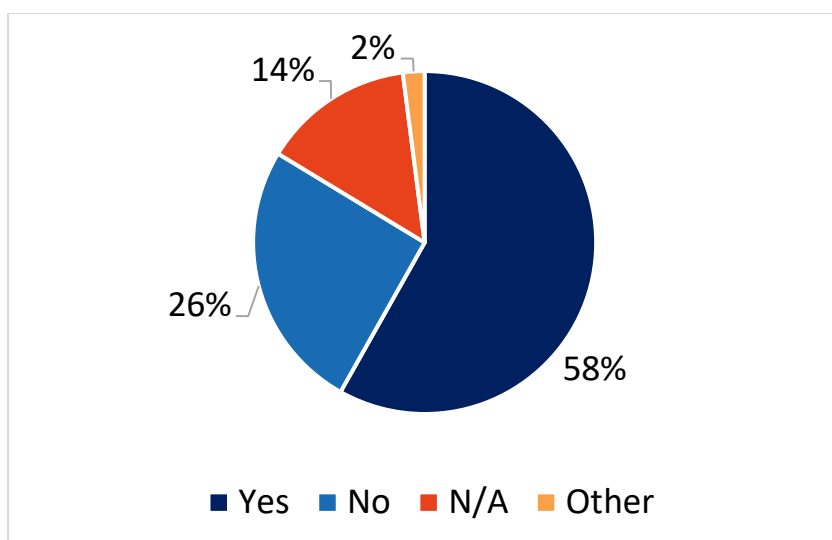
Type of service



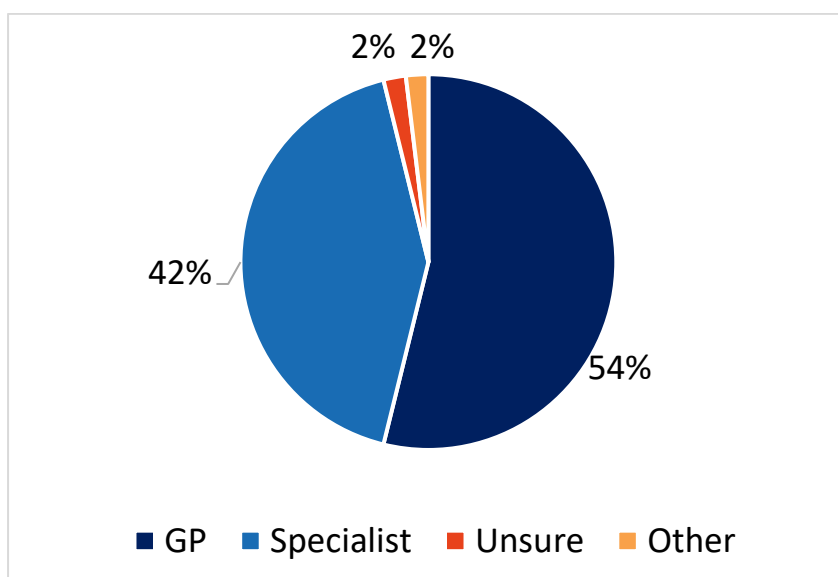
Availability of accessible features



Wheelchair manoeuvrability

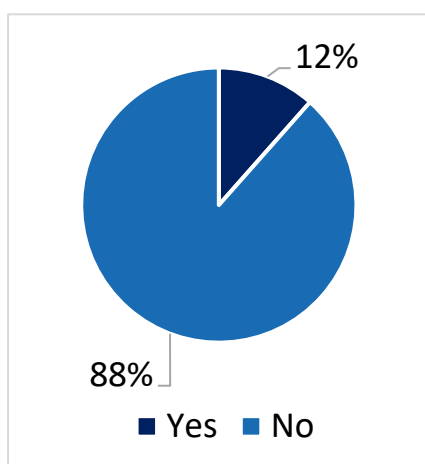


Referral source



Appendix C: Mobile imaging services

Have you used a mobile imaging service in NSW?



Was the mobile imaging service accessible?

