SUBMISSION TO SENATE INQUIRY INTO THE AVAILABILITY AND ACCESSIBILITY OF DIAGNOSTIC IMAGING EQUIPMENT AROUND AUSTRALIA

Introduction

Diagnostic imaging services in Australia are world class and an essential part of our healthcare system. Despite these facilities, access has not proven to be equitable across geographical areas, socio-economic status and disease type. One or more of these indicators results in unecessary disparities in patient care.

Rare and less common cancers have significantly lower survival rates than their common counterparts, and although comprising approximately 30% of cancer cases, they account for a disproportionate 50% of cancer deaths. Early diagnosis is critical for improving survival outcomes for cancer patients and reducing the burden on the Australian community; late diagnosis significantly increases the cost to the healthcare system, as health care expenditure is highest in the last six months of life.[i]

Challenges with Diagnostic Imaging for Cancer Patients

In preparing RCA's response to this Inquiry we reached out on our social media channels to our patients for their own experiences of diagnostic imaging across Australia. Here are some of their responses highlighting the issues around up-front costs, travel costs, and the disproportionately late diagnosis of their rare and less common cancers.

As these patients describe below, there are enormous challenges for cancer patients, especially those with rare cancers, in accessing appropriate diagnostic imaging tests.

Geography

For many patients in Australia, location and proximity to services is one of the major barriers to accessing diagnostic imaging services.

'My grandfather had to travel 3 hours each way for his first MRI scan, at which point neither his scan or petrol costs or anything were covered, despite getting a cancer diagnosis from the MRI.'

Additionally, if there is no item number, patients are not eligible for transport subsidy schemes (state-based) which many rely upon to get to the service provider.

Research has consistently shown that rural and remote Australian's have poorer health outcomes than their urban counterparts. Due to the high set-up and operational costs of comprehensive diagnostic imaging practices, providers are found more frequently in metro areas. It is not necessarily cost-effective to have these services in very remote areas, therefore funding arrangements for patient travel and accommodation subsidies need to become much more robust to deal with the challenges presented by distance. Geographical barriers **need** to be mediated by user-friendly and accessible transport and accommodation subsidy schemes. The current state-based travel schemes lack consistency and are funded as an add on healthcare benefit where they need to be viewed and funded as essential and first line. Timely access to diagnostic imaging should not be determined by someone's bank balance or postcode.

Radiation

Diagnostic imaging services that emit radiation are at times unsuitable. Where radiation emitting scans, which are the go-to MBS listed service for a particular cancer, are deemed unsuitable or unsafe by the treating physician, there should be a mechanism in place to ensure an alternative, yet no less effective imaging service is also available at a subsidized rate for patients.

"My concerns with the majority of diagnostic imaging equipment regard the radiation they emit. Having Gorlins Syndrome, most of us try to steer clear of such things as we are more susceptible to skin cancer. I recently had a CT scan done on my skull to check for Kerato cysts… after mentioning this in a support group quite a few people warned me about the radiation CT scans produce. The only alternatives for people with Gorlin's are MRI or Ultrasound…one being quite expensive and the other, as far as I know doesn't do the job properly."

Having cancer and/or a higher susceptibility to radiation is not a justifiable reason for our health system to discriminate and provide a lesser standard of subsidised care. Such discrimination only serves to create inequality of care along income lines. Where a GP, radiologist or specialist decides a patient's health may preclude them from obtaining their appropriate MBS listed imaging service because of radiation toxicity, the only subsidised or available option should not be a *less* accurate or appropriate non-toxic imaging service.

Ideally, where accurate non-toxic imaging, such as MRI is required, an MBS item number should be able to be activated so that GP's, specialists and radiologists can provide an alternative to diagnostic nuclear medicine such as CT, with no danger of inaccuracy to the patient or additional, unfair expense. The MBS listing importantly not only provides a partially or fully-funded necessary service for the patient, but also enables patients to seek a travel subsidy when they are geographically isolated from imaging services, helping to avoid further regional health inequality.

Cost

If a diagnostic imaging service does not have a Medicare Benefits Schedule (MBS) item number, it can be an out of pocket cost of up to $1000 for the patient for just one imaging service, this is despite early diagnosis proving to save the healthcare budget down the line.

> *"My daughter has to have 6 monthly MRI's and I worry about whether or not Medicare will cover this still once she is an adult and will she have to join a 'queue ' once she can no longer be referred through the paediatric ward. I know it's very expensive."*

> *"Diagnosed with Pancreatic Neuroendocrine in September 2015, I needed a PET scan however it was $900 which we didn't have, so was offered the 'next best thing' being a GAT Scan, this was offered at no out of pocket cost to me, but was only available to me if I participated in the Austin Hospital's study (which I gladly did as research is important). The day before my Whipple on 10th December 2015, the surgeons arranged for me to have the PET Scan done as they had some concerns about the tumour being on a main artery. I do not know how they managed it, but they did. It is embarrassing & stressful when you can't afford these things which your specialist teams need in order to help you. It would be a huge relief to not have that added stress."*

> *"I was diagnosed with GIST October 2016. I had a PET scan that was $900 and have CT scans every two months which are fully covered. I also had two PET*

scans a week apart in May this year but as I was on a trial at the time these were covered under the trial."

Where some Australians may be able to foot a $900 imaging bill, even where it is to identify a cancer, many cannot. The purpose of Medicare is not being fulfilled if a patient misses out on the best imaging service, and thus the best chance at accurate diagnosis, because of their bank balance.

Inequity across disease + clinical situation

An issue that quite acutely affects those with rare and less common cancers, is that services and treatments available for one indication are often not available for a very similar indication – disadvantaging people arbitrarily by their disease type. This is a systemic issue of both the PBAC and the MSAC.

An example of this discrepancy is the MBS benefits given to metastatic squamous cell carcinoma originating in the head and neck (usually smoking related) versus metastatic squamous cell carcinoma originating in the skin (usually sun exposure related). These two cancers are biologically identical, with the only difference being their organ of origin, the effectiveness of PET in observation and clinical care therefore is the same yet the former is covered by the MBS and the latter, is arbitrarily not.

Additionally, there are examples where an arbitrary difference in a patient's clinical situation determines whether or not their access to imaging will have an MBS item number or not. A colorectal cancer patient with suspected metastatic disease is only eligible for a PET that is supported by MBS benefits *after* the primary cancer has been resected. This is despite the biology of the tumor remaining constant before and after resection. It is cost effective and clinically standard to observe metastatic disease *before* treatment (such as resection) so that treatment is not commenced where it may be futile.

These arbitrary restrictions and challenges to patient access impact on wallets, clinical profiency, the health budget and most importantly, the health of sick patients.

New Challenges

The advent of genetic testing means that genes with an associated high risk of cancer are able to be identified. We have seen this most popularly with the BRCA1/2 carrier and its associated high breast cancer risk. This technology is exciting as, if harnessed properly, it enables early detection – which of course helps prognosis, lowers the need for more invasive and expensive treatments, eases the healthcare budget burden and ultimately saves lives. This kind of genomic knowledge is changing the way we understand the nature of cancer – by directing our gaze to its molecular structure – rather than just its anatomical origin. Rare cancers are often part of cancer susceptibility syndromes. We must ensure that diagnostic imaging for those with high risk cancer susceptibility syndromes, such as whole body MRI is considered standard clinical care.

Not all cancers are created equal, but cancer patients should have equity in care regardless of their cancer type. Li-Fraumeni Sydndrome (LFS) and its associated responsible gene (TP53) carries an extremely high cancer risk. Research has identified whole body MRI (WBMRI) as providing strong evidence to detect surgically resectable cancers in the population with LFS. This detection rate occurs at 3 times the rate of breast MRI in high risk breast cancer population. Despite this there is a view that randomised trials will be required to establish WBMRI as standard clinical practice. Randomised trials are impossible to achieve in the LFS population because of its rarity, and the ethics of submitting patients (1 in 14 adults and 1 in 7 children) to a control arm of the trial.

Cancer risk is *greater* in LFS than it is for hereditary breast cancer. Screening for hereditary breast cancer is accepted practice (as it should be). Why then should screening for high risk cancer suscebtibilty syndromes like LFS require a higher evidentiary standard than for more common conditions like breast cancer? Such a situation is both impractical and unjust.

LFS is one example of a rare cancer susceptibility syndrome illogically carrying a greater evidentiary burden than similar common counterparts. Disease type – which already disadvantages rare and less common cancers with poorer prognosis' and proportionately less access to PBS listed medications, should not continue to further entrench inequality through lack of access to screening for high risk populations. Such a situation is economically, clinically and morally unsound.

Summary

This submission should be taken with the consideration that where used properly, imaging is not just a cost but also a benefit. Effectively utilised imaging improves patient outcomes and reduces the economic burden on the health system. Geographical circumstances, as well as clinical situation and income status all currently interplay to create an arbitrary uneven playing field for cancer patients. Avoiding late diagnosis means that interventions can be simpler, cheaper, and result in better health outcomes for patients.

Genomic technology represents both an opportunity and a challenge. A greater understanding of cancer and its genetic drivers means that we have the technology to be able to detect cancer in its early stages in high risk populations. This inquiry needs to ensure policymakers are aware of the importance of being able to harness this technology effectively. The MSAC's understanding of the challenges presented by rare cancers but also the great opportunities to effectively clinically intervene will be essential in decreasing the disparities faced by rare cancer patients in Australia.

[i] Langton et al. (2016). Health service use and costs in the last 6 months of life in elderly decedents with a history of cancer: a comprehensive analysis from a health payer perspective. British Journal of Cancer (2016) 114, 1293–1302.

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