Submission No 443

INQUIRY INTO HEALTH OUTCOMES AND ACCESS TO HEALTH AND HOSPITAL SERVICES IN RURAL, REGIONAL AND REMOTE NEW SOUTH WALES

Organisation: Genetic Alliance Australia

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Genetic Alliance Australia welcomes this Inquiry into reporting of health outcomes and services in rural, regional and remote New South Wales.

Genetic Alliance Australia was formed in 1988 in response to the need for peer support for those with rare genetic conditions. We provide support to those affected directly and indirectly by rare genetic conditions providing information, resources and peer support.

The response to this Inquiry will be focused on

> *(g) an examination of the staffing challenges and allocations that exist in rural, regional and remote NSW hospitals and the current strategies and initiatives that NW Health is undertaking to address them*

in the context of the provision of genetic counselling services available.

Having a Diagnosis

There is much emphasis placed in having a diagnosis of a condition. For rare genetic conditions, delays in obtaining the correct diagnosis commonly referred to as a 'diagnostic odyssey.' There may be frequent specialist consultation, treatments to pay through out-of-pocket expenses, with often little or no improvements in health, resulting in continues searching. For parents, this is emotionally draining, combined with the demands on time, employment and relationships. For those living in rural, regional and remote locations this is compounded. This may require relocation to more populated localities and services, leaving behind family and known supports. For indigenous peoples, leaving family and country is an additional emotional burden. While, having a diagnosis enables resourcing from support services such as NDIS and educational these services may be limited in rural, regional and remote areas placing additional stress and increasing the disadvantage experienced in health, education and employment

With knowing one has a rare condition, a diagnosis is greatly valued by the rare disease community. Knowing the reason for ill health provides a clinical and psychological reference point facilitating treatment, reducing the diagnostic odyssey and improving mental health. The risks are also acknowledged; survivor guilt and challenges to family narratives of health and parentage for inherited conditions.

A diagnosis fits with the biopsychosocial model of health. Work by Borrell-Carrio (2004) proposes clinical practice with

> *a biopsychosocial-oriented clinical practice whose pillars include (1) self-awareness; (2) active cultivation of trust; (3) an emotional style characterized by empathic curiosity; (4) self-calibration as a way to reduce bias; (5) educating the emotions to assist with diagnosis and*

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forming therapeutic relationships; (6) using informed intuition; and (7) communicating clinical evidence to foster dialogue, not just the mechanical application of protocol.

This approach facilitates a patient- clinical relationship in line with western contemporary medical practice.

The availability and growth of genomic technology to facilitate a diagnosis has led to an increase in community demand for this service as well as its use within the public health services.

Time delays

Currently there exists within NSW a significant delay in obtaining appointments with genetic counsellors or clinical geneticists. This delay is often cited in enquiries to Genetic Alliance Australia, in the hope of obtaining a quicker consultation, to confirm this is usual or to ask if private services can be obtained. Further, for those in rural, regional and remote areas service provision may be only obtained at major centre, resulting in additional costs in travel and time.

This is compounded as these positions are staffed on a parttime bases, with one regional locality advising of a staff vacancy for over 18 months. For those living in NSW rural, regional and remote area areas this is an inequity of service provision. Failure to deliver timely and accurate information will reduce confidence in genomic technology and NSW health services resulting in poorer health outcomes and ripple effects for all the community of NSW.

It is noted that the 12 month time delay have also been acknowledged nationally in the Supplementary Information to the National Health Genomics Policy Framework 2018-2021. It is with concern this is still experienced in NSW.

Recommendation

The NSW health genomic workforce is expanded to meet community and clinical demand.

Workforce

With the growth of genomic technology, community knowledge of this technology and the need for effective treatments, there is a growing demand by the community for genomic testing. It follows that a workforce is required to provide genetic testing and counselling.

As the General Practitioner provides a gateway in to most health referrals there needs to be genomic training for these service providers as well as referral pathways. The pathways for those in rural, regional and remote populations should not place them at a disadvantage to their metropolitan cousins with regard to timeliness or costs.

Additionally, a census of the workforce described 22.9% of clinical geneticists as over 55 years of age. Further, only 33.4% of genetic counsellors were certified. This article does not have a state-by-state breakdown, nevertheless, these figures may be indicative of the NSW workforce. This builds the case for a deficit in the NSW health workforce that requires prompt action to reduce the significant delays currently experienced and more extensive delays in the future.

As part of the NSW Health Genomics Strategy Implementation Plan 2018 -2020, page 6 describes the task of 'Undertake a baseline audit to describe clinical genomic services in NSW' This task is described as complete. At the time of writing this submission, I have not been able to obtain a copy of this report.

Recommendation.

> Annual reporting of genomic workforce, service demand and service provision needs to be instigated by NSW Health, similar that provided by Cancer Institute NSW. This will facilitate data collection, and importantly provide transparency of services provided for those in the metropolitan, rural, regional and remote locations.

Health Economics

The health economic calculations of genetic testing, workforce and resulting treatments is an emerging dimension. The use of DALY metrics used for health economics and clinical utility has criticisms for this methodology as it is limited to economic productivity aspects only.

The cost benefit of accurate genetic diagnosis is in removal of treatments that are ineffective or harmful. Ineffective treatments increase health costs by continued questing and demand for services, harmful treatments increase costs by the need to remedy negative impacts to health. Knowledge of inherited conditions may modify individual behaviours to include healthy lifestyle choices to reduce risk also reduces health system costs. Likewise, engagement with screening to prevent late onset disease so reduce personal health impacts, also impacts health system costs.

Recommendation

> Active analysis of ongoing health system costs needs to be devised that suits the NSW community and to best serve the interests of the rural, regional and remote residents.

Genetic Alliance Australia would like to acknowledge the support for patients by patient support groups, who have limited time, capacity and energy in providing much needed services filling a gap between public health and the individual.

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