

# SUMMARY OF KEY FINDINGS

HEALTH AND  
SOCIAL IMPACT  
ASSESSMENT IN  
NEUROFIBROMATOSIS  
IN AUSTRALIA

JUNE 2024

1.



THERE IS A NEED TO CLOSE THE TIME GAP BETWEEN SYMPTOM ONSET AND DIAGNOSIS OF NF, ENSURING ACCESS TO EVIDENCE BASED TREATMENT OPTIONS.

NEARLY A QUARTER OF SURVEYED NF PATIENTS WAITED OVER 4 YEARS FOR A NF DIAGNOSIS.

FACTORS CONTRIBUTING TO DELAY OR ERROR IN DIAGNOSIS INCLUDE LIMITED KNOWLEDGE BY HEALTHCARE PROFESSIONALS (29%), WAIT TIME TO SEE A SPECIALIST (19%), AND LACK OF ACCESS TO NF SPECIALISTS AND SERVICES DUE TO LOCATION (15%).

2.



NF AFFECTS ALL FACETS OF A PERSON'S LIFE, WITH SIGNIFICANT IMPACTS ON THEIR MENTAL HEALTH, PHYSICAL HEALTH, SOCIAL RELATIONSHIPS, WORK, EDUCATION AND FAMILY PLANNING DECISIONS.

71% REPORTED A SIGNIFICANT OR MODERATE IMPACT OF NF ON THEIR MENTAL HEALTH.

THE RATES OF DEPRESSION (28%), GENERALISED ANXIETY DISORDER (17%) AND PANIC DISORDER (7%) AMONG SURVEY RESPONDENTS WERE HIGHER THAN AUSTRALIAN GENERAL POPULATION AVERAGES OF 11.7%, 8.2% AND 6.3% RESPECTIVELY.<sup>22</sup>



Over 1 in 3 (34%) reported taking time off education and over 1 in 2 (57%) reported taking time off work due to NF.



1 in 2 (50%) reported NF had a moderate or significant impact on family planning decisions.

3.



THERE IS LIMITED ACCESS TO CARE COORDINATION AND MULTIDISCIPLINARY TEAMS, AND A LACK OF FORMALISED CARE PATHWAYS FOR NF PATIENTS.

ONLY 15% ARE VERY SATISFIED WITH NF-RELATED CARE COORDINATION, 7% WITH THEIR TRANSITION FROM PAEDIATRIC TO ADULT CARE, AND 20% WITH DISCUSSING CONCERNS OR FEARS REGARDING NF WHEN ACCESSING SERVICES.

NEARLY 1 IN 10 COULD NOT ACCESS A SPECIALIST.

4.



EXPERIENCES OF INEQUITY ARE AMPLIFIED FOR PEOPLE WITH NF LIVING IN REGIONAL AND RURAL AREAS.

1 IN 3 RURAL RESPONDENTS AND 1 IN 4 REGIONAL RESPONDENTS NEED TO TRAVEL MORE THAN 400 KILOMETRES TO ACCESS THE NEAREST NF SPECIALIST OR CLINIC, COMPARED TO 7% OF METRO RESPONDENTS.

A FURTHER 54% OF RURAL RESPONDENTS AND 39% OF REGIONAL RESPONDENTS NEED TO TRAVEL BETWEEN 100-400 KILOMETRES TO ACCESS A NF SPECIALIST OR CLINIC, COMPARED TO 5% OF PEOPLE IN METRO AREAS.

5.



MANY HEALTH PROFESSIONALS ARE NOT FULLY AWARE OF NF. THIS LIMITS THEIR ABILITY TO PROVIDE APPROPRIATE TREATMENT AND ONGOING MANAGEMENT OF NF.

6.



THERE IS A SIGNIFICANT EMOTIONAL AND FINANCIAL BURDEN ON NF CAREGIVERS. 90% OF WHICH ARE FEMALE.

NEARLY 4 IN 5 CAREGIVERS (77%) REPORTED A SIGNIFICANT OR MODERATE IMPACT ON THEIR MENTAL HEALTH DUE TO CARING FOR A CHILD OR PERSON WITH NF.

NEARLY 3 IN 10 (29%) CAREGIVERS REPORTED TAKING EXTENDED TIME OFF WORK.

## SUMMARY OF RECOMMENDATIONS

1.

DEVELOP AND IMPLEMENT A NATIONAL STRATEGIC APPROACH THAT DRIVES EQUITABLE AND TIMELY CLINICAL CARE FOR NEUROFIBROMATOSIS.

2.

ENSURE DELIVERY OF COORDINATED CARE ACROSS A PERSON'S NF LIFESPAN AS PEOPLE WITH NF REQUIRE ACCESS TO A RANGE OF MEDICAL AND SOCIAL SUPPORT SERVICES.

3.

DELIVER TARGETED SUPPORTS FOR THE MENTAL HEALTH AND WELLBEING NEEDS OF NF PATIENTS AND THEIR CAREGIVERS.

4.

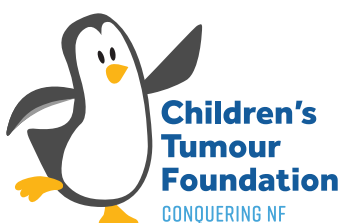
INCREASE NATIONAL AWARENESS AND EDUCATION OF NF TO ELEVATE KNOWLEDGE OF CONDITION IMPACT, AND VARIABLE HEALTH AND SUPPORT NEEDS OF THE NF COMMUNITY.

5.

ADDRESS KNOWLEDGE GAPS AMONG HEALTHCARE PROFESSIONALS OF NF TO IMPROVE DIAGNOSIS, TESTING AND TREATMENT, AND FURTHER ENABLE HEALTHCARE PROFESSIONALS TO MEET THE HEALTH AND SUPPORT NEEDS OF THOSE DIAGNOSED WITH NF.

6.

INCREASE DATA COLLECTION, INVESTMENT IN GENOMICS AND RESEARCH INTO NF, AND ACCESS TO CLINICAL TRIALS TO DRIVE INNOVATION AND NF INTERVENTIONS AND CARE.



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