

The TSC Family Survey 2014

Understanding Tuberous Sclerosis in Australia

Results of the survey – March, 2015

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Introduction

During 2014 the TSC Family Survey was conducted by The Australasian Tuberous Sclerosis Society (ATSS). ATSS has now changed its name to Tuberous Sclerosis Australia (TSA) to coincide with the launch of Tuberous Sclerosis Complex New Zealand (TSCNZ). The name TSA will be used in this document to refer to the organisation.

This report only includes the data from the Australian respondents. The New Zealand data will be reported separately.

This version of the report is intended for the committee members of TSA. A second version will be published for the general public after discussion with the committee.

Objectives

The TSC Family Survey had the following objectives:

- To find out more about people living with TSC in Australia.
- Gather feedback on current activities of Tuberous Sclerosis Australia (TSA).
- Understand areas of need that TSA may be able to address.
- Provide a way for people living with TSC to build their feelings of ownership over the TSA.
- Identify those who are willing to contribute to the organisations through volunteering, sharing their story, or fundraising.

The need for further information about the people living with TSC in Australia and New Zealand has been identified in the 2011 Strategic Plan and the TSA management committee felt that this had become high priority activity to support the growth of the organisation.

Methodology

The TSC Family Survey was adapted with permission from the survey conducted by the Tuberous Sclerosis Association (United Kingdom) during 2012 and 2013. More information about this survey including results is available at:

➡ www.tuberous-sclerosis.org/_literature_122192/Membership_Survey_Results_2013

The survey questions were modified to suit the specific goals of the Australian and New Zealand survey and also to adapt to local conditions. The survey length was shortened to be completed within 20 minutes resulting in several questions from the UK survey being excluded. Where possible, questions were modified to fit standards from the Australian Bureau of Statistics.

An early version of the survey was piloted with 10 volunteers who provided feedback on how long the survey took and how easy it was to complete. This feedback resulted in the simplification of a number of questions.

One version of the survey was produced for use in Australia and another for New Zealand. The Australian version is included in Appendix 1.

The survey was configured for online responses in the Qualtrics survey tool. A paper copy was sent to all subscribers to the Reach Out magazine in May 2014. This was approximately 200 families living with TSC. The survey was also available for download from the TSA website.

The survey was promoted through the following channels:

- The Reach Out magazine;
- TSA email newsletters;
- TSA Facebook group and page.

To reduce the cost of conducting the survey and to minimise errors, respondents were encouraged to fill in the survey online. They were encouraged to do this through a movie ticket draw.

The survey work was conducted during 2014 as shown in figure 1.

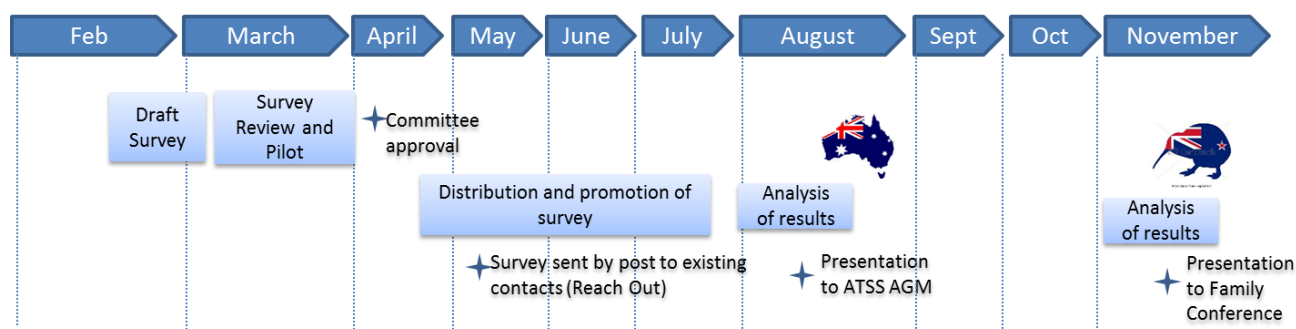


Figure 1: Timeline of the TSC Family Survey Project

The survey work, including design, data analysis and reporting was done by Clare Stuart, Project Manager with Tuberous Sclerosis Australia. Input and review were done with volunteers, including the management committee of Tuberous Sclerosis Australia. Data was de-identified during analysis to protect the privacy of the respondents.

The survey was a project that was funded by accumulated reserves of TSA. These funds have been provided by donations, fundraising, memberships and investment income. The total cost of this project at the time of writing was \$1,950. This includes an allocation for staff time spent on the project.

To understand the recommendations, the relevant section of the report should be read.

Part 1: Who completed the survey?

Recommendation 1: TSA considers the importance of engaging with a wider group of TSC affected individuals and their families. This could include adults living independently with TSC, culturally and linguistically diverse population, the indigenous population.

If reaching this group is important to TSA, future research should consider:

- A survey with a wider recruitment strategy, e.g. promoting the survey through health professionals and other organisations that may be in contact with these individuals;
- Another research method such as focus groups or telephone calls.

Part 2: How does TSC affect them?

Recommendation 2: TSA should prioritise aspects of TSC that have significant impact on the lives of people with TSC. This could be done: within existing TSA services (e.g. resource directory, published information, topics at educational events); in the development of new services; and collaborations with other organisations.

The aspects of TSC that had significant impact identified in this survey were:

- TSC Associated Neuropsychiatric Disorders (TAND)
- Epilepsy
- Broad wellbeing of the entire family, including family relationships and social participation
- Financial costs

All TSA committee members read the open text responses to this survey question to gain a richer understanding of the impacts of TSC on the respondents. These are included in Appendix 2.

Recommendation 3: TSA develops and promotes the TSC Professionals Network to provide information about health professionals who are experienced and up to date on TSC management.

Recommendation 4: If a future survey is done, TSA should consider asking specifically about common mental health issues in TSC such as anxiety and depressive disorders.

Part 3: How do individuals with TSC and their families use health services?

Recommendation 5: TSA should contact the emerging TSC clinics identified by respondents and understand the services available.

Recommendation 6: TSA should consider which professionals are coordinating care for TSC affected individuals when planning professional education activities.

Recommendation 7: TSA should promote the guidelines for TSC diagnosis, surveillance and monitoring to individuals with TSC and their families to improve the quality of care being received.

Part 4: How do individuals with TSC and their families use TSA services? What suggestions do they have for TSA?

Recommendation 8: TSA should establish ongoing evaluations of all activities. Evaluation outcomes should be used to improve services where possible. Specific areas to focus on should include:

- email and phone support
- whether newly diagnosed families are finding out about TSA around the time of diagnosis
- reasons that TSA services are not being used by some individuals and their families with TSC

Recommendation 9: TSA should consider shorter events in multiple locations, flexible delivery such as webinars and recorded sessions to meet the diverse preferences of the TSC community.

Recommendation 10: The TSA committee should consider the rankings given by survey respondents when refreshing the TSA strategic plan during 2015.

Part 5: Fundraising

Recommendation 11: TSA should follow up with the 12 respondents who provided their contact details and are willing to help as a part of the TSA fundraising plan.

Recommendation 12: TSA should continue to improve the way fundraisers are thanked and continue to ask fundraisers how they want to be thanked.

Part 1: Who completed the survey?

Results

- The Australian survey was completed by 88 individuals. 92% of respondents were from parents or carers of a person with Tuberous Sclerosis. Only seven individuals with TSC responded to the survey.
- 82% of respondents were Australian born and 95% speak English at home. 99% reported that they speak English very well. There were no responses from people of Aboriginal or Torres Strait Islander descent.
- The respondents lived in all parts of Australia and in metro, rural and remote areas roughly reflecting the Australian population. See figures 2 and 3.

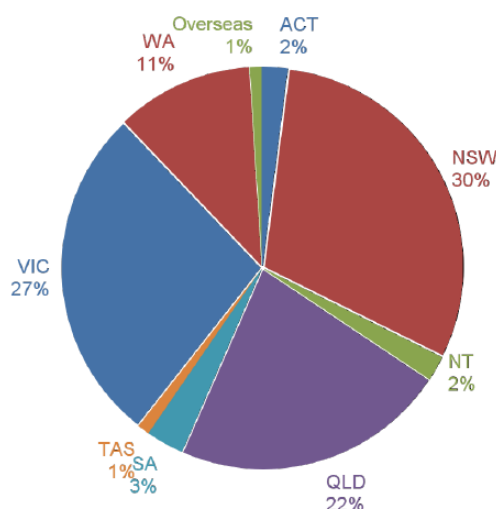


Figure 2: Distribution of responses by State and Territory

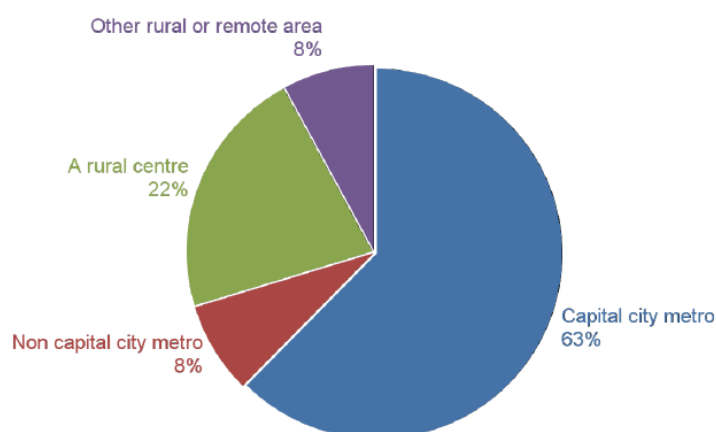


Figure 3: Distribution of responses by metropolitan, rural and remote areas

- The carers that responded included several grandparents and one child of a person with TSC. 90% of respondents only had one family member with TSC.
- The ages of the carers/parents respondents are shown in figure 4. The ages of their children are shown in figure 5.
- The ages of the individuals with TSC who responded is shown in figure 6.

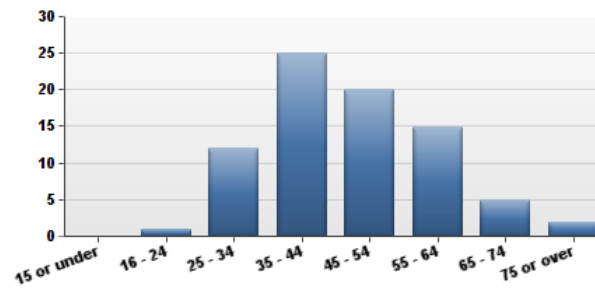


Figure 4: Ages of parent/carer respondents

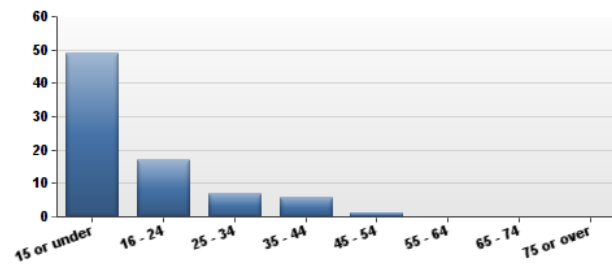


Figure 5: Ages of the parent/carer respondent's children with TSC

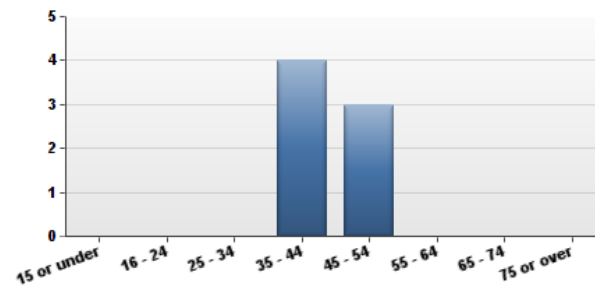


Figure 6: Ages of the respondents who had TSC themselves

The overall response rate was quite high in comparison to the UK survey which received 208 responses within a much larger TSC population. Using prevalence rates of TSC of one in 8000, there could be as many as 2750 people in Australia with TSC. It is not known how many are diagnosed. TSA estimates we are in regular contact with approximately 400 families affected by TSC. 88 responses correspond to 22% of this group.

The group of seven individuals living with TSC is a smaller number than expected. This reflects the historical focus of the organisation.

The cultural and linguistic diversity of the respondents does not reflect the diversity of the Australian population. For example, 20% of the Australian population speak a language other than English at home while only 5% of survey respondents do.

This result from a written survey only available in English is not unexpected.

There is no evidence to suggest that TSC is more or less prevalent in any race or culture, so it is reasonable to assume that the true TSC population is more diverse than the group of survey respondents.

Recommendation 1: *TSA considers the importance of engaging with a wider group of TSC affected individuals and their families. This could include adults living independently with TSC, culturally and linguistically diverse population, the indigenous population.*

If reaching this group is important to TSA, future research should consider:

- A survey with a wider recruitment strategy, e.g. promoting the survey through health professionals and other organisations that may be in contact with these individuals;*
- Another research method such as focus groups or telephone calls.*

Part 2: How does TSC affect them?

Results

- The respondents were provided with a list of conditions commonly associated with TSC. They were asked to report if these affected themselves or the person they cared for. The choices were “yes”, “no” or “I don’t know”. Table 1 shows each condition with the most common at the top:

	Number of respondents indicating “Yes”	% of respondents
Skin problems	77	88%
Epilepsy	70	80%
Learning difficulties	66	75%
Kidney tumours or cysts	63	72%
Intellectual disability	56	64%
Challenging behaviour	51	58%
Other (e.g. eyes, liver)	42	48%
Autism	37	42%
SEGA brain tumour	29	33%
Mental Health issues	22	25%
Mobility problems	21	24%
ADHD	14	16%
Lung issues (e.g. LAM)	9	10%

Table 1: Reported frequency of conditions associated with TSC

- Figure 7 shows the frequency of each condition in the order they were asked:

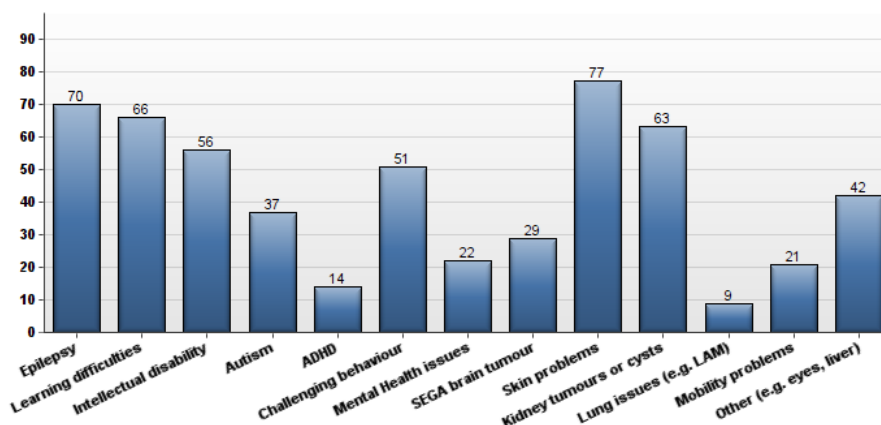


Figure 7: Reported frequency of conditions associated with TSC

- The next question asked respondents to report on the impact that these conditions had on their lives. The full results are shown in figure 8.

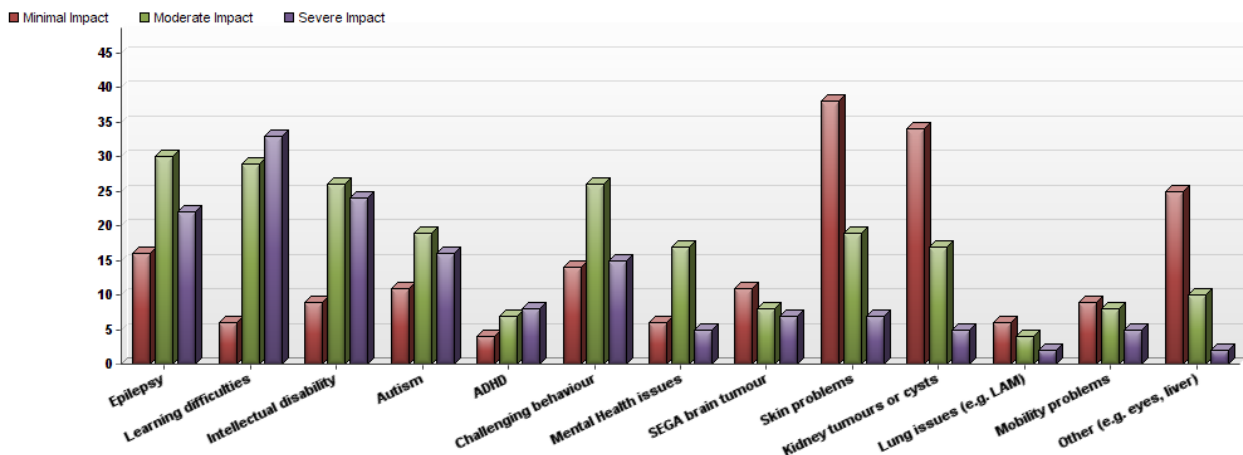


Figure 8: Impact of TSC associated conditions on respondents' lives

- The conditions that were reported most as having severe impact were:
 - Learning difficulties
 - Intellectual disability
 - Epilepsy
 - Autism
 - Challenging behaviour
- This section also asked respondents to describe how TSC affects them. 65 out of 88 respondents (74%) provided an open text response. This qualitative data has been analysed for themes Clare Stuart, who has both a personal and professional experience of TSC. The common themes in the responses are shown in table 2.

Theme	Frequency
TSC Associated Neuropsychiatric disorders (TAND) including behaviour, developmental delays, mental health and education.	26
Epilepsy and seizures	17
Socialising	12
Fear of what will happen in the future	10
Access to medical specialists knowledgeable in TSC	10
Kidneys	8
Financial burden of TSC	8
Time taken for medical appointments	8
Impact of TSC on family relationships	7
Lack of independence	7
SEGA brain tumour	5
Skin conditions associated with TSC	5
Other medical aspects of TSC	5
Identifies as being mildly affected by TSC	4
Genetics and family planning	4

Table 2: Themes identified in open text responses to how TSC impacts them

- Open text that were representative of some of these themes were:

My biggest concern is his social interactions, in the home, at work and with minimal friends. I worry about what the future holds and whether he will be ever able to independent. I worry that he will be lonely.

Parents of a teenager with TSC

Although our son has been with a service provider we feel that we are always “on call”. Our son has never completely accepted his second home. We do have holidays but with a great deal of stress because we always return to find there have been dramas and acting up.

Elderly parents of an adult with TSC

Our main concern is the unknown/ fear of what can happen at any time with TS but it has taught us to live in the now and be mindfully present in our lives.

Unfortunately she also has another serious chronic illness and so we spend quite a bit of time at the hospital for constant monitoring. I do worry about her finding someone who will love and accept her with her health conditions and the risk of having a child with TS. However, we try not to spend too much time worrying as things change in science and medicine all the time and who knows what will happen.

I am happy to talk to other parents about how TS has mildly affected our child but I often feel different to the parents whose children suffer far more life changing consequences of TS

Parent of a child with TSC

Analysis

The survey respondents are not a representative sample of TSC affected individuals in Australia. The answers were all self-reported and not verified by any health professionals. In addition, the ages of the TSC affected individuals varies and many TSC associated conditions develop with age. For these reasons the self-reported frequencies of various TSC associated conditions cannot reasonable be used as an estimate of prevalence of these conditions within the wider TSC affected population. Having understood these limitations, the reported frequencies of TSC lesions/tumours are not inconsistent with those reported in medical literature.

This data about TSC associated conditions is most useful in understanding the needs of the respondents for both information and support on these associated conditions. The data matches the profile of calls and emails asking for support to TSA.

The respondents highlighted TSC associated neuropsychiatric disorders (TAND) as having a significant impact on their lives, including learning difficulties, intellectual disabilities and challenging behaviour. Access to therapists and early intervention services was identified in several open text responses as a challenging area.

Only 25% of respondents reported being affected by mental health issues. This number is lower than the prevalence suggested by some research, particularly in mood and anxiety disorders. This may be due to underdiagnoses of these conditions or due to respondents not associating these conditions with the label mental health issues.

Epilepsy, particularly seizures that are not controlled with medication, continues to be a common concern. Seven open text responses identified this as the single biggest impact TSC had on their lives.

Many open text responses that described areas of most concern to respondents focussed on non-medical aspects of TSC such as social interactions, fears about the future, independent living and family relationships.

Access to medical professionals that know about TSC was identified as a challenge.

Open text responses also identified the disruption that numerous medical tests and appointments have on their lives and financial costs associated with TSC as a concern.

The rich information and stories provided in the open text responses are valuable input for TSA. As the organisation refreshes its strategic plan in 2015, these responses should be considered.

Recommendation 2: *TSA should prioritise aspects of TSC that have significant impact on the lives of people with TSC. This could be done: within existing TSA services (e.g. resource directory, published information, topics at educational events); in the development of new services; and collaborations with other organisations.*

The aspects of TSC that had significant impact identified in this survey were:

- *TSC Associated Neuropsychiatric Disorders (TAND)*
- *Epilepsy*
- *Broad wellbeing of the entire family, including family relationships and social participation*
- *Financial costs*

All TSA committee members read the open text responses to this survey question to gain a richer understanding of the impacts of TSC on the respondents. These are included in Appendix 2.

Recommendation 3: *TSA develops and promotes the TSC Professionals Network to provide information about health professionals who are experienced and up to date on TSC management*

Recommendation 4: *If a future survey is done, TSA should consider asking specifically about common mental health issues in TSC such as anxiety and depressive disorders.*

Part 3: How do individuals with TSC and their families use health services?

Results

- 43% of respondents reported attending a TSC clinic. Six identified clinics TSA considers still in development or with a specific focus (e.g. LAM). Figure 9 shows the clinics identified by respondents. Mater Children's Hospital in Brisbane is now part of the Lady Cilento Children's Hospital, Brisbane.

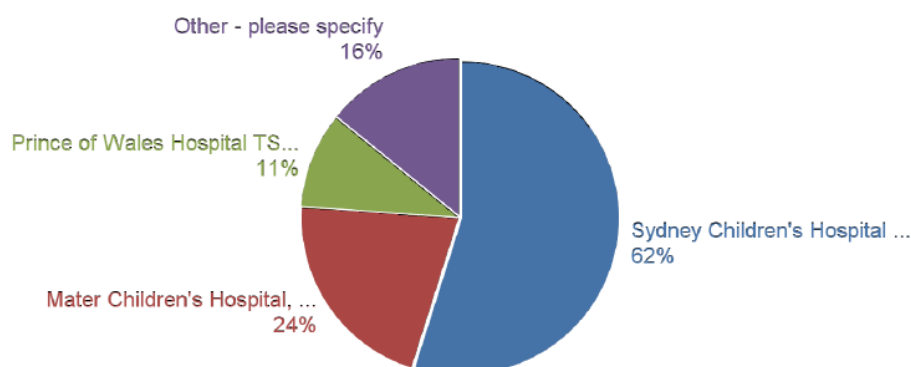


Figure 9: TSC clinics visited by respondents

- 85% mostly visited the same General Practitioner.
- Responses to who manages TSC care varied as shown in table 3. Many respondents identified more than one medical professional.

Professional Managing TSC	Frequency
Paediatric Neurology	21
Neurologist	15
General Practitioner	13
Paediatrician	11
Nephrologist	2
General Physician	1
Other	15

Text responses include parent managing overall care and where more than one specialist was reported as managing the TSC.

Table 3: Manager of TSC Care

- 51% of respondents were aware of the TSC guidelines for diagnosis, surveillance and treatment

The results show that some clinics are in development and may expand their services for people with TSC.

Recommendation 5: *TSA should contact the emerging TSC clinics identified by respondents and understand the services available.*

The high number of respondents visiting the same GP suggests that educating these specific GPs may be a way to improve TSC knowledge of the professionals that are seeing TSC patients.

Neurologists, general practitioners and paediatricians are the most common professionals taking on a care co-ordination role. A significant number did not identify a single professional as managing overall care which may suggest that the individual with TSC or the parent is doing this important activity.

Recommendation 6: *TSA should consider which professionals are coordinating care for TSC affected individuals when planning professional education activities.*

There was only limited knowledge of the guidelines for TSC diagnosis, surveillance and monitoring.

Recommendation 7: *TSA should promote the guidelines for TSC diagnosis, surveillance and monitoring to individuals with TSC and their families to improve the quality of care being received.*

Part 4: How do individuals with TSC and their families use TSA services? What suggestions do they have for TSA?

Results

- 59% of respondents found out about Tuberous Sclerosis Australia (previously ATSS) around the time of diagnosis.
- Many respondents have known about the organisation for many years. The responses to this question are shown in figure 10.

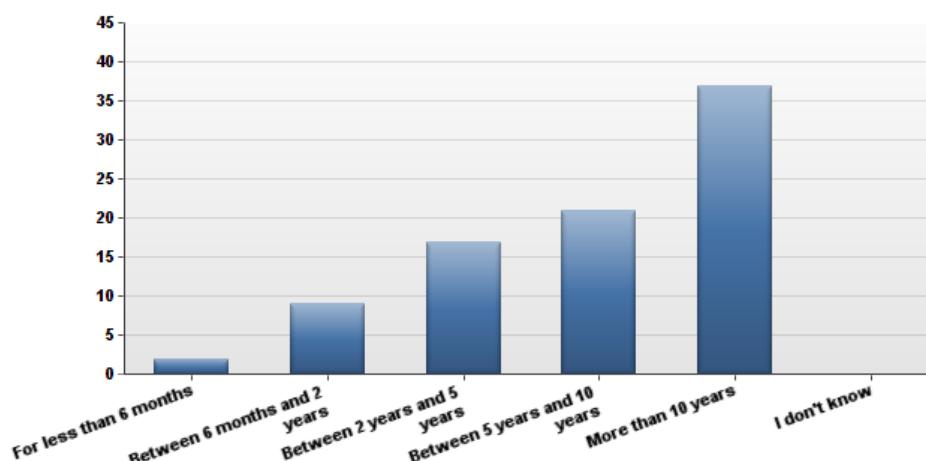


Figure 10: How long respondents have known about the TSC organisation

- 45% of respondents had never been to an event organised by Tuberous Sclerosis Australia. The reasons for not attending previous events are shown in table 4:

Reason for not attending (multiple selections permitted)	Count
The event was too far away from my home	17
The dates did not suit	10
I was not emotionally ready to meet others affected by TSC	8
I could not get care for my family members	7
The event did not interest me	2
Other	9
Text responses included medical appointments and emergencies.	

Table 4: Reasons for not attending TSA events

- There were mixed responses to how far people would travel for an event.
- The types of events that were of interest are shown in figure 11.

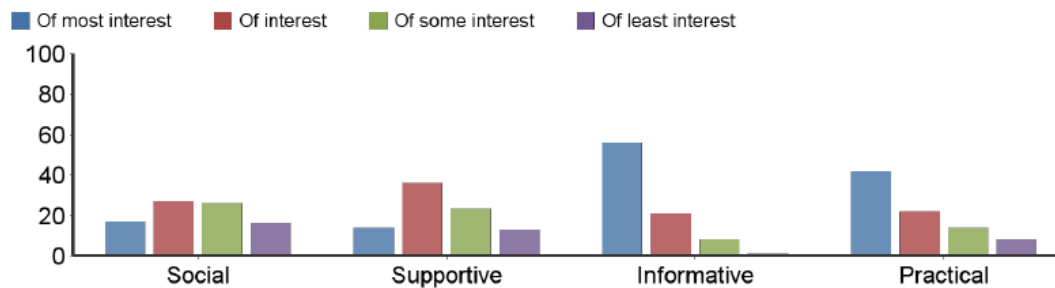


Figure 11: Types of events respondents reported interest in

- The preferred length of event also varied. These responses are shown in figure 12.

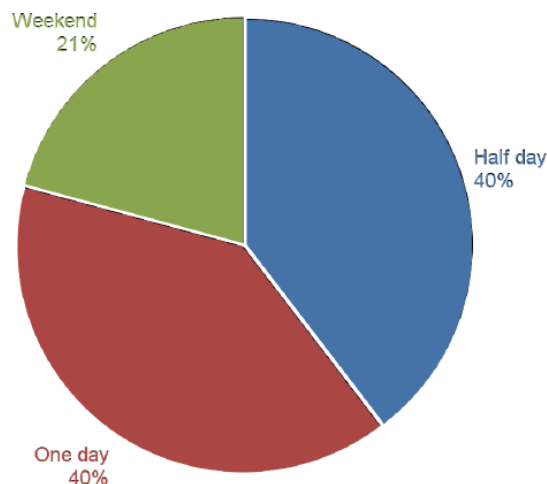


Figure 12: Length of event preferred by respondents

- 65% were interested in webinars; 30% not sure
- The most commonly used TSA services were the Reach Out magazine, website, Facebook and email newsletters. Phone and email support were much less frequently used.
- Most TSA services were highly rated. A small number of respondents were dissatisfied with email and phone support they had received in the past. One specific issue was timeliness of responses. The survey did not collect enough data to understand these issues further.

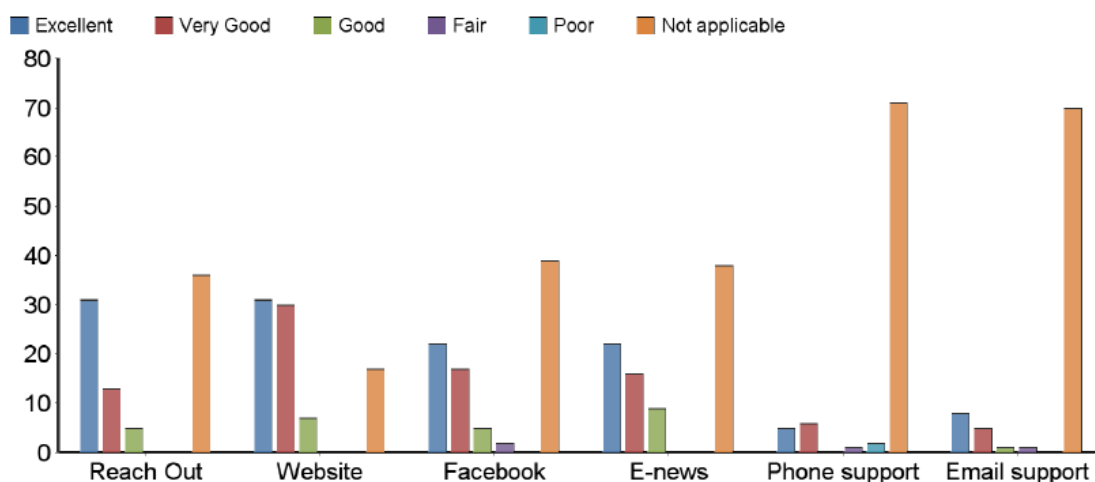


Figure 13: Use and rating of TSA services

- The next question in this area asked respondents to rank a list of possible activities that TSA could undertake. The results of this ranking are shown in table 5. The first piece of data displayed for each option shows the number of respondents that ranked the activity as highest priority (#1). The second piece of data shows the mean rank. A lower mean suggests the activity was considered more important than an activity with a higher mean ranking.

Activity	Ranked as Mean	
	#1	rank
Provide information about TSC	21	4.54
Help connect TSC families to medical professionals	9	5.46
Provide advice about living with TSC	7	5.66
Educate professionals about TSC	6	5.8
Fund research	12	5.94
Raise awareness of TSC	5	6.43
Provide emotional support to people living with TSC	4	6.46
Lobby and campaign to improve health care for people affected by TSC	5	7.15
Practical (for example for advice on government benefits, services that may assist you live your life)	3	7.35
Host conferences for medical professionals and researchers	5	7.51
Advocate for individuals and families	5	7.79
Lobby and campaign to improve social services and benefits for people affected by TSC	0	7.9

Table 5: Ranked activities

- Respondents were also asked about overall satisfaction with TSA. 87% were either extremely or mostly satisfied. This is shown in figure 15.

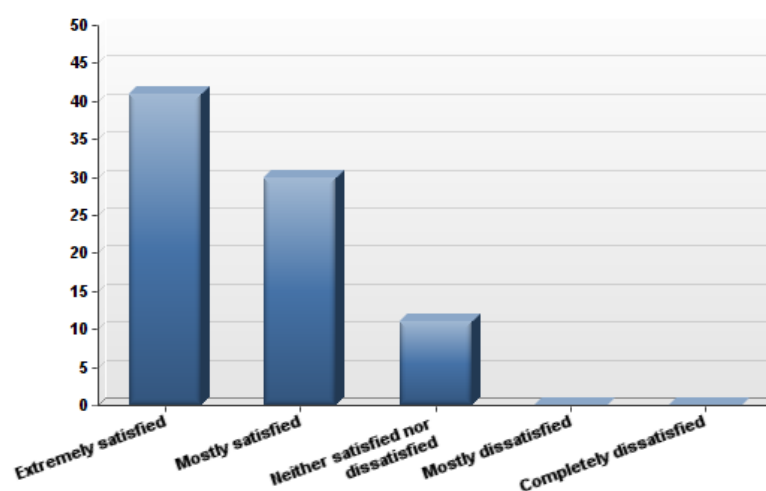


Figure 14: Overall satisfaction with TSA

- Open text provided some additional insight into respondents' use of and opinion of TSA services. These fell into three categories:

- Specific requests, such as
"Would like to see more videos on behaviour and how to handle it."
 One respondent described how support provided on new diagnosis could have been more practical and more supportive. One respondent identified specific information missing from the TSA website.
- Compliments, such as
"I have made contact with ATSS a number of times and the service has been good on these occasions"
"The Facebook group has been a godsend; in allowing me to get support in a community of people that truly identify with our situation. I also feel that I can contribute to others in the group which gives me a sense of empowerment".
"Feel that the improved website and particularly Reach Out are great."
- Providing reasons why TSA services were not used. For example
"As my daughter is not severely affected, we do not need these support services"
"At the moment as the carer I like to read what is happening regarding TS. Could not deal with any other interactions."

Because the time since diagnosis varied amongst respondents, it is not clear what proportion of individuals diagnosed with TSC today finds out about TSA.

A large number of respondents did not use many TSA services. The survey did not gather information about why that is. Possible reasons could be: they have no need for the information or support; that they were not aware of the service; or they did not find the service helpful or relevant to them.

Most TSA services were highly rated. However because there were some respondents that rated email and phone support poorly there may be ways service could be improved.

Recommendation 8: *TSA should establish ongoing evaluations of all activities. Evaluation outcomes should be used to improve services where possible. Specific areas to focus on should include:*

- email and phone support
- whether newly diagnosed families are finding out about TSA around the time of diagnosis
- reasons that TSA services are not being used by some individuals and their families with TSC

The responses regarding events were varied.

Recommendation 9: *TSA should consider shorter events in multiple locations, flexible delivery such as webinars and recorded sessions to meet the diverse preferences of the TSC community.*

Much of the feedback on TSA services was very complimentary. TSA committee, volunteers and staff should be proud of the positive feedback received.

The ranking of activities provides some guidance on relative priorities.

Recommendation 10: *The TSA committee should consider the rankings given by survey respondents when refreshing the TSA strategic plan during 2015.*

One major limitation of the survey is that it only recruited people who are in contact with TSA. It is likely that those who are very dissatisfied with the services offered by TSA would not have completed this survey as they may not have heard about it or not taken the time to contribute in this way to the TSA.

Recommendation 1 (from earlier in this report) includes a recommendation to actively engage with this group in future research.

Part 5: Fundraising

Results

- 46 respondents chose to complete the optional questions about fundraising for TSA.
- The first question asked respondents to identify ways they would be willing to contribute to fundraising. These responses are shown in table 6.

Volunteer opportunity	Number volunteered
Volunteering to support fundraising organised by others	23
Organise your own fundraising event	11
Setting up a local fundraising group	3
Source raffle/auction prizes	10
Recommending TSA as a charity of the year partner to your employer or child's school	16
Write a testimonial about your experiences with TSC and TSA	23
Provide photos of yourself or your children for use in TSA campaigns	23
Ask your friends and family to support TSA using a personalised letter	11
Talk to your family and friends about including TSA in their will	6
Other(s)	3

Table 6: Ways respondents were willing to help TSA fundraising

- The next question asked about ways respondents would like to be thanked for fundraising. The majority selected the option "I do not need to be thanked for fundraising", perhaps as they did not intend to fundraise. For those that did not, the results are shown in table 7.

Method of being thanked	Number
Send me a thank you email	6
Send me a thank you letter in the post	2
A short article in Reach Out, the TSA magazine	1

Table 7: Preferred method of being thanked for fundraising

Analysis

Recommendation 11: TSA should follow up with the 12 respondents who provided their contact details and are willing to help as a part of the TSA fundraising plan.

The question regarding being thanked for fundraising likely reflected the humility of the respondents. External fundraising research suggests that thanking donors and fundraisers is a key predictor of repeat donations and fundraising efforts.

Recommendation 12: TSA should continue to improve the way fundraisers are thanked and continue to ask fundraisers how they want to be thanked.

Further information

A copy of the survey is available at:

➡ tsa.org.au/survey

Contact TSA for more information:

Clare Stuart, clare@tsa.org.au