Follow-up question to the 2025 tick-borne disease Senate Inquiry from Ticna Inc

I, Peter Owen, was asked to follow up with some **overseas tick testing laboratories at the inquiry on January 29, 2025.**

The following is a list of the most common laboratories Australians often pay out of pocket for tick testing.

Lab Synopsis
Igenex in Usa
ArminLabs in USA and Europe
Vibrant Labs In USA
Galaxy Labs in USA
DNA Connections
Tezted lab in Europe
DualDar in Europe

Igenex in the USA. This is the No. 1 lab recognised by many overseas practitioners and probably most used by Australian patients if they can afford it.

https://igenex.com/

New culture testing

https://igenex.com/culture-enhanced-pcr-testing/

About testing limitations NO MATTER THE LAB
https://igenex.com/tick-talk/is-lyme-disease-testing-really-that-bad/

Many Australians test positive in this lab for many tick infections not just Lyme
My first test in 2012 was positive for Lyme USA strain at this Igenex lab. I had travelled overseas, but many Australians have not and also test positive to many strains in this and other overseas labs.

My personal thoughts on labs that test positive for the USA strain in overseas labs and Australian authorities and researchers dismiss this as being accurate especially when Australians have NEVER travelled overseas. I feel that it would be very probable that these test positive for the Australian strains and they cross-react with the various Lyme USA or other strain testing.

Think about it. If Australian labs can quite quickly dismiss other tick testing as cross-reacting with other pathogens, (they do this for Rickettsia here) then the same could apply in these cases. What this means is that Australians are indeed infected and most likely with our unique borrelia strains and because we do not have specific and sensitive tests for these unique Australian borrelia other Lyme tests for overseas strains are picking up these Australian strains but saying they are these USA strains. Especially if the more accurate tsting availble by research indicates no USA strains of borrelia are found. This is a conuns=drum that needs to be addressed. We simply cannot wait as a patient community suffering in limbo while healthy, unaffected researchers and medical authorities sort this out for years to come and we remain denied of treated.

https://www.lymedisease.org/igenex-australian-blood/

and this
Emerging incidence of Lyme borreliosis, babesiosis, bartonellosis, and granulocytic ehrlichiosis in Australia

This research by Dr Peter Mayne in 2011, which no one has countered to say his findings are inaccurate, was NOT included in Allen and Clarke's assessment of borrelia being in Australia.

https://pmc.ncbi.nlm.nih.gov/articles/PMC3258014/

From his research about **Igenex** labs
"IGeneX is a major laboratory specializing in TBDs. It is a reference laboratory recognized by the American College of Pathologists, and is Clinical Laboratory Improvement Amendments, Medicare, and Medicaid approved thus satisfying licensing requirements for most of the US states to perform high complexity clinical testing. IGeneX has also met licensing requirements in the states requiring additional licensing: California, Florida, Maryland, New York, and Pennsylvania. Statements concerning laboratory performance and validation in the area of quality assurance in LD testing are available on the IGeneX website.[20] "

This analysis is from a world-leading physician who treats complex tick patients.
https://www.treatlyme.net/guide/best-lyme-tests

ArminLabs. Another great overseas lab and a close 2nd.

https://arminlabs.com/en/

and here

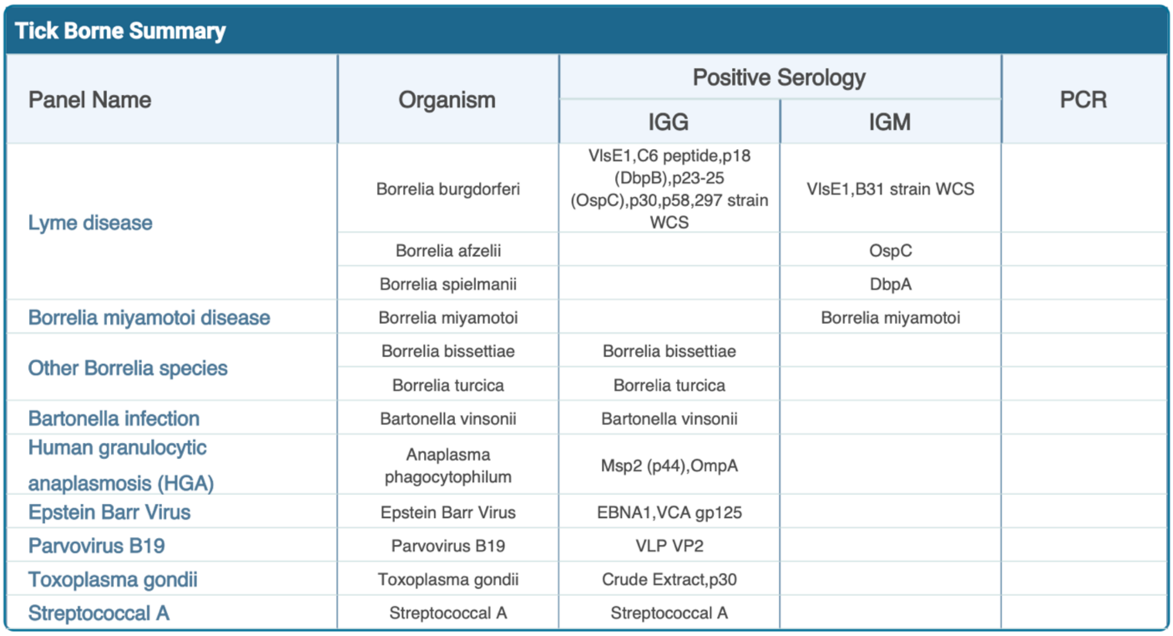
https://aonm.org/basic-information-on-testing/

I tested positive again for the second to Lyme in 2013 at the previous Infectolabs in Germany which changed its name to Arminlabs. I had tested negative for Lyme in ARRL Australian labs so far, though. Even if I tested positive, regardless the lab would have instructed the doctor that it would be a "false positive". No conversation was done about my many overseas travels before my getting sick.

Vibrant Laboratories in the USA
This is a relatively new lab but is recognised as a great lab also by many practitioners in the USA

https://vibrant-wellness.com/test/TickborneDiseases

I tested again positive to Lyme in 2023 at Vibrant Lab. My results FYI



Tick Borne Summary

Panel Name	Organism	Positive Serology		PCR
		IGG	IGM	
Lyme disease	Borrelia burgdorferi	VlsE1,C6 peptide,p18 (DbpB),p23-25 (OspC),p30,p58,297 strain WCS	VlsE1,B31 strain WCS	
	Borrelia afzelii		OspC	
	Borrelia spielmanii		DbpA	
Borrelia miyamotoi disease	Borrelia miyamotoi		Borrelia miyamotoi	
Other Borrelia species	Borrelia bissettiae	Borrelia bissettiae		
	Borrelia turcica	Borrelia turcica		
Bartonella infection	Bartonella vinsonii	Bartonella vinsonii		
Human granulocytic anaplasmosis (HGA)	Anaplasma phagocytophilum	Msp2 (p44),OmpA		
Epstein Barr Virus	Epstein Barr Virus	EBNA1,VCA gp125		
Parvovirus B19	Parvovirus B19	VLP VP2		
Toxoplasma gondii	Toxoplasma gondii	Crude Extract,p30		
Streptococcal A	Streptococcal A	Streptococcal A		

https://blog.vibrant-wellness.com/the-new-standard-how-advanced-technology-can-enhance-lyme-tickborne-detection
https://www.nature.com/articles/s41598-020-75036-2

Galaxy labs also a great USA lab
It may have the most accurate bartonella testing
https://www.galaxydx.com/

DNA Connections
https://dnaconnexions.com/

Somewhat limited test as it tests for only 4 borrelia strains
I do not know many Australians who choose this lab. Igenex and Armin are the most popular with Vibrant then Galaxy behind that.

https://dnaconnexions.com/lyme-test/

Tezted Lab
They presented at the Senate inquiry and are passionate to help Australians.
https://www.tezted.com/

DualDur microscopy tick testing in Europe

https://dualdur.com/en/home/

Dr Walter Tarello - The Need for a One Health Policy
Dr Walter does NOT have a lab but shows how vets who use microscopy daily in their practice for fast diagnosis of their animals can test for and find infections in microscopy slides. This fast diagnosis also leads to speedy treatments and recoveries something that people in Australia do not get. Something also that Australia should have established even as

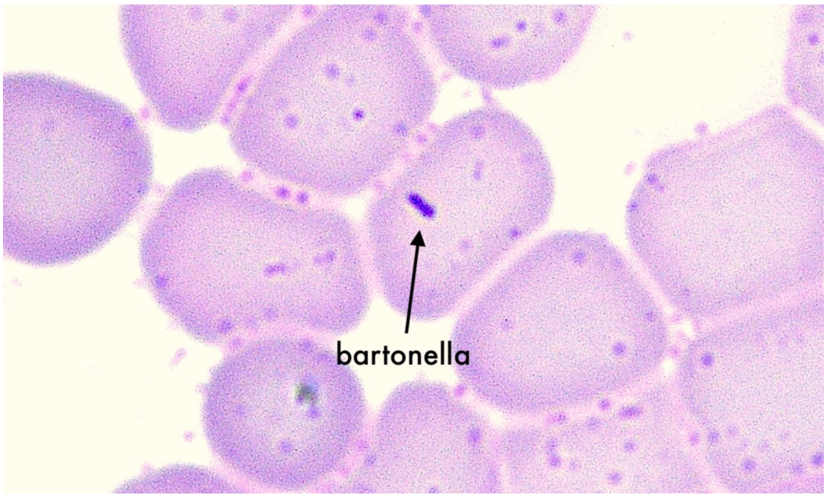
a 2nd round testing follow-up is microscopy testing. It may not determine the exact strain or species, but does that matter as these infections should not be in people?

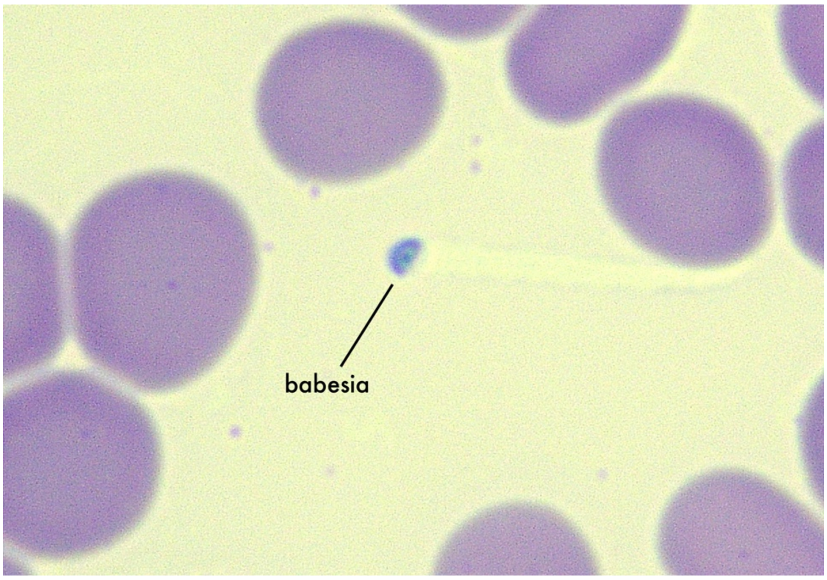
I included my microscopy results from Dr Walter Tarello in both Ticna and Peter Owen personal submissions. This indicates the potential to establish this type of testing in Australia.

My friend, who has been very sick and bedbound now, has also just completed this test I referred him to, and these are some of his results. He has been discounted by doctors for years in Australia like I was. He also has travelled extensively overseas and worked as a ranger in the Australian bush.

He has no borrelia but has Bartonella like I also do, which significantly affects the brain and Babesia, which drains you of energy and causes severe breathlessness and fatigue.

AS YOU CAN SEE IF IT NOT JUST LYME THAT CAUSES THE PROBLEMS. IT ALSO IS NOT JUST ISSUES FROM TICKS THAT CAUSE THE PROBLEMS. IT ALSO IS NOT JUST INFECTIONS RECOGNISED IN AUSTRALIAN TICKS THAT ARE THE PROBLEM.





https://petconnection.ae/about-us/

https://www.amazon.com.au/Chronic-Fatigue-Forgot-Epidemic-revived/dp/1662946813

Dr Tarello paper where he cured himself and his wife of Chronic Fatigue Syndrome
https://pubmed.ncbi.nlm.nih.gov/11561958/

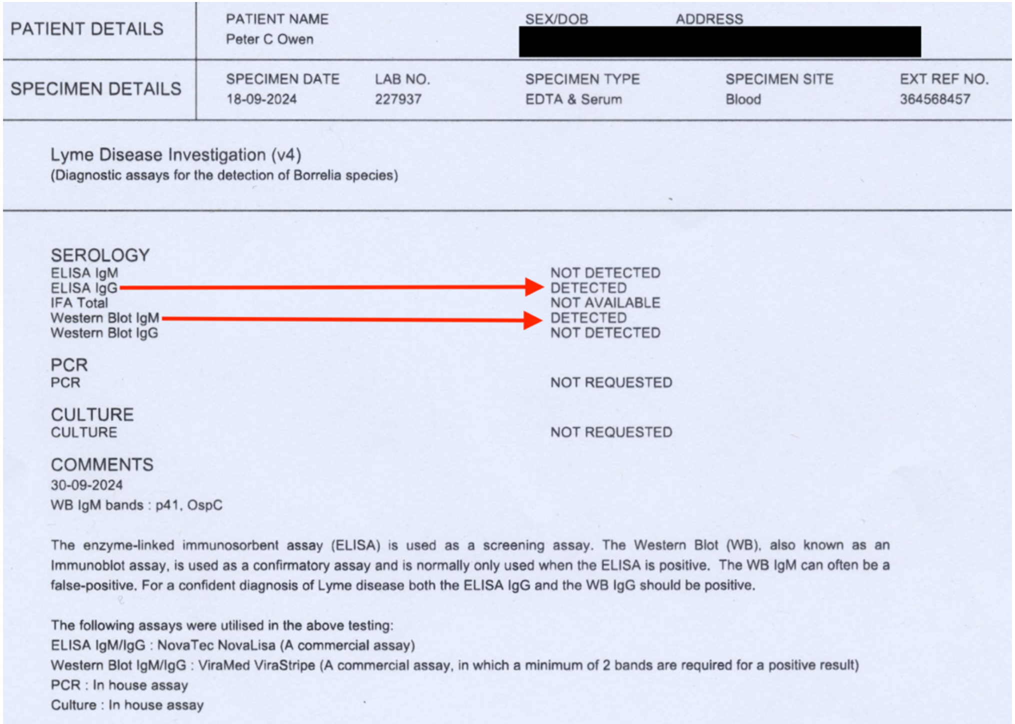
Australian labs
I think they can also test at Westmead Hospital in Sydney. I think there may only be two Australian labs now testing for human tick infections available to doctors and the public commercially.

https://www.rch.org.au/specimen-collection/Lyme_Borreliosis_Serology/

Australian Biologics, a private lab that used to test for tick infections in people and ticks, does not test for any tick diseases OR test ticks now.

Australian Rickettsia Reference Laboratories ARRL
This is the main Australian lab used to test for Lyme. I do note that the private owner of this lab submitted to this senate inquiry. His response is very lacking and shows IMO the huge stalemate and potential negative bias we have with people in a position of power about tick-borne infections. These people who are unaffected by tick disease themselves are quite happy to just wait it out for slow-moving research they seem to need for proof. It's a shocking no-win for the patient population. This stalemate HAS TO BE BROKEN for thousands of patients' health.

https://www.rickettsialab.org.au/tests-performed
My test results September 2024



PATIENT DETAILS	PATIENT NAME Peter C Owen		SEX/DOB [redacted]	ADDRESS [redacted]	
SPECIMEN DETAILS	SPECIMEN DATE 18-09-2024	LAB NO. 227937	SPECIMEN TYPE EDTA & Serum	SPECIMEN SITE Blood	EXT REF NO. 364568457

Lyme Disease Investigation (v4)
(Diagnostic assays for the detection of Borrelia species)

SEROLOGY

ELISA IgM	NOT DETECTED
ELISA IgG	DETECTED
IFA Total	NOT AVAILABLE
Western Blot IgM	DETECTED
Western Blot IgG	NOT DETECTED

PCR

PCR	NOT REQUESTED

CULTURE

CULTURE	NOT REQUESTED

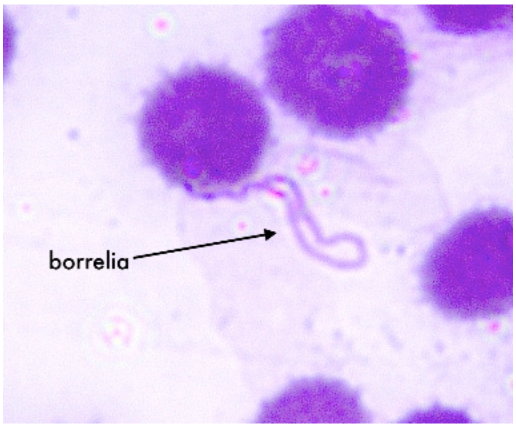
COMMENTS
30-09-2024
WB IgM bands : p41, OspC

The enzyme-linked immunosorbent assay (ELISA) is used as a screening assay. The Western Blot (WB), also known as an Immunoblot assay, is used as a confirmatory assay and is normally only used when the ELISA is positive. The WB IgM can often be a false-positive. For a confident diagnosis of Lyme disease both the ELISA IgG and the WB IgG should be positive.

The following assays were utilised in the above testing:
ELISA IgM/IgG : NovaTec NovaLisa (A commercial assay)
Western Blot IgM/IgG : ViraMed ViraStripe (A commercial assay, in which a minimum of 2 bands are required for a positive result)
PCR : In house assay
Culture : In house assay

According to this testing they indicate this is a negative test as Elisa is positive but Western blot IgM is positive but they say a false positive without explanation but IgG is negative.

My recent microscopy which counters their claim of a negative test.



This test is after I had the 8 weeks of oral doxycycline in 2021 and was told by an Infectious Disease doctor in Melbourne I was cured.

This shows just how inaccurate pathology testing is, and we rely on this as proof as our symptoms are not taken seriously even to start antibiotic treatment early. For 22 years, I have been infected and proven from many DIFFERENT overseas labs many times, which in the most part were ignored by Australian doctors as they said these were not NATA accredited. Another biased dogma by authorities to prevent treatment for Australians. This adds another false positive ARRL test to the 6 I have had over the last 10 years to my list of failures here with testing.

I will also add again that **my POSITIVE tests initially for Rickettsia at the ARRL lab were discounted as cross-reaction with "something else**". Never explained what they cross-react with. But that alone proves the inadequacy of even the Australian Rickettsia testing when it cross-reacts with "something else". Would this be allowed for cancer or HIV testing?

My doctors did not rerun my second test for at least 8 months, which was negative. So again, I received NO treatment. Yet in 2020, I tested positive again at ARRL for Rickettsia, so I remained infected all this time with Rickettsia, but the testing was not accurate and specific to determine this. It's an atrocious state of affairs and would not be accepted anywhere else, yet here we are with the DOH and the medical profession happily accepting these inadequate tests.

ARRL use an Elisa and Immunoblot for their Lyme testing. Still, they DO NOT provide the immunoblot bands in the test results,* which other labs always do. So as a patient community, we wonder why they seem not obligated to provide complete test results, which include the western or immunoblot blot band data. However, they are also inaccurate as they are based on an immune response from the patient, which does not always happen with early OR late infections. Making it hard to treat those chronically infected early and treat them for a long time.

I also think ARRL can only screen for 3 Borrelia species. One is for the USA, and two are from Europe. There are 20 known species of Lyme and a lot more of other borrelia species,

https://en.wikipedia.org/wiki/Borrelia
"Of 52 known species of *Borrelia*, 20 are members of the Lyme disease group (with an additional 3 proposed),[6] 29 belong to the relapsing fever group, and two are members of a genetically distinct third group typically found in reptiles"

So how can this Australian Rickettsia lab detect all borrelia species in Australia for the known Australian borrelia found already in research here AND all the other varieties overseas that when people travel they could get? Frankly, they can't. Plus, there are so many more tick infections now, and they do NOT have tests for all these strains either such as for borrelia, babesia, bartonella, Anaplasma, Ehrlichia and the South American Strains of Baggio Yoshinari species of borrelia and even the USA Southern Stari borrelia species

https://en.wikipedia.org/wiki/Southern_tick-associated_rash_illness

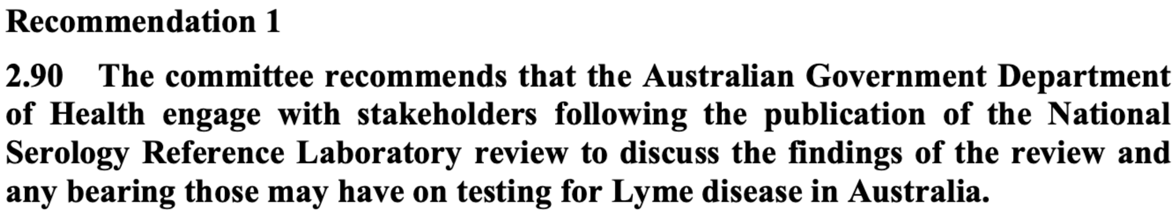
https://en.wikipedia.org/wiki/Baggio%E2%80%93Yoshinari_syndrome

HUGE OVERSIGHT IN TESTING AUSTRALIAN VS OVERSEAS LABS
As part of the 2016 Senate Inquiry they required to test the accuracy both with specificity and sensitivity of "Lyme" borrelia samples with a comparison of various labs from Australia and overseas.

HOWEVER, AUSTRALIAN RICKETTSIA LABORATORIES ARRL THE MAIN LAB USED FOR TESTING LYME DISEASE HERE WERE NOT PART OF THIS TESTING PROCESS.

WHY WAS THAT?

This was in recommendation 1 of the 2016 senate inquiry



Recommendation 1

2.90 The committee recommends that the Australian Government Department of Health engage with stakeholders following the publication of the National Serology Reference Laboratory review to discuss the findings of the review and any bearing those may have on testing for Lyme disease in Australia.

Yet the Department of Health DOH said they completed this testing and found Australian testing to be of a world standard. The research paper is a complicated read, BUT there were many limitations and variables in the results showing inconsistencies and inaccuracies. These would not be allowed in say HIV or cancer testing.
https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0214402

Below is the Thank you to the labs involved and ARRL are NOT on this list.

"The NRL would like to thank the following people:
All the participating laboratories for their willingness to provide specimens and their open

collaboration:
Dr Tim Brooks; Dr Amanda Semper, Rare and Imported Pathogen Laboratory, Public

Health England, Porton Down, UK
Ms Jennie Burke, Australian Biologics Testing Services, Sydney, Australia
Dr Bernie Hudson; Mr Bruce Wong, NSW Health Pathology, Royal North Shore Hospital,

Sydney, Australia
Australian Red Cross Blood Service, Australia
Dr Jennifer M Robson, Sullivan Nicolaides Pathology, Brisbane, Australia
Dr Armin Schwarbach, ArminLabs Augsburg, Germany
BCA-LAB, Augsburg, Germany
Dr Jyotsna Shah, IGeneX Inc. California, USA
NRL staff for their significant contribution in specimen handling, testing and recording the

results for this study:
Dr Kate Zhang, Ms Jing Jing Cai, Ms Nilukshi Arachchi, Ms Tamara McDonald, Ms Jenny Catimel

THE PROBLEMS WITH TESTING - A WORLDWIDE ISSUE WITH EVERY TICK INFECTION.
Australian labs are well behind many overseas labs.

https://igenex.com/tick-talk/an-overview-of-the-types-of-borrelia-that-cause-lyme-disease/

The limitations of Western or Immunoblot antibody testing
https://lymecare.org/posts/wbvsib/

"However, their limitations, particularly in detecting early or persistent infections and distinguishing active disease from past exposure, underscore the need for continued innovation."

Richard Horowitz who presented at the 2016 Senate Inquiry who I believe after was completely ignored after for his help in Australia by the DOH and Aleen and Clarke in developing that faulty DSCATT pathway is one of a number of world leaders into treating tick borne affected patients

https://medicaldetective.substack.com/p/lets-talk-about-testing-for-lyme-blood-tests

"Lyme testing can be unreliable, as can testing for certain other tick-borne diseases, and a broad screening approach is needed"

"As a result, you will see all sorts of claims of accuracy of Lyme testing by different doctors and websites, but the key point is this: A standard ELISA test followed by a Western blot test from a local laboratory *will miss approximately half of those infected with Lyme disease*, as they are notoriously inaccurate—which is why you need to use a really good specialty lab, as they will test for more than one strain of *Borrelia* species. Ask your healthcare provider to run a Immunoblot blood test through a reliable laboratory. I recommend **igenex.com** lab in California, as my first line test, as they use several of the most common strains causing disease to improve their testing. And we have clinically validated their findings for more than 2 decades."

"**The Western blot test and Immunoblot has 5 bands (proteins) that are specific for Lyme exposure; these are the 23, 31, 34, 39 and 83/93 kDa bands**.* The 58 kDa band is also a band frequently seen in Lyme disease, and if other diseases have been ruled out, any one of these bands on an Immunoblot with the right symptoms means you likely have been exposed to Lyme. The more bands you have, the higher the probability of exposure, but to be clear: if you have a multisystemic illness with migratory pain and have ruled out other diseases, even one specific Lyme band on an Immunoblot with a high score on the HMQ tells me you have been exposed to a *Borrelia* species. And some of the sickest patients don't make antibodies, which is why standard two-tiered testing can also be negative."

***This is what I mentioned that ARRL DOES NOT SUPPLY THESE BAND REFERENCES IN THEIR TEST RESULTS. WHY NOT?**

Lyme Tests
https://www.lymedisease.org/lyme-disease-test/
More here
https://www.envita.com/lyme-disease/understanding-lyme-disease

Lyme testing by the CDC which is followed by both Europe and Australia as well jhas been set up for surveillance of tick disease NIT for human diagnosis

https://www.lymedisease.org/lymepolicywonk-lyme-disease-testing-the-cdc-labcorp-and-stories-that-dont-add-up-2/

"the CDC notes that the "surveillance case definition was developed for national reporting of Lyme disease; it is not intended to be used in clinical diagnosis."

The treatment has been set up by one organisation IDSA in the USA, and both Europe and Australia also BLINDLY follow their guidelines even though they are not helpful and lead to remission for long-term affected patients. This has to change as well and patient individually treated for their multiple complex chronicity.

THE NEED FOR NEXT GENERATION SEQUENCE TESTING
Or whatever this new generation testing that was discussed in the senate inquiry, and I discussed this here with an Australian parasitologist working in Japan.

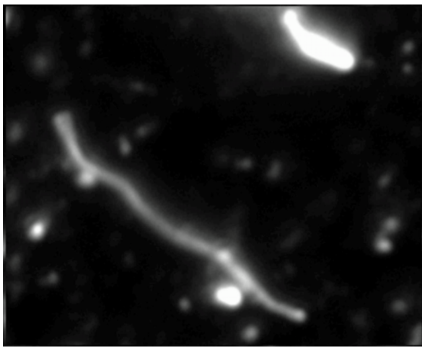
https://www.youtube.com/watch?v=WS-pEGoKkk4
His research
https://scholar.google.com.sg/citations?user=IPHyNiMAAAAJ&hl=en

THE NEED FOR MICROSCOPY TESTING

Dr Walter Tarello is one very experienced microscopy practitioner who could be utilised to help establish this technique in Australian labs like the government National Reference Laboratory

Australia could do this via this National Government lab with the proper training.
https://www.nrlquality.org.au/

In UK via Europe lab
https://www.parasiteclinic.co.uk/product/interest-tick-borne-infections-lyme-disease-co-infections-western-blot-uk/
https://dualdur.com/en/home/
https://lymediagnostics.com/2020/05/20/dark-field-microscopy-in-lyme-borreliosis/



THE NEED FOR TESTING OF THE TICKS

That is another issue. There is **NO testing laboratories** that the public can reliably, accurately and affordably test **for the actual ticks** to see IF they do have any infections inside. Overseas, there are many free and cheap tick testing labs. I am sure we could get already established Vet research tick testing to be available for people to test ticks from them.

Some overseas examples in USA and there are more as well
Now, many of these can test for FAR MORE varieties of infections in ticks than in people.
https://igenex.com/tick-test/ Igenex can also test your tick
https://nyticks.org/
https://www.tickcheck.com/landing/lyme-disease?
https://ticktests.com/
https://www.ticknology.org/

https://www.tickcheck.com/
https://www.tickreport.com/
https://geneticks.ca/about-geneticks/
https://cvmdl.uconn.edu/tick-testing/options/
https://www.esu.edu/dna/tick-diagnostics/index.cfm
https://www.beboplabs.org/tick-identification/
https://ag.umass.edu/resources/tick-testing-resources

In UK and Europe
https://arminlabs.com/en/tests/tick-test Armin labs also test ticks
https://biobest.co.uk/lyme-disease-testing-by-pcr/
https://biolytix-laboratories.com/en/tick-test/

If there were a **National federally funded accredited tick testing lab**, this could also add to the surveillance data needed. So a service to the public would have a win-win to add what diseases were found in ticks in what areas collected by the public. It's a way to use citizen science as well.

Peter Owen
President Ticna

TIC NA TICK-BORNE ILLNESS
Community Network Australia Inc.
www.ticna.org.au info@ticna.org.au
Educating the public about tick-borne illness
Implementing change through knowledge

2025 SENATE INQUIRY ADDITIONAL IDEAS

THE PROBLEM IN AUSTRALIA - THE NO LYME DOGMA

IF supposedly research says it has NOT found the 3 borrelia strains ie the one USA **Borrelia** Burgdorfer and 2 European strains **Borrelia** garinii and Borreliella afzelii in Australia BUT have found at least 5 other different borrelia strains here why has the emphasis over the last 20 years at least been just to deny the USA and to a less degree the European Lyme strains. Why have they broadly not accepted that Australian strains exist and could cross-react with the overseas strain testing (both here and in overseas labs) and that the tests could be positive to a BORELLIA regardless of the species or strain?

LET'S TREAT EARLY BASED ON PATIENTS' HISTORY REGARDLESS OF TEST RESULTS

Interesting that if a patient has Rickettsia, Anaplasma, or even some type of Borrelia, the best first-round antibiotic is the same for all these infections. So why not treat for 4 weeks early?

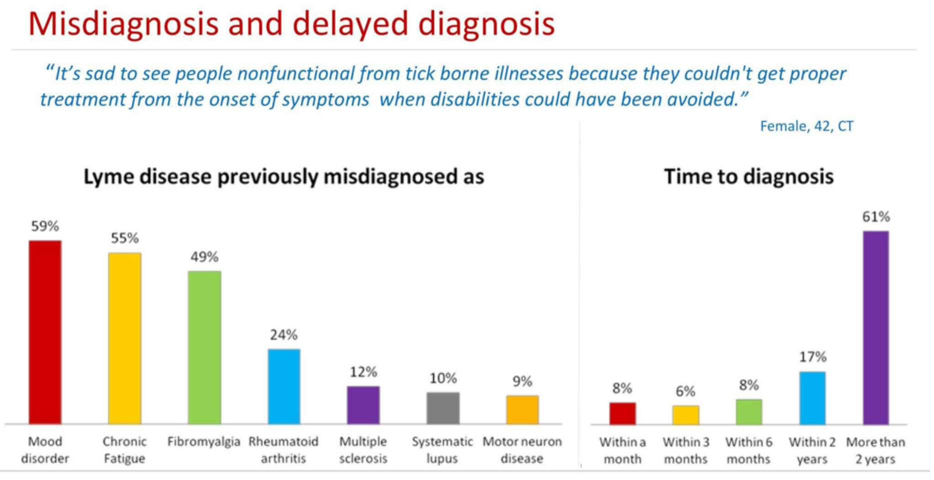
THE HARM OF DOING NOTHING OUTWEIGHS TREATING EARLY

Properly treating a suspected tick infection with 4 weeks of a safe antibiotic combined with safe preventative probiotics early would be far better than no treatment and just endlessly waiting and watching patients suffer, regardless of testing positive or not. It is a clinical determination with testing only as a backup. The patient outcome of improved symptoms is your clinical measure.

No medical practice should have this "do no harm by doing nothing" as the standard level of "care". This is fear-based medicine often brought on by the fear of APHRA.

Much more needs to be achieved moving forward, and the Australian patient community is desperate to advance prevention and care.

Misdiagnosis is huge for our community, and so is the delay in correct diagnosis.
This is from USA data, and as we do not have data here, it also extrapolates to Australia. Just replace overseas Lyme with Australian tick infections, including Rickettsia, which, although "recognised" here, also is often missed. Many go on to getting and MECFS diagnosis instead.



Misdiagnosis and delayed diagnosis

"It's sad to see people nonfunctional from tick borne illnesses because they couldn't get proper treatment from the onset of symptoms when disabilities could have been avoided."

Female, 42, CT

WHAT ELSE IS NEEDED

I had outlined some other issues in my address and inquiry submission. Below are some points reiterated that will hopefully form a part of the new and more extensive recommendations your committee outlines to fast track.

REMOVE DSCATT AS A NAME

Hopefully, this inquiry has highlighted that many chronically ill patients are not just affected by tick infections and the elusive Lyme or even borrelia. As a community, we are complex, and our conditions can be multifaceted and affected by many vector infections, not just ticks. Plus, many are affected by mould, mycotoxins, and other issues. It’s why a functional medicine approach with very learned and broadly disciplined doctors who understand the complexity of what infections, toxins, and other problems can do to every organ of the body is needed. So, categorising us as “DSCATT patients” is pigeon-holing us incorrectly. Plus as we can see from that Pathway, it fails miserably at the testing part of the process, hence missing many people and then many fall incorrectly diagnosed as DSCATT, which may as well be MUS Medically Unexplained patients.

REMOVE PSYCHOLOGY/PSYCHIATRY INTERVENTIONS AS TREATMENTS.

I think the committee could see the ludicrousness of having psychiatry as a treatment intervention when that $1 million of money would have been better spent on better testing, education, social media awareness and anything else to improve treatment for our patient community.

ESTABLISH TICK AND VECTOR BORNE DISEASE WORKING GROUPS

In the USA, they established working groups that involved many patients and other organisations, as well as other groups and specialists across many disciplines. This outlined precisely what was needed moving forward. This needs to be established and ongoing in Australia. It is not active at the moment in the USA. More here from past report to replicate for Australia
https://www.hhs.gov/ash/advisory-committees/tickbornedisease/reports/index.html

CHRONIC CARE CLINICS

There is a huge need to establish Chronic Care Clinics or similarly named clinics that can encompass MORE than just tick-affected people. In my patient support community, Conquering Chronic Illness, (CCI) I see far more similarities and overlap than differences**. It would make logical and economic sense to have established clinics suitable to see the newly diagnosed and alienated Long Covid community as well as MECFS, Fibromyalgia, mould/mycotoxin, as well as the vector communities with both tick and mosquito-borne affected patients understood and treated in one accessible and Medicare affordable place.**

conquering
CHRONIC ILLNESS

Supporting patients with MECFS, Long Covid, Fibromyalgia, Tick & Vector infections, Mould/Biotoxins, MCS, EMF sensitivities & Autoimmune & Chronic pain conditions.

PATIENT GROUP FUNDING

As patient groups, we know precisely what our community needs, and we can deliver support while patients are being adequately treated. We get thousands of newly bitten people joining and contacting us as they are not getting the help they need within the medical system. Our community can safely make “homes” for these people. I am sure we have saved many from suicide simply by our presence, yet we are grossly undervalued as a patient resource.

The vast majority, who also may not be full charities, volunteer their time to do this, and many, like myself, do not want to be paid. However, we would like access to funding to put programs in place to build and support the community. My communities with CCI combined with Ticna, with the help of Victorian government peer support funding, received $20,000. I developed FREE online Qi Gong, Yoga, Meditation, breathwork, health coaching, and more classes and education programs, formulated and targeted for the house and bedbound limited ability community. This was amazingly received. But as funding has run out and is no longer available, we are at a loss again in continuing these much valued programs and classes.

I have included two surveys for these. One demographic, representative of our groups, which is over 80% female and the other feedback and testimonials about our classes. I hope this committee can also include funding for our patient support ventures in their recommendations.

This is in simple terms is what else is needed

STOP MORE – The general healthy public being bitten through **education and awareness** via socials, tourist outlets, parks and outdoor workers, sports, camping and scouts, etc.

FUND MORE - Research and include broader researchers. Fund patient groups as well.

FIND MORE - Through constant tick **surveillance** and data collection

COLLECT MORE – Data through **making every infection notifiable.**

EDUCATE MORE - **Doctors and the public**. **Utilise the best of overseas clinicians** as consultants and educators.

TREAT MORE – Allow more doctors to **treat earlier and longer** and use more tools to treat long-term and holistically. This DOES NOT mean only just more long-term antibiotics,

ALLOW MORE

Allow more treatment options and allow more freedom to do so without the unnecessary scrutiny of APHRA. Allow utilising off label drugs, herbs and treatments like Hyperthermia, HBOT, Oxone, IV and more. **Investigate the best overseas treatment clinics**. I keep hearing and reading that DOH and APHRA always say they need quality evidence-based resources, and yet, these in this field rarely come, and patients can’t wait. The evidence will come from treating patients safely and also having clinical trials with actual patients in real settings and developing case studies. Not through research with researchers who have no clinical background.

HELP MORE - with changes to Medicare rebates for the chronically ill. Adapt family allowances to be more equitable for one family member who is sick. Make rebates greater or free in Chronic Care Clinics to fast-track recovery, saving multiple millions in the long term. This would fast-track recovery and get patients back to full health, working and paying taxes rather than being long-term burdens on the medical system.

CONSULT MORE - We must keep our patient community in closer contact with research, education initiatives, and other things that benefit our community. But often we sit waiting in silence as to any progress. It’s been over 5 years since the tick testing was undertaken, yet we have received no updates. It’s been 9 years since the first Senate inquiry, and nothing has improved for us OR the public. There is also NO OVERSIGHT by any authorities after money has been allocated. There must be oversight and regular reporting to governments and the patient community.

As a patient representative, I welcome the opportunity to participate in any collaborative project involving tick-borne diseases. To assist with social media and other awareness and education, research, testing, treatment ideas etc. My personal life experience with tick-borne diseases both overseas and here, as well as my background as a scientist with a BSc, running my own business and as an avid amateur researcher, I would be an asset to help make positive changes. Any committee needs patient representatives involved as collaborators in the process.

Finally, a huge thank you to the Senate Community Affairs References Committee advocates who have devoted their time to reinvestigating this shocking state of affairs for the tick and other chronically ill affected community.

Senator Penny Allman-Payne
Senator Linda Reynolds
Senator Louise Pratt
Senator Wendy Askew
Senator Maria Kovacic

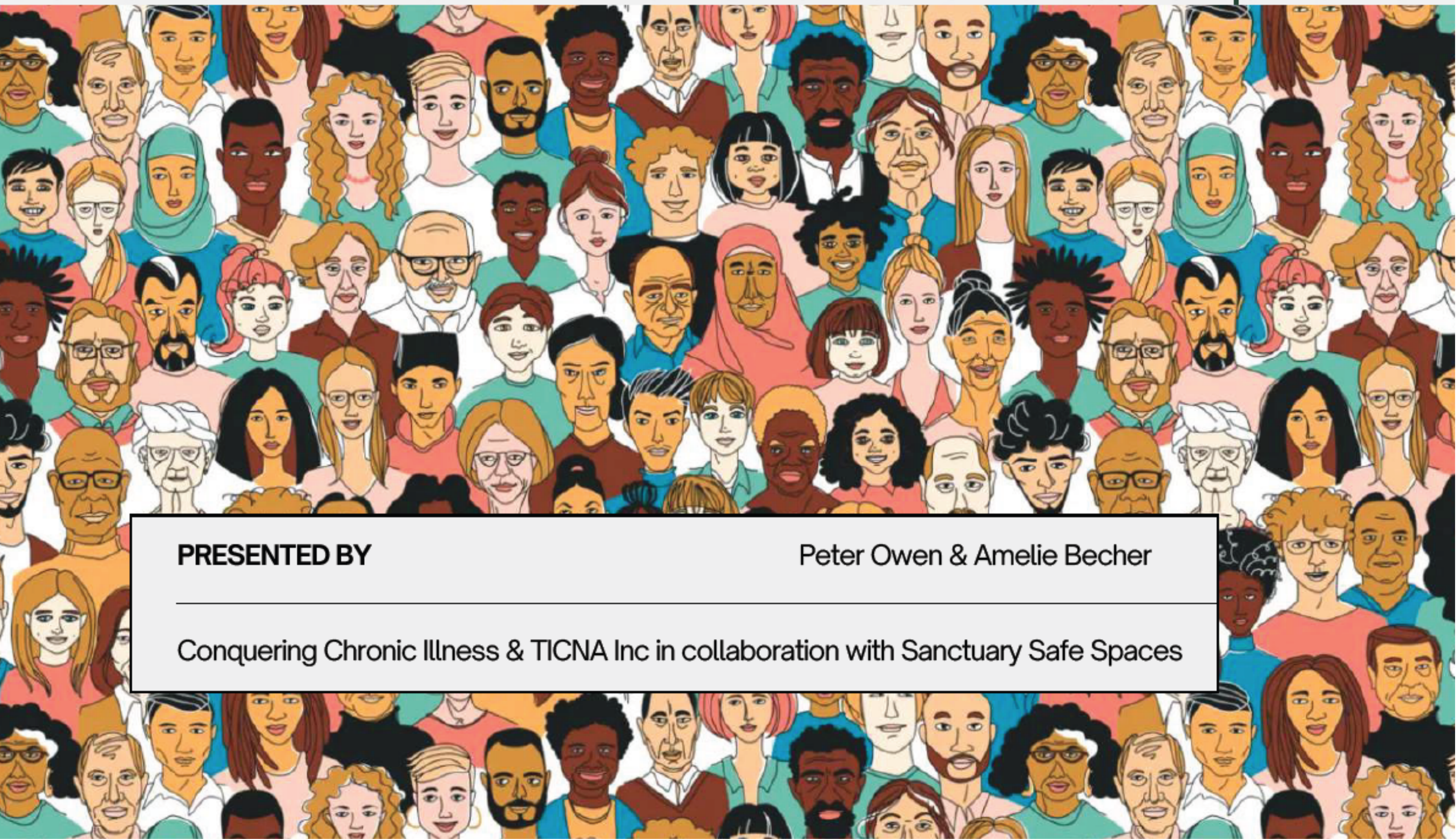
Peter Owen
President Ticna

TICNA TICK-BORNE ILLNESS
Community Network Australia Inc.
www.ticna.org.au info@ticna.org.au
Educating the public about tick-borne illness
Implementing change through knowledge

Improving Health Survey - April 2024

2024

Meeting the needs of Australia's growing "invisible" chronically ill population.



PRESENTED BY Peter Owen & Amelie Becher

Conquering Chronic Illness & TICNA Inc in collaboration with Sanctuary Safe Spaces

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According to the Australian Bureau of Statistics report released in December 2023
Eight in ten (81.4%) people had at least one long-term health condition and
One in two (49.9%) people had at least one chronic condition.
Almost nine in ten (86.6%) people with a chronic condition experience multimorbidity.

These are concerning statistics for our country. Yet, while the chronically ill population is growing, the support provided by the Australian healthcare system is not.

Conquering Chronic Illness and TICNA Inc. have collaborated with Sanctuary Safe Spaces to investigate the statistics of our unique chronic invisible illness patient community more deeply.

The following outlines the data compiled from our April 2024 survey, providing a representative snapshot of the lived experience of an invisible, sadly mostly ignored section of Australia’s chronically ill population.

https://www.aihw.gov.au/reports/burden-of-disease/australian-burden-of-disease-study-2023/contents/summary

About Conquering Chronic Illness (CCI)

CCI was conceived over 8 years ago as an online Facebook education & patient support group. The idea of this group was developed by one unwell patient who could see a need for a different all-encompassing group that included people with varying condition names who had very similar symptoms, experiences and needs.

He formed this to help proactive like-minded people with similar overlapping symptomatic conditions of **ME/CFS, Fibromyalgia, Mould/mycotoxin illness, tick (inc overseas Lyme) and other vector infections & Multiple Chemical Sensitivity (MCS) & EMF sensitivities.** It has now expanded to include many with **Long Covid** & other **autoimmune and chronic pain** patients. It has grown from zero without paid marketing and little promotion to help serve nearly 1100 members. It has a public page and a private group.

The principal facilitators volunteer 100% of their time in admin and organisational roles, predominately from their homes and sometimes their bedrooms as they remain unwell. CCI's next step is to become a full DGR-status charity. CCI has a website in development but is waiting for more funding to complete an educational patient community resource.

CCI previously received $10,000 in funding from the Victorian government. With that, it has delivered **FREE** online support to members via **tailored movement, Yoga, Qi Gong & Breathwork classes, many health practitioner presentations and free or significantly financially subsidised education courses.**
The CCI et al volunteers recognised a missing need, so they developed these classes and programs specifically tailored to our community

This has been extremely beneficial for bringing communities together, especially over the Pandemic period and these online classes, in-person cafe catch-ups and email communications have been supportive for many who felt alone in their illness journey. Although started in Melbourne Victoria, it now reaches people Australia-wide and from our recent survey people are keen to continue the hugely beneficial support of classes and programs.

Public Facebook page
https://www.facebook.com/conqueringchronicillness.org/
CCI/Ticna YouTube Channel
https://www.youtube.com/@conqueringchronicillness836
Our free classes and programs are shared and promoted on the Sanctuary Safe Spaces website. **https://www.sanctuarysafespaces.org/**

About Ticna and Sanctuary Safe Spaces.

Ticna Inc. is an acronym for Tick-borne Illness Community Network Australia and became an incorporated body in Victoria in 2018 and is an LTD company. Its primary aim is to factually educate the public about ticks and other vectors and their diseases in Australia and from ticks and other vectors overseas and, secondary, to support currently unwell tick-affected patients. It is also volunteer-run by the same person who volunteers and oversees CCI.

It previously received $10,000 in private funding which enabled Ticna to become established and develop & provide over 40,000 public tick education brochures that before the Pandemic were able to be distributed Australia-wide. We also provided in-person education talks about ticks and their diseases to various groups like Probus, Lions clubs etc, that sadly had to cease due to the pandemic. The Ticna website is still under development as it is waiting for more funding. **https://www.ticna.org.au/**

Some of the Ticna private funding was diverted back to support patients during the pandemic. Ticna has a private Facebook group that supports patients and a Public page to educate the public. **https://www.facebook.com/TICNAinc**

Ticna also received $10,000 in Victorian government funding and along with CCI and in collaboration with Sanctuary Safe Spaces organisation, free classes and programs were developed and also shared and promoted by our collaborators on the TICNA, CCI and Sanctuary Safe Spaces social media and website to broaden the audience and get best value from the investments.

Sanctuary Safe Spaces is a perfect fit to collaborate with CCI and Ticna as their facilitator's aim matches our group's goals.

Sanctuary began when the founder experienced a lack of understanding and support for those suffering from chronic illness due to mould & bacteria caused by water-damaged buildings. The existing support groups (Toxic Mould Support Australia & Overseas equivalents) were often extremely triggering to the nervous system so Amelie wanted to create a space that was easily accessible and felt safe for the nervous system. A place where people could turn to for hope and healing. It has grown to welcome anyone struggling with the health of their nervous system, regardless of the initial cause.
Sanctuary is self-funded by Amelie with occasional donations from the participants of the sessions which she hosts multiple times each week.

All CCI, Ticna and Sanctuary free classes and programs are shared and promoted on the Sanctuary Safe Spaces website. **https://www.sanctuarysafespaces.org/**

The aims of our survey:

- To understand the demographics of the Conquering Chronic Illness, TICNA & Sanctuary Safe Spaces Community

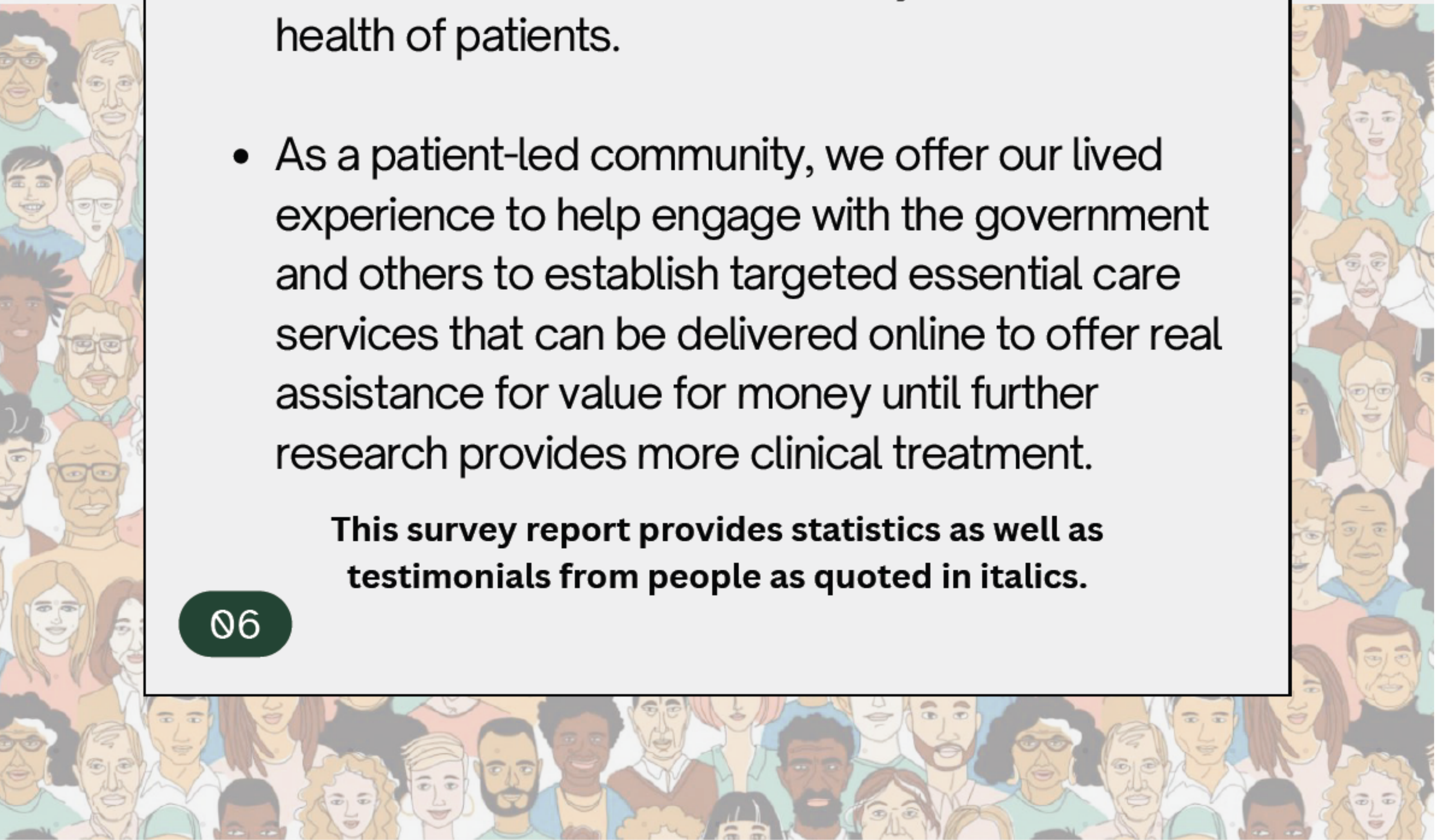
- Understand how the current health system helps and where improvement is needed for our chronically ill patient population.

- Understand the immediate support needs of our chronically ill population.

- Outline real-world patient data that helps provide funding needs to continue actively engaging with the invisible chronic illness patients directly, for the betterment of the community and mental health of patients.

- As a patient-led community, we offer our lived experience to help engage with the government and others to establish targeted essential care services that can be delivered online to offer real assistance for value for money until further research provides more clinical treatment.

This survey report provides statistics as well as testimonials from people as quoted in italics.



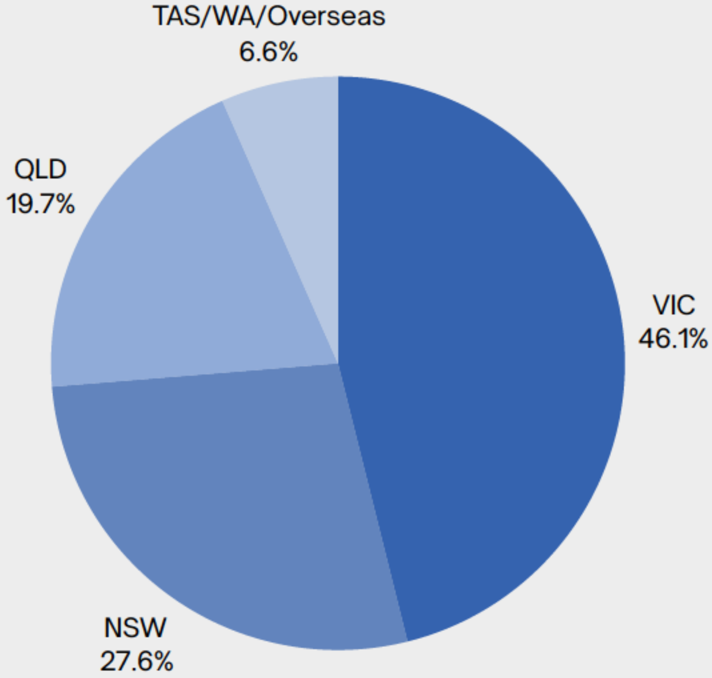
A snapshot of our community

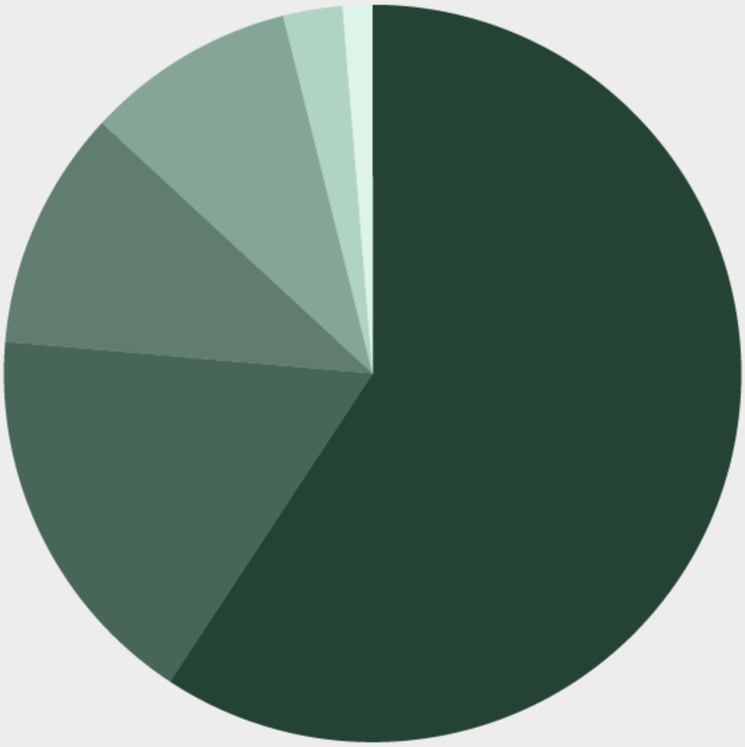
2024

81.6% were born in Australia

96.1% Speak English as their primary language

96.1% do NOT identify as Aboriginal or Torres Strait Islander

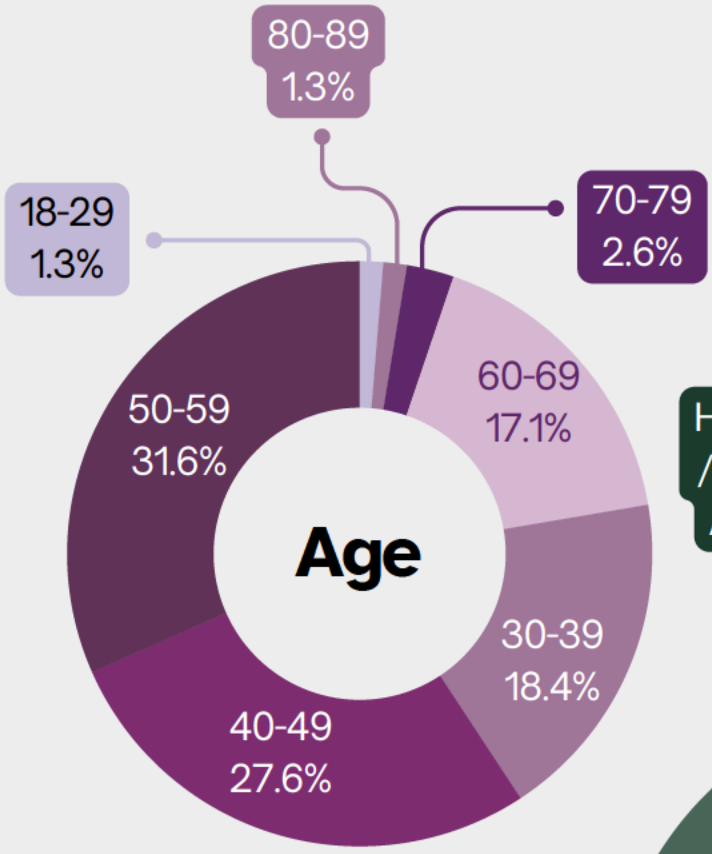


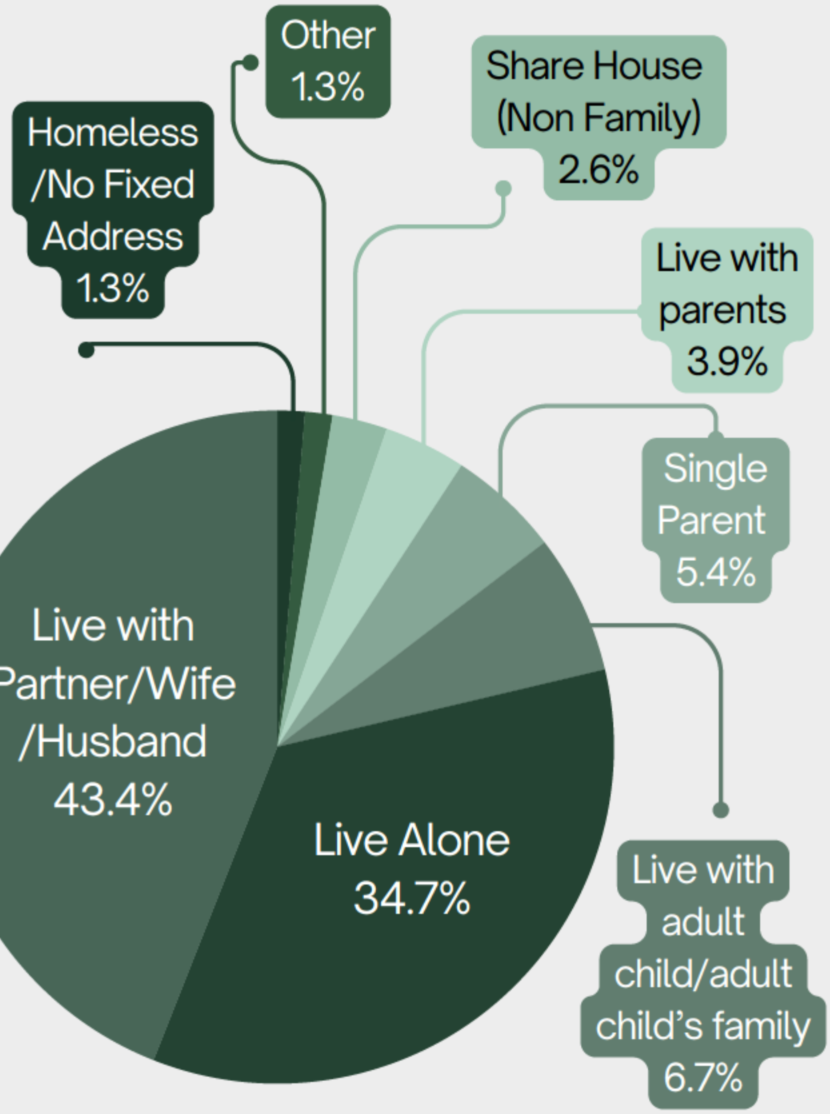


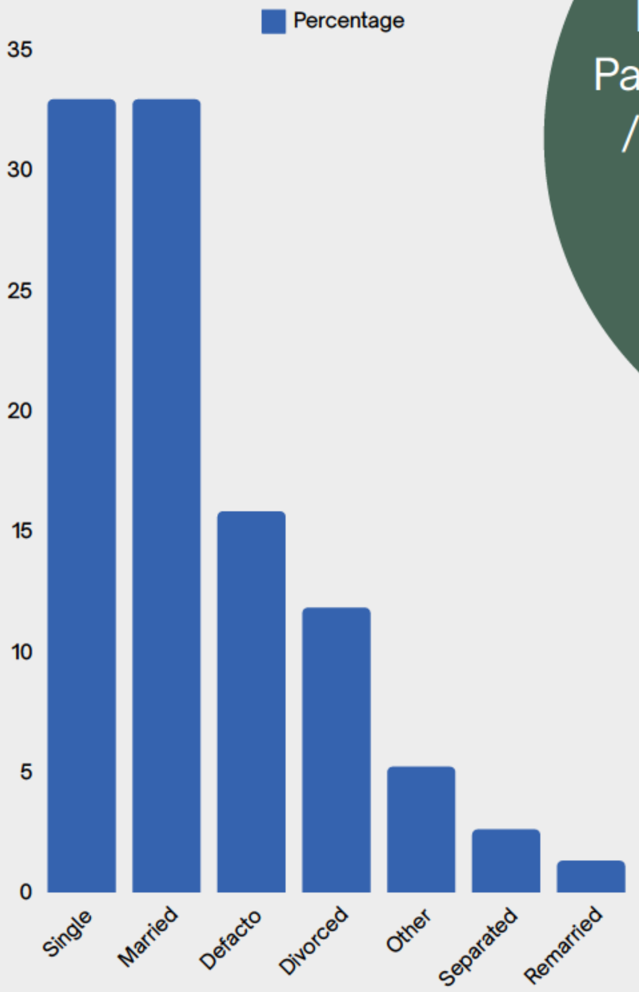
Location (%)

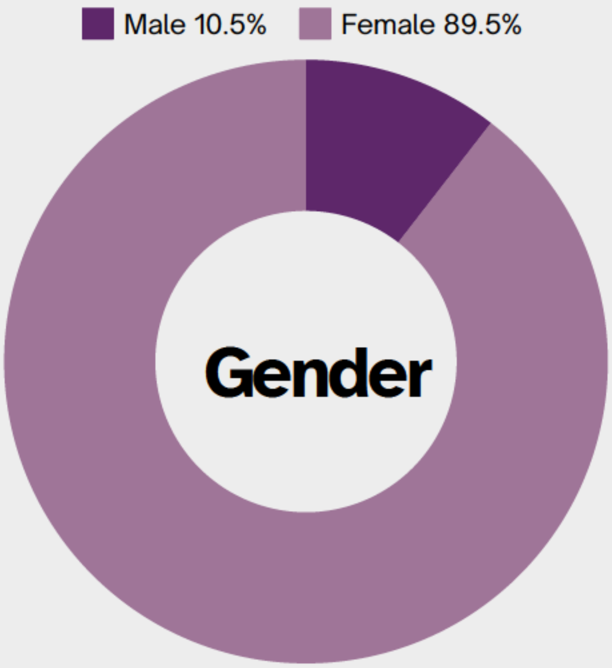
59.3%	City Suburbs
17.1%	Large Town/Regional Suburb
10.5%	Remote/Rural
9.2%	Small Town
2.6%	City CBD
1.3%	No Fixed Address

Living situation



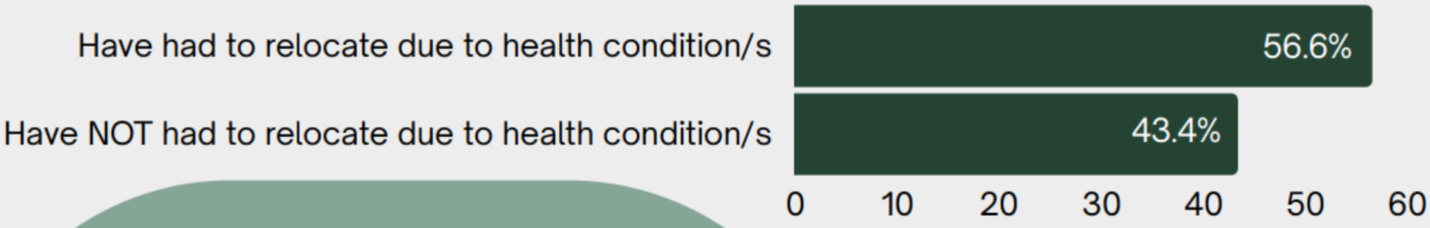




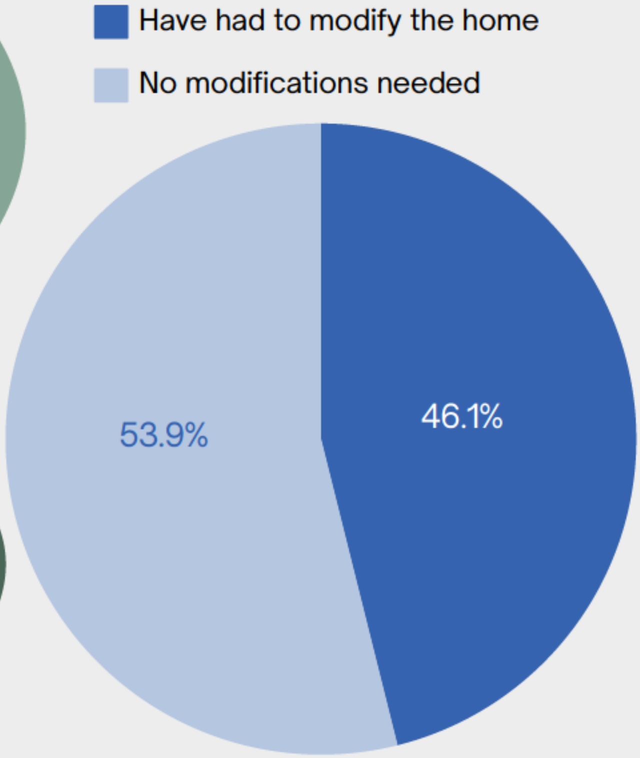


Home relocation & modification needs

Home relocations have often come about due to water ingress and mould and mycotoxin issues causing serious health problems in our patient community.



I spend a fortune running hospital grade air purification and dehumidification systems to ensure my home remains at a mould level safe enough for my health to not deteriorate further.



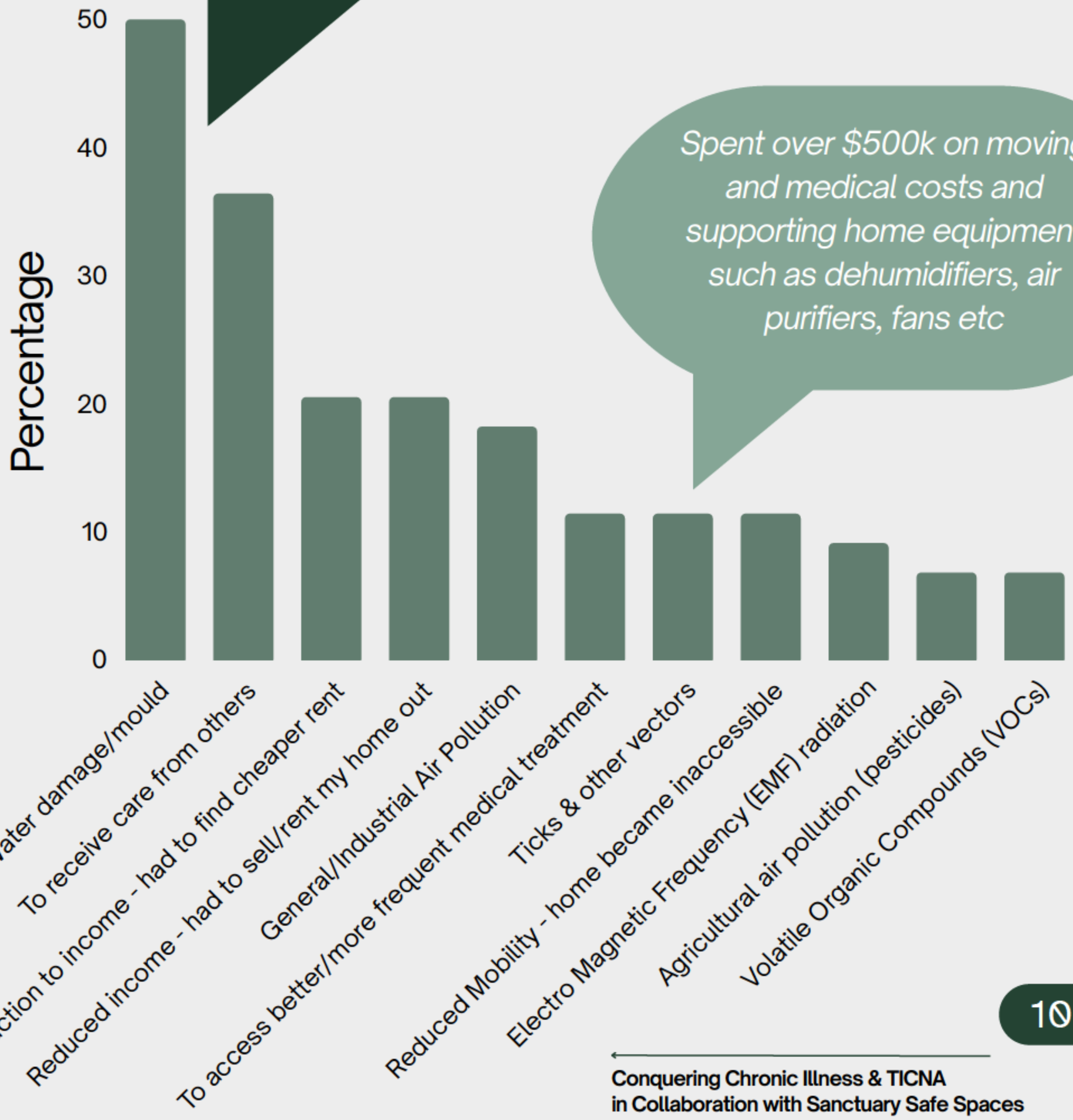
I have mobility issues so I will slowly have to add various modifications to accommodate this.

I had 4 x professional building inspections done to remedy home then find a new home without water damage, plus repairs due to water damage, plus mould testing. We discarded many household items, clothing, furnishings, electronics due to mould/CIRS recommendations. This was tremendously expensive.

Home relocation & modification needs

In recent years, approximately $25,000 has been spent on healthier floor-coverings (from carpet to tile), mould remediation and healthier insulation (including a thorough vacuum of the ceiling cavity). This was necessary due to Multiple Chemical Sensitivity - one of a few chronic conditions I live with. The necessary water and air filtration ad to this cost significantly. There are still spaces in my current home that I'm unable to access safely.

Spent over $500k on moving and medical costs and supporting home equipment such as dehumidifiers, air purifiers, fans etc



Home relocation & modification needs

Because I'm still super sensitive to mould (and many other things) I've had to set up a decontamination shower outside and an outdoor dressing room/ laundry so that I can keep my indoor clothes seperate from my outdoor clothes as I cannot risk my "safe bubble" home from becoming contaminated with mould mycotoxins from the places I go for appointments or the vehicles and public transport that I catch.

I've had to move multiple times due to water damage, and I've had to discard of the majority of my belongings which has cost many thousands of dollars not claimable on insurance. I was homeless for almost a year (sleeping in my car, a tent, a caravan or outside sleeping rough) in search of a home that had a mould level low enough for me to breathe in.

I quickly used up my savings surviving, and couldn't work, so finding somewhere i could rent cheap enough was difficult, sharing is also difficult because often people don't understand CFS/ME and it's a horrible experience.

Home relocation & modification needs

To truly live in a mould free environment a lot has to happen including professional treatments: Mould Remediation between $1606 - $2486; Air conditioning treatment $610; Building biologist assessment (cause no visible mould can still have mycotoxins in the air and on surfaces about $1500 - $2000 Roofing: $5005 Remove trees from around the house $3740 (as the shade encourages mould) When all this didn't remove the mycotoxin load, I had to move and start the inside treatment process again in the new place.When I moved I also had to replace all my clothes, soft furnishings... anything porous. This is all before medical treatments - none of my conditions can be treated by a GP or Medicare-funded specialist and only one medication is government funded.

I have mobility issues so I will slowly have to add various modifications to accommodate this.

Spent over $500k on moving and medical costs and supporting home equipment such as dehumidifiers, air purifiers, fans etc

[Low tox] Mattresses, bedding, clothing. Ones I tolerate are very expensive

Mobility aids such as shower chair, stools placed in different spaces, purchased a couch that also acts as a day bed.

Had to live where there was cleaner air than a city

Home relocation & modification

In recent years, approximately $25,000 has been spent on healthier floor-coverings (from carpet to tile), mould remediation and healthier insulation (including a thorough vacuum of the ceiling cavity). This was necessary due to Multiple Chemical Sensitivity - one of a few chronic conditions I live with. The necessary water and air filtration ad to this cost significantly. There are still spaces in my current home that I'm unable to access safely.

Install a stair chair

Bath chair, bathroom grab rails

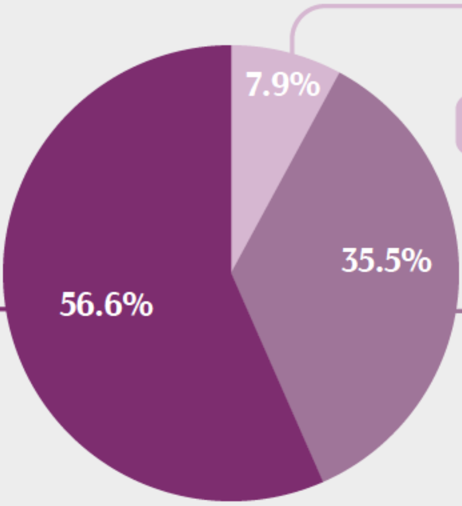
We have made the house have no stairs. .

Aircon units in 3 rooms due to heat intolerance

I needed to buy two dehumidifiers $600 each

Water damage x3 episodes. 1st episode house was completely gutted 8 yrs ago after 4 yrs legal fight through VCAT, cost $170,000 but compensated $100,000 & moved out for 4 months. 2nd episode was 5 yrs ago and mould was spread throughout the home by remediator, needed to move out for 2 months, went through insurance company but cost us several thousand. 3rd episode 2 yrs ago, still going though insurance company, trouble getting quotes, going to cost approx $180,000 and we will need to move out for at least 2 months.
Plans to build disability ramp access to Home

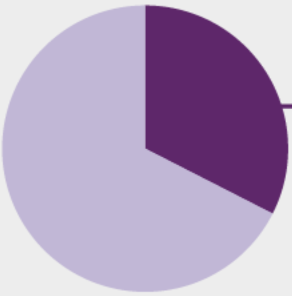
Decisions around Children & Pets



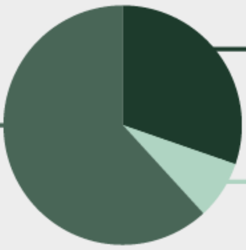
Decision/ability to have children was impacted by chronic illness

Uncertain/Other

Decision/ability to have children was NOT impacted by illness



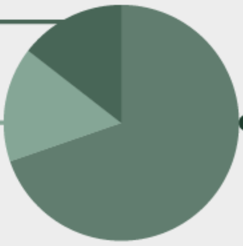
Of those with children, 32.5% are showing symptoms of chronic illness and/or developmental disorders or disability



30.3% Have a pet to help improve their mental health

7.9% Have a pet to help improve their physical health

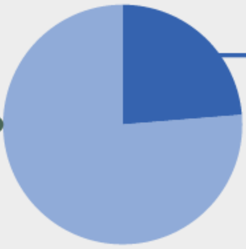
Those with pets



14.5% struggle to care for their pet due to their financial situation

15.8% struggle to care for their pet due to their health

Those without pets



23.7% Wish they had a pet to help improve their mental &/or physical health but can't due to finances or housing being unsuitable

Chronically Ill children

Of the 32.5% of chronically ill survey participants with children (who also show signs of chronic illness &/or developmental disorders or disability) we found that:

50% had 1 Biologically descendant child (sharing genetics)

25% had 2 Biologically descendant children (sharing genetics)

25% had more than 2 children OR described other family dynamics where their children did not share genetics

75% were female & 25% were male

50% Had 1 or more Teenagers (13 - 19 years)

25% Had 1 or more Toddler aged children (1 - 3 years)

25% Had 1 or more School Aged children (6 - 12 years)

25% Had one or more young adults (20 - 25 years)

25% Have a disability

25% Have a suspected disability

25% Are homeschooled due to their health conditions/disabilities

ALL of the children with chronic health conditions and/or learning disorders or disability require extra support from parents & extended family, their medical team and their community.

Extra support and accommodations are required from all who attend school or a workplace.

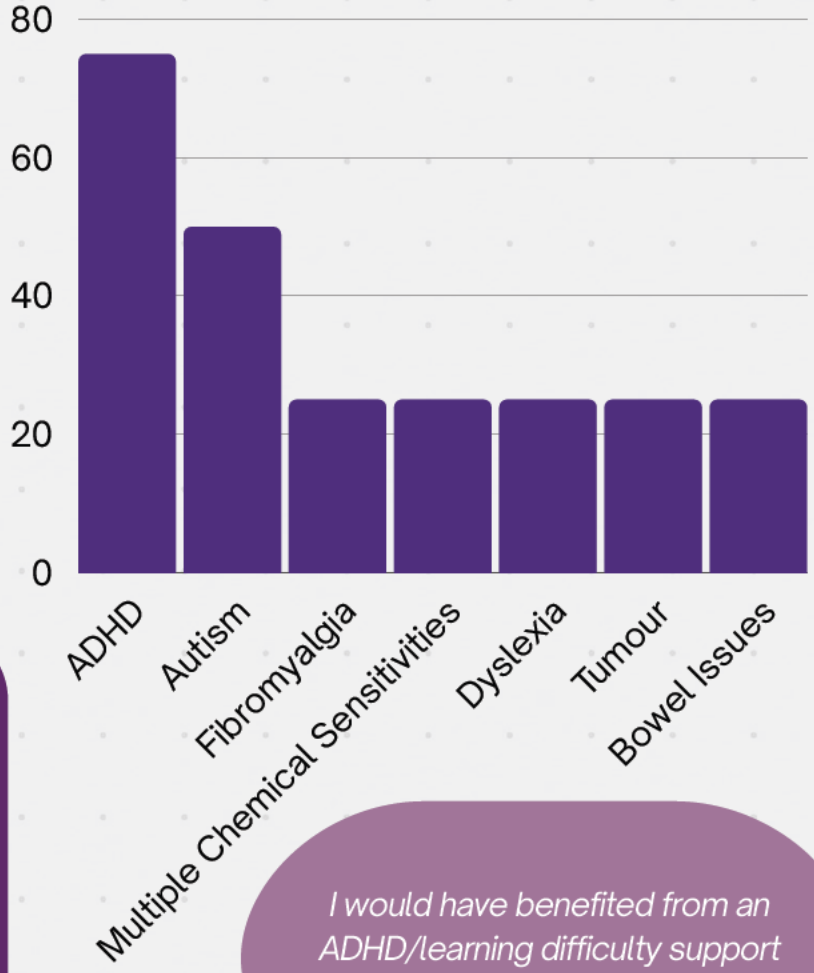
50% receive support from the NDIS.

Those who are single or re-partnered parents:

50% receive help from their ex-partner for the extra needs of their child/children, whilst 50% do not

Chronically Ill Children

The length of time each child has been unwell varies depending on the diagnosis, ranging from 2 to 15 years and some ongoing, predicted to impact them for life.



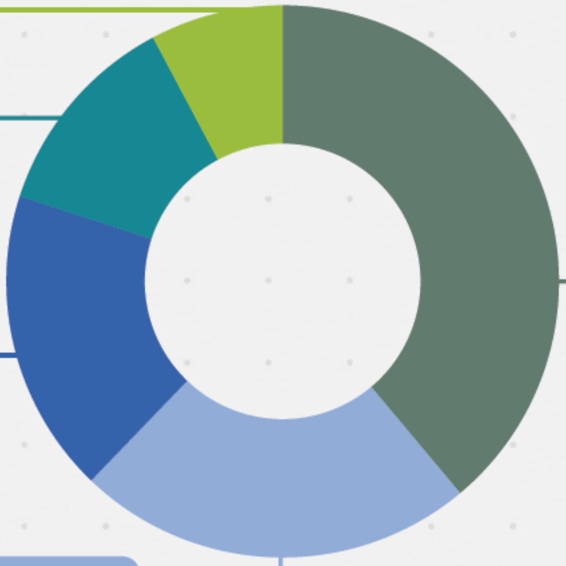
50% of survey participants felt that the following support groups would have been useful:

- Support group for parents of children with chronic illness/disorder/disability
- Support group for children & teenagers with chronic illness/disorder/disability
- Support group just for carers
- Support for parents with disabilities

I would have benefited from an ADHD/learning difficulty support group during my daughter's teens

“If I had known my daughter's ADHD diagnosis earlier, I would have accessed some support services or coaching for her and myself as parent at a minimum. I don't believe these services are actually sufficiently funded. The out of pockets for coaching being around $170 per session with no rebate, or psychologist services have waiting lists that are very long, and again the price is prohibitive for a non-working parent.
ADHD can cause a child to be chronically disorganised (eg running late, forgetting important items, forgetting they have work, not completing tasks etc), and oppositional. Having a parent with at times severe brain fog has made the task of parenting her well extremely challenging. I would have benefited from some funded support in areas of gardening and housework as a carer or in my own right, so that I had a bit more energy for her needs.”

Support Networks



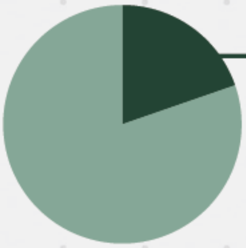
7.8% Have forged supportive friendships through TICNA

12.2% Have forged supportive friendships through Sanctuary Safe Spaces

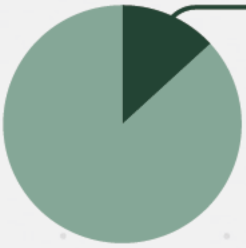
17.8% Have forged supportive friendships through Conquering Chronic Illness

23.3% Have some supportive family *but struggle to see them due to health

38.9% Have some supportive friends *but struggle to see them due to health



19.7% don't have a support network in their area



13.2% don't have a support network AT ALL

Paid Carer 13.2% Receive support from a paid carer

Family/friend/volunteer 19.7% Receive support from an unpaid carer

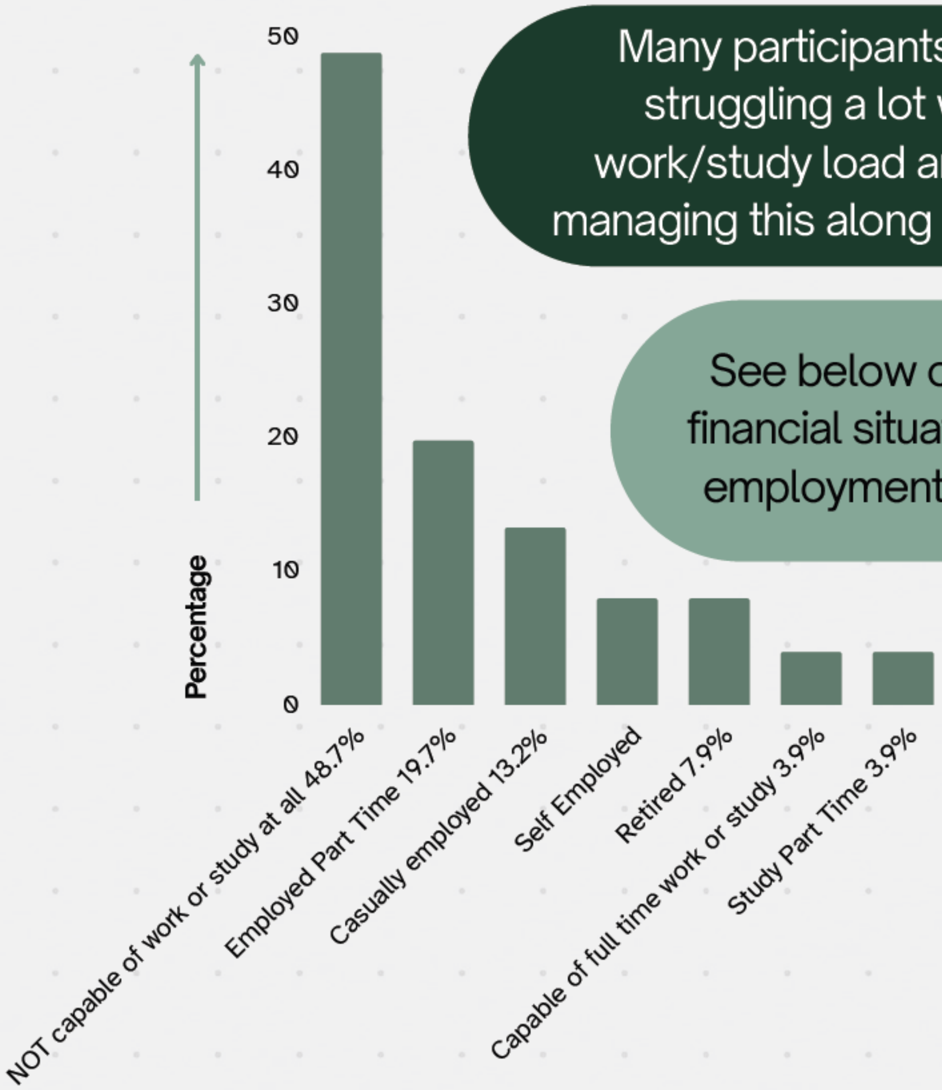
42.1% Rely on a supportive partner

But only 6.6% of supportive partners receive a carer payment

Education & Employment

Many participants describe struggling a lot with their work/study load and difficulty managing this along with life tasks

See below comments regarding financial situations forcing return to employment whilst unfit for work.



I can't cope with full time work. I usually work 3 to 4 days a week, and rest on the other days

Lack of mental and physical energy, constant general malaise interfere with any attempt at activity

I'm far too ill to have the energy or cognitive ability to do any work

Very high persistent chronic fatigue and brain fog. Management of gut health takes a lot of time.

Currently on light duties at work and reduced hours, due to Ill health

The impacts of Chronic Illness on economic participation

I struggle and push through the day of work, and then go home and lie on the couch, have a nap and then repeat all the next day

I don't have the physical or cognitive ability to hold a job

Symptoms are completely random. Deadlines are impossible

I can work, but part time only. I work on split days Monday, Wednesday and Friday to have rest days between...

... My health varies from fabulously well, to awful if I push a bit physically like mowing the lawn

I can't focus or concentrate for long. I get exhausted easily and react to smells, fumes etc

Unpredictable symptoms, fatigue and brain fog that reduces my capacity to drive

Can only work 1-15 hours per week, varies a lot

Cognitive disfunction, chronic pain, chronic fatigue, unable to drive, cannot be around fragrance or chemicals or noisy environments, can not use public transport

The impacts of Chronic Illness on economic participation

1. **Fragrance**. Most people and indoor environments are saturated in fragrance and other chemicals that are disabling in their effects

2. **Fatigue** and **cognitive difficulties** as a result of ME/CFS
.

3. **EHS (Electrohypersensitivity)** makes it difficult to be about the abundance of wireless technology that now so commonplace.

Retired prematurely due to chronic fatigue and headaches

I pulled out of my one subject of university last year as the brain fog I experience was too overwhelming to be able to assimilate information adequately enough to continue studying

I am [working] but regularly get burnt out if taking on too much. Starting own business due to teaching being too full on

Symptoms do not allow it. Mostly home bound

When I was working 5 days I would barely do anything at home and rest all weekend to recover to go back to work

40% overall functioning capacity

Debilitating physical and cognitive fatigue

The impacts of Chronic Illness on economic participation

Fatigue, post exertional malaise, brain fog, unrefreshing sleep, flu-like symptoms, neck pain, anxiety, depression and other symptoms of Myalgic Encephalomyelitis are made a lot worse when I work. I now only work once a month for half a day. I work in a much less demanding job now as a receptionist, despite being a qualified dietitian. My degree took me 5 years to complete. And now I do not use it. I also still have HECS debt due to not being able to work enough and earn enough due to my chronic illness.

...on a bad day when just talking is exhausting, how am I meant to have energy for anyone let alone customer service?

I struggle to study due to my long list of disabilities and complex chronic health conditions but I have to study in order to receive a rental subsidy otherwise I would be homeless

Far, far too sick! No energy, no concentration. Can't travel, dizzy, nauseated, weak, malaise 24/7, headache, pain and more!

The impacts of Chronic Illness on economic participation

> *I have crashes sometimes daily. They aren't always predictable. It also takes almost all of my energy to shop, walk my dog, cook, housework & attend to limited social and interest opportunities. [Long Covid has increased] propensity to crash, and added great restriction to when & how I can safely socialise. Covid has added greatly to my level of isolation. And greatly to the cost burden of my illness*

> *Unpredictability of my condition is hard. I can have really good days, but can crash and have really bad days and i feel terrible, so it makes me unreliable. I hate that. I can't do long hours, half a day, there is no way i can sustain my energy for a full day*

> *As I can't exist in any building other than my safe bubble home without my health deteriorating I will have to set up my own online business instead. This will be a struggle to set up and maintain but I don't have any choice really*

> *Have had Tick borne illness most of my life, had to leave school because I could no longer write an essay or remember what I read due to illness impacting my brain, also have fatigue and severe derealisation which keeps me housebound*

> *I am in a wheelchair most of the time due to pain. I am on THC/CBD oil so I am unable to drive. I get super tired during the day and so I need a 1.5 hour nap at lunchtime. These mean that I have to work from home which has affected job opportunities. I lost my last job as I was unable to work full time hours. My current job is as a contractor and I'm currently not able to do enough to earn a wage due to pain and fatigue. Stress makes my pain worse so I can't have a job that is too stressful.*

The impacts of Chronic Illness on economic participation

Can only do extremely limited hours. Fatigue and brain fog common. Need to lie down regularly. Any level of stress creates flare ups in my illness. Illness can be unpredictable so hard to commit to anything as frequently can't follow through

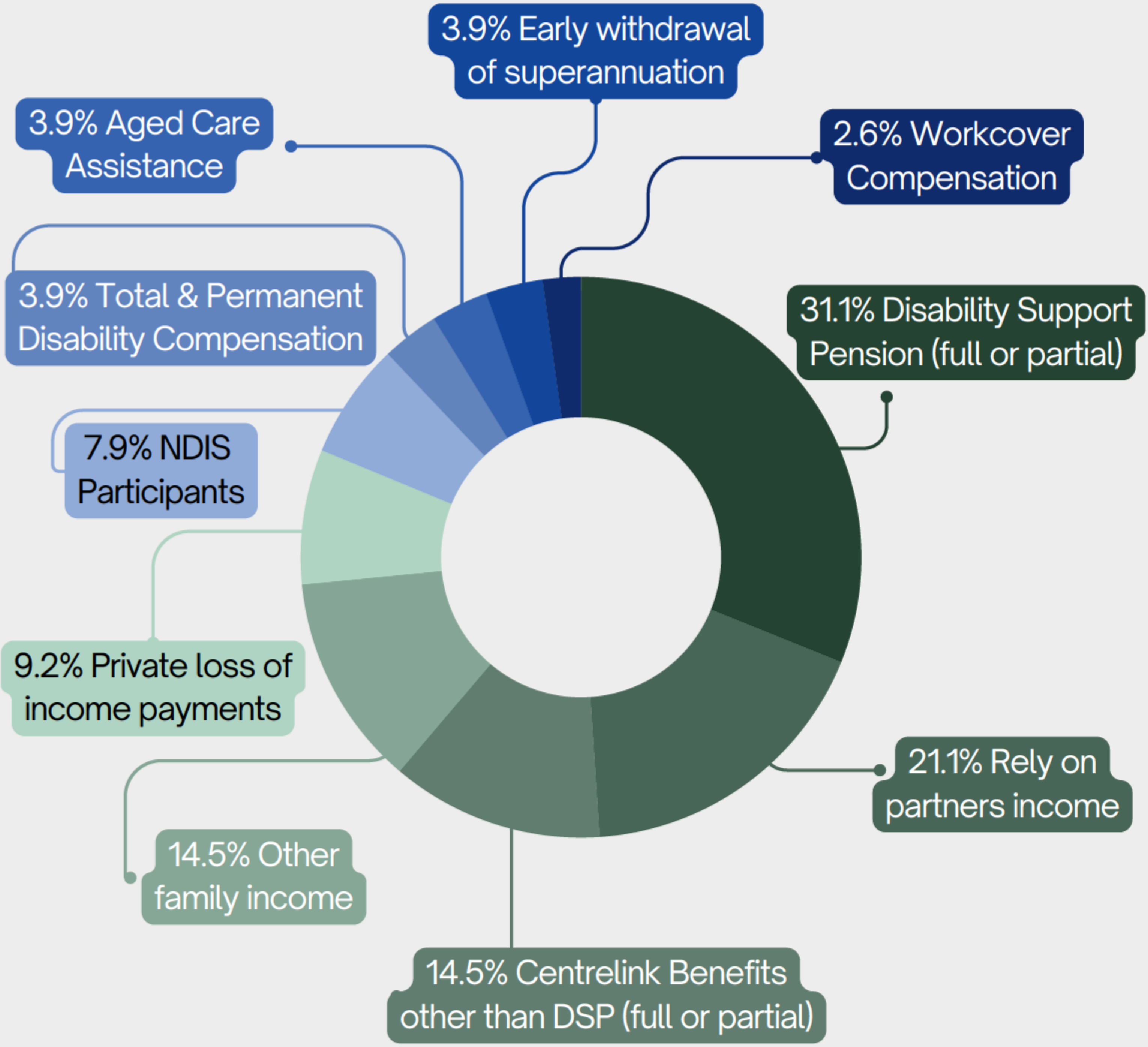
Bedbound part of every day for over 8 years and unpredictable symptoms day to day mean I cannot commit to any work or study

Cognitive impairment and fatigue plus burden of physical symptoms compound to make the pace of study very hard to keep up with. Can only work a job where i could " choose my own hours " ie work when i'm able and body/mind cooperate. Very stressful and uni no longer very accomodating...

For long periods I was unable to think, speak, listen, or read. If I try to push through I then get migraine, including vomiting and nausea, and extreme pain which nothing relieves until it passes (as I can't keep medication down once it starts). Even having another person nearby is too much sensory overwhelm when I'm very unwell. Because we are at risk of losing our home I went back to work one morning a week when I was still pretty unwell. I would come home at lunch time, eat a preprepared meal and then go to bed and be unable to get up for 5 days. I would then have a day where I could wash my clothes, another day I could prepare food (for the rest of the week), and back to work for my half day. I'm up to three mornings a week now and honestly I would be better not working it's still hard.

Not enough energy, orthostatic intolerance, heat intolerance, cognitive decline due to brain fog and word finding difficulties, unable to drive to and from work past a 20 min round trip, reduced mobility - difficulty walking 100m+ and using stairs

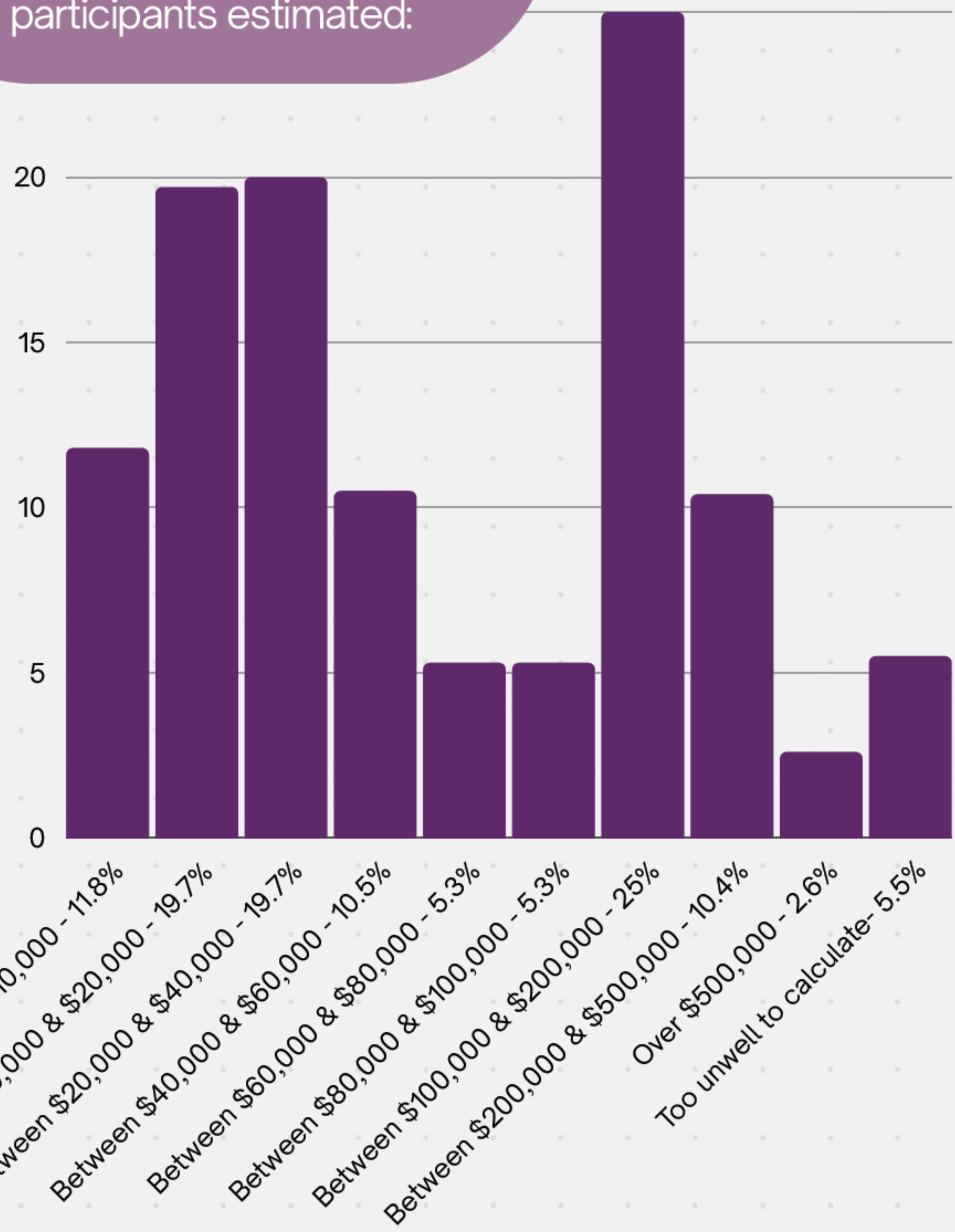
Other income sources



15.8% have not been able to access any of the above financial payments or assistance

Expense of chronic illness

When estimating the total amount spent on their health to date (out of pocket costs) participants estimated:



Financial impacts of chronic illness

i lost my job i had to leave my home and rent it out as i couldn't pay the mortgage i currently don't contribute to the household im living in i've maxed out two credit cards

I was the bread winner so very abruptly had to retire and apply for a DSP. Despite being obviously disabled physically it took several attempts.

Income protection only lasted a couple of years, super used for overseas treatment and no super left, tpd payment wasn't much and was put in the mortgage and been drawn on to make medical payments and help with living expenses and bills. No govt help for mortgage payments despite us both on centrelink - if we were renting we would receive money towards rent for landlords mortgage: this needs to be campaigned with governments to be changed it's not fair .

I no longer have savings, I no longer have financial means for anything beyond existing, I owe $50000 to family member which was borrowed for health treatments

I am stuck in a DV relationship because I can't afford to live on my own (financially) and I need a carer on a day to day basis (which is currently done by my husband)

Financial impacts of chronic illness

...also the cost of food and water...i have been so sick just normal foods make me ill and my condition goes downhill. Tap water made me sick and foggy would you believe, so i have to buy spring water and special bread and special this and that..it's expensive! But it stops me being sick so i have to, it's really hard to explain that simple vegetables that are healthy for someone else can make me really sick, but they do, so my shopping is always going to cost more.

We had to sell our home. None of my medication is covered cause it all had to be compounded cause of allergies

Im in debt am below the poverty line and live on rice and beans

I became ill when I was 12 years old and I've been reliant on disability support pension since I was 17 years old despite my efforts to get well/get qualified/get work. I am stripped to the bone and my chances at any sort of financial freedom or adult experiences is abysmal. The limited job options and job support for those with myalgic encephalomyelitis is severely lacking.

I have no savings, my only asset is an old car shared with my partner that needs a lot of repairs, and I rent (I do not own a property)... All of this is not due to poor management of my income, but due to ongoing medical and health related expenses in combination with only being able to work part time. Most of my income after daily living costs is spent on medical expenses. My superannuation is also very low as I have only ever worked part time, seasonal or casual roles since finishing university due to my health conditions.

Financial impacts of chronic illness

I've borrowed copious amounts of money from my parents and they've had to help financially support me throughout my entire adult life. I've been on Centrelink benefits since I left home at 18 but these payments barely cover cost of living let alone the high costs of chronic illness treatments and medications. I've experienced two DV relationships where I was trapped as I couldn't afford to leave and live alone. I had to withdraw what little superannuation I had & I'm currently selling all the assets from my old business and may have to sell my car to ensure that I can pay my rent, bills and ongoing medical expenses.

I have no savings, my only asset is an old car shared with my partner that needs a lot of repairs, and I rent (I do not own a property)... All of this is not due to poor management of my income, but due to ongoing medical and health related expenses in combination with only being able to work part time. Most of my income after daily living costs is spent on medical expenses. My superannuation is also very low as I have only ever worked part time, seasonal or casual roles since finishing university due to my health conditions.

My marriage failed due to my illness, incurring great financial losses, and loss of financial support, legal costs, family therapy etc

Financial impacts of chronic illness

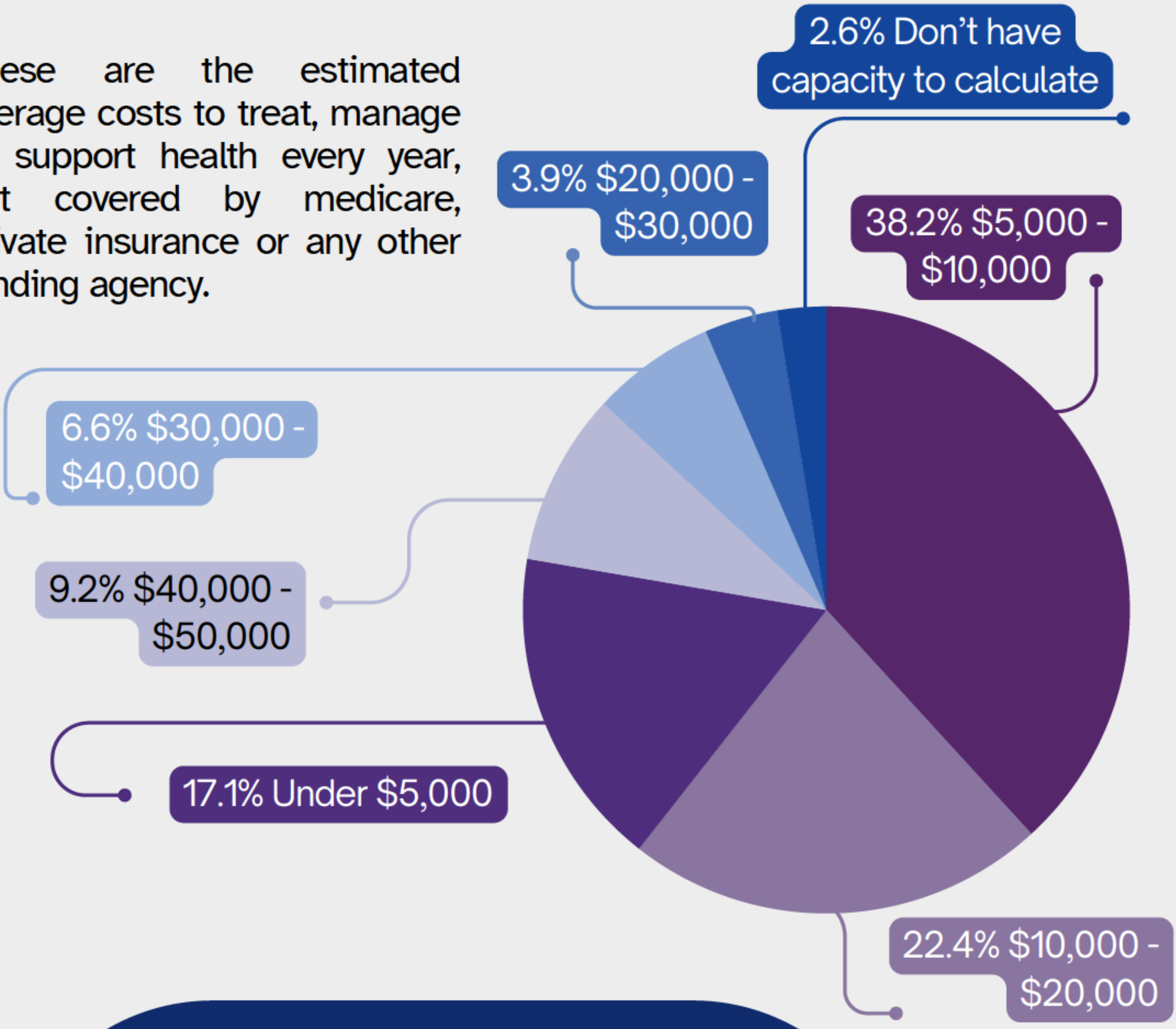
We are still possibly going to lose the house. We have just made a second application for hardship, and would still have to pay interest only which is $3000 a month. My partner has gone from being a uni lecturer when his contract ended, coinciding with my health, he is now working days in admin and nights as a waiter. He's exhausted.

I've had to borrow money on numerous occasions, from a family member and against my life insurance (which I struggle to repay).

Indirect costs such as missing appointments and incurring fees or missing scheduled pre paid activities, getting parking fines/ speeding fines due to brain fog. Also paying extra for food delivery services as I don't feel well enough to get my own food often.

Estimated annual ongoing out of pocket costs

These are the estimated average costs to treat, manage or support health every year, not covered by medicare, private insurance or any other funding agency.



The comment was made ***"Can't spend what you don't have"*** which raises a valid point that the ongoing required expenses may be a lot higher than the ability to afford this ongoing care.

Medicare & Private health

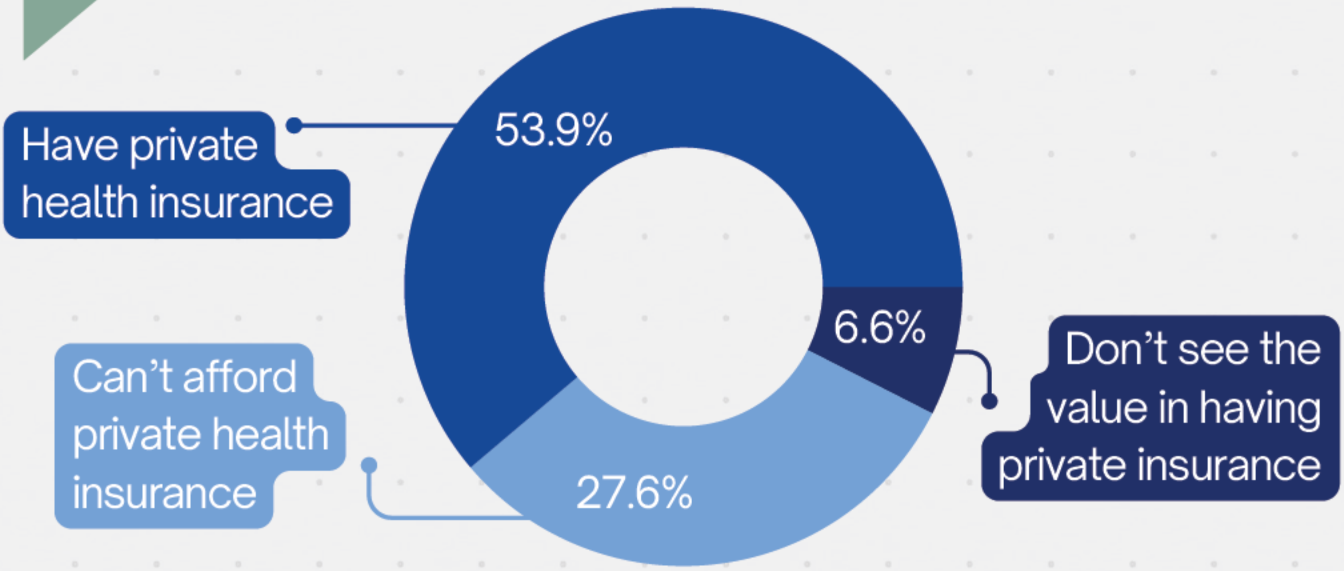
Whilst the majority don’t reach their medicare threshold (38.2%) and the majority of those who DO reach it, do so in the later part of the year (17.1% between September & December) it’s not because they’re not needing medical services, in fact quite the opposite was commented upon:

I don’t reach the rebate because I can’t afford to

My medical consultations & treatments aren't covered by Medicare

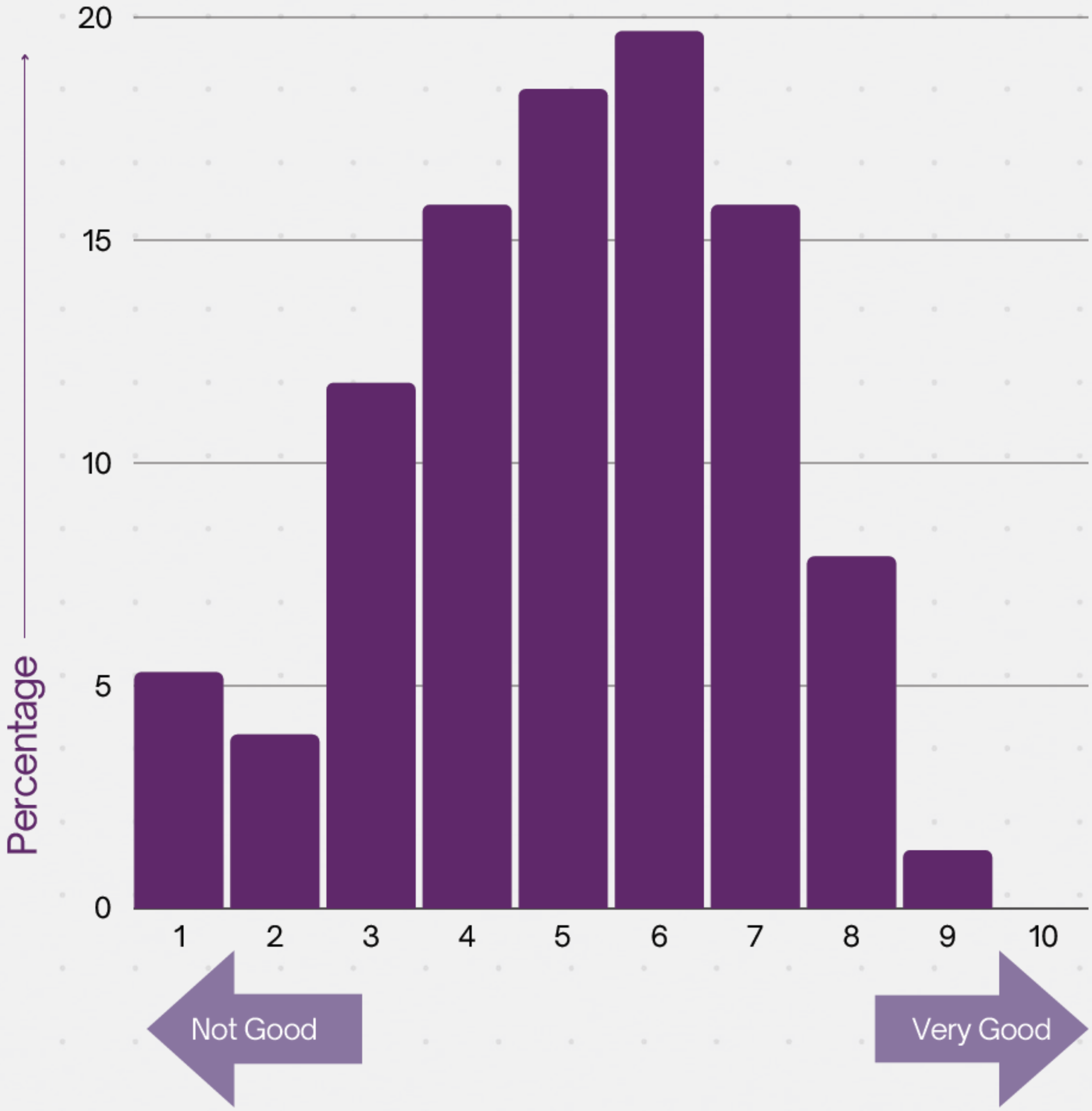
There is no recognised medical treatment for my condition, so medical costs are related to other problems

We have so many people (adult kids) in the family we don’t get there, and my meds are not on PBS

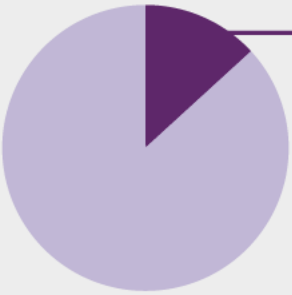


Mental health

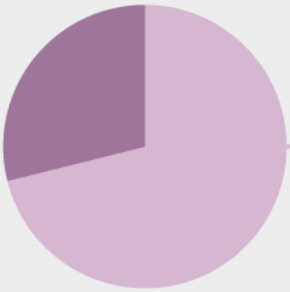
When asked to rate their mental health on a scale from 1 (Not good) to 10 (Very good) they responded:



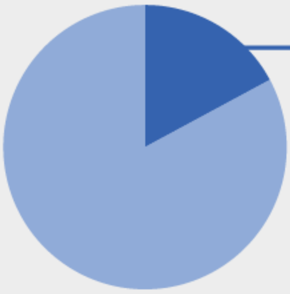
Mental health



Only 13.2% consider their mental health overall to be good

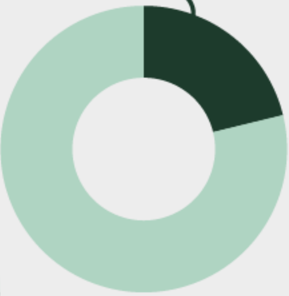


71.1% say their mental health fluctuates



15.8% have been hospitalised for mental health

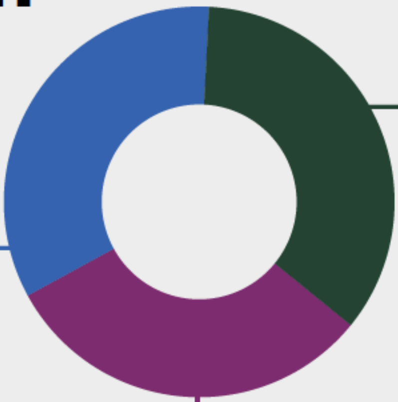
51.3% have had suicidal thoughts



14.5% have made suicide plans

3.9% have attempted suicide

Mental health



33.8% attend regular counselling or therapy

35.5% need more mental health support but can't afford it

31.6% take medication to help manage their mental health

Mental health

I was mentally healthy prior to becoming unwell and even about 6 months in I was hopeful and pragmatic - while we went through savings that we had. After a year when I was even more sick, in pain much of the time and unable to think speak or engage at all, feed or wash myself, etc, I lost all hope for the future, my children live interstate and I haven't been able to visit them and there was no hope that I could ever do this again, financially or physically. My partner is believing and supportive but not very practically helpful. He doesn't really cook so for long periods when I couldn't he would eat takeaway and I would just - not really eat. I was actively suicidal. I began seeing a psychologist but there was a 6 month waitlist. I am now feeling hopeful that I am getting better and my quality of life is good enough - I can eat, wash myself, potter around the house and garden most days, and leave the house a few times a week.

It's difficult to find competent/appropriate [mental health support]...

My current state is good, it's improved dramatically since having good progress with my physical health.

Mental health

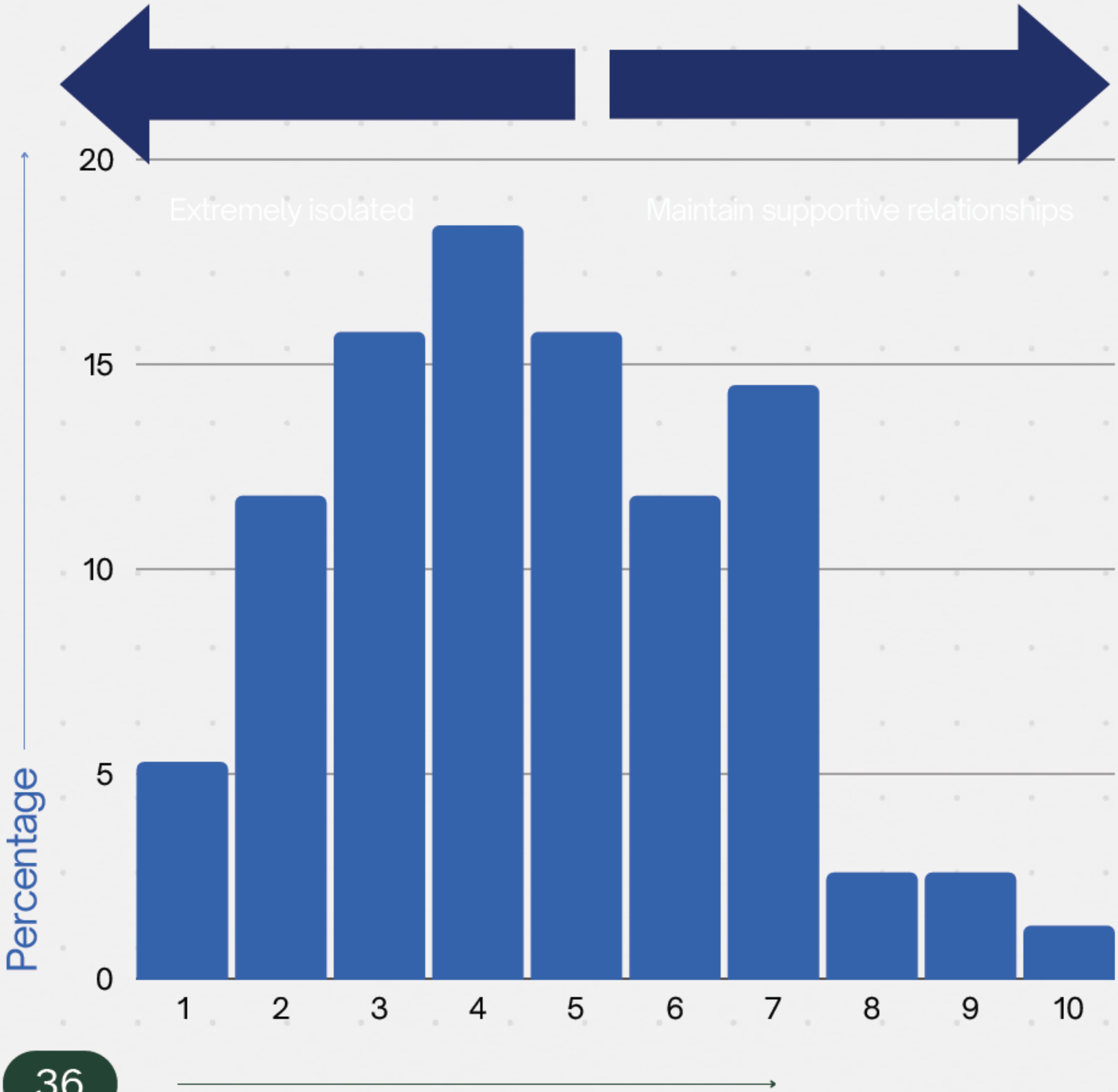
My mental health is good now, but only since my chronic condition was identified and steps taken to manage it. Before that, I was suicidal and hospitalised a few times, and have had a lot of counselling.

I have had counselling and taken medication for mental health in the past I think partly because of lack of recognition of Lyme Disease by Australian medical authorities

Struggling to find mental health support that is suitable

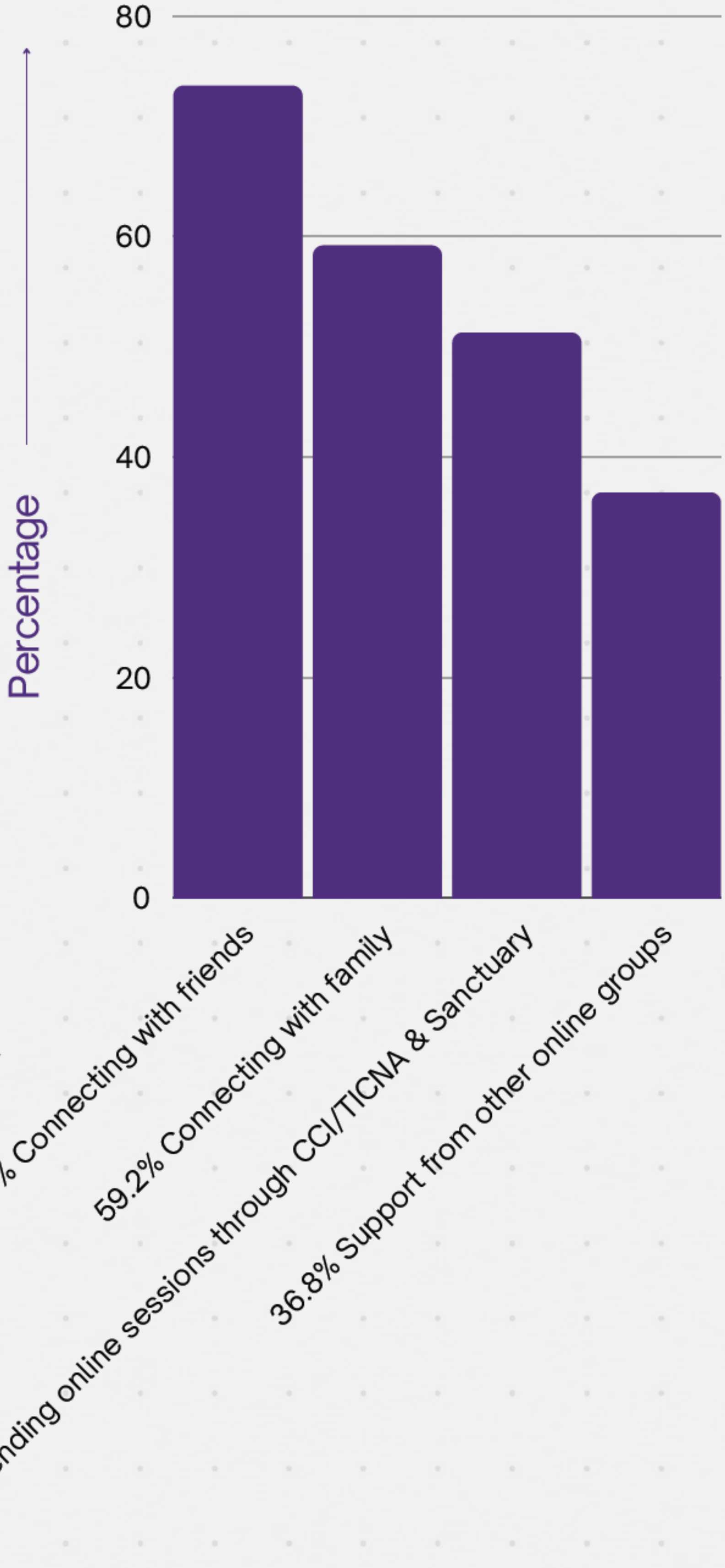
Support Networks

When asked to rate their feelings of isolation on a scale from
1 = Extremely isolated & feel like I can't relate to anyone to
10 = Despite my illness I maintain strong & supportive relationships
they responded:

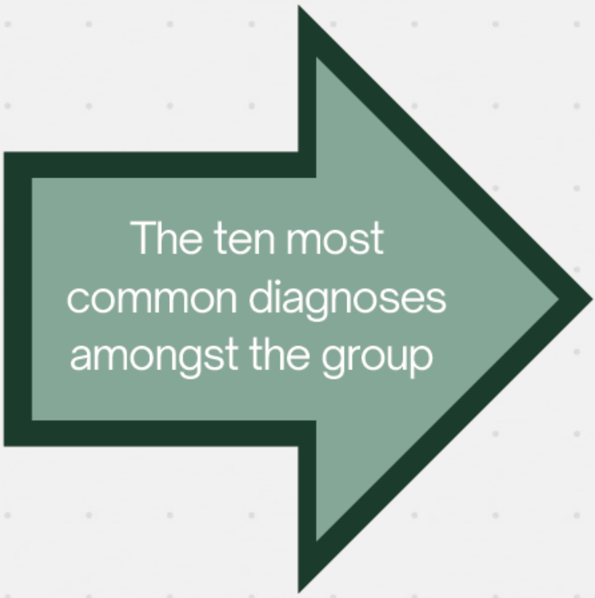


Support Networks

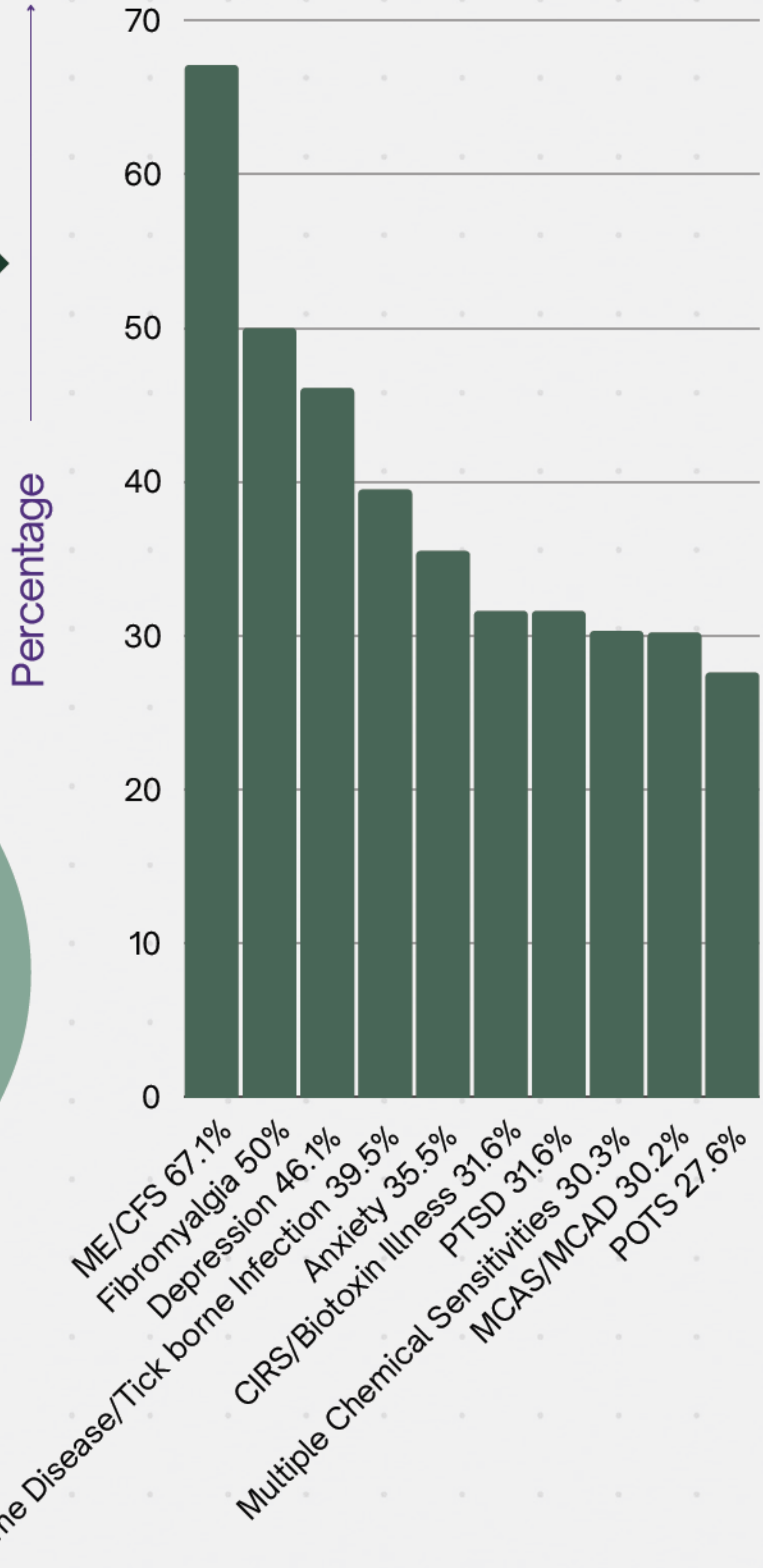
We asked participants to elaborate on the importance of the online sessions offered by CCI/ TICNA & Sanctuary. This information is in the separate Testimonial survey response.



Diagnoses

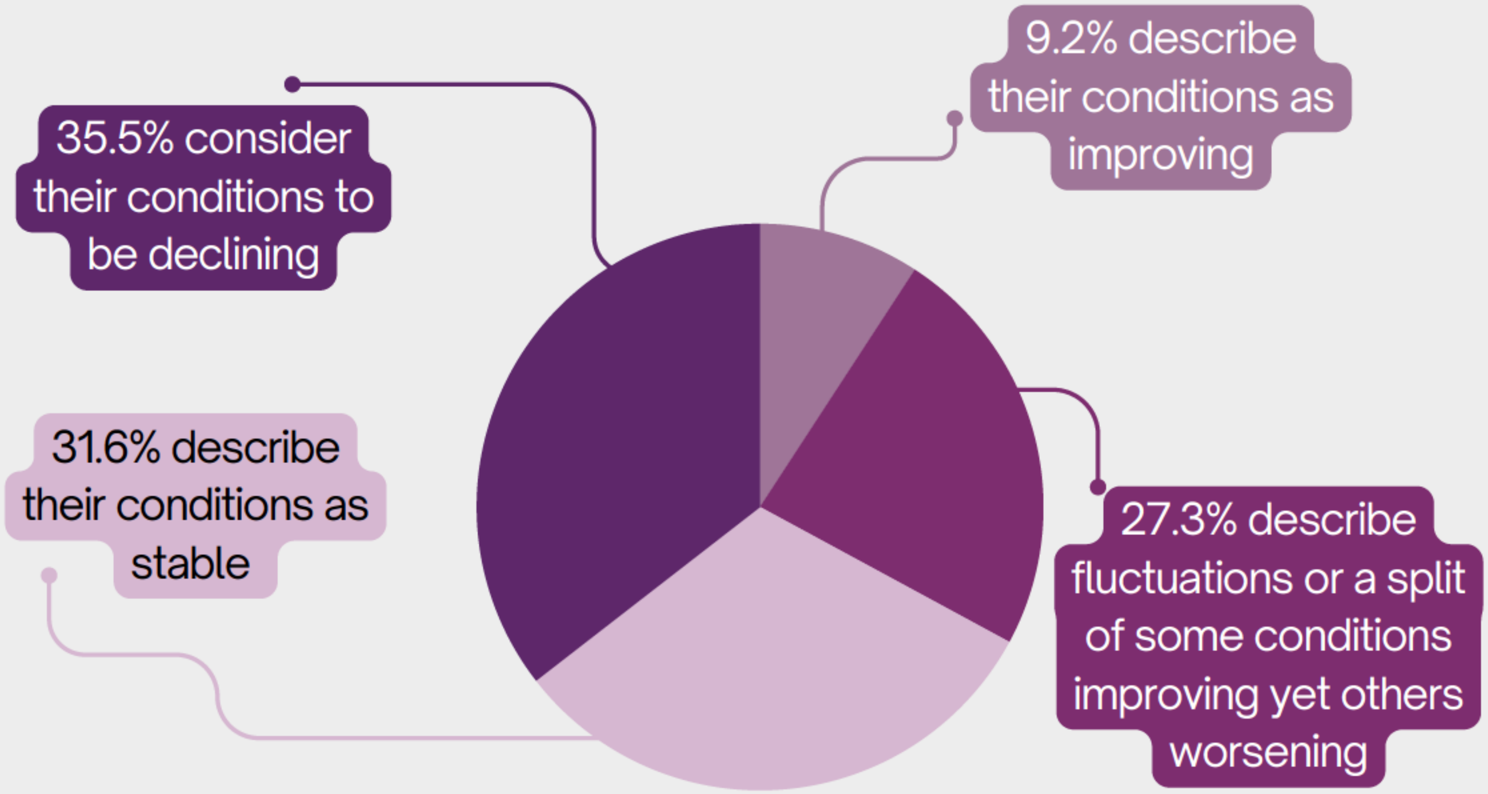


The ten most common diagnoses amongst the group



All participants have multiple diagnoses

Diagnoses



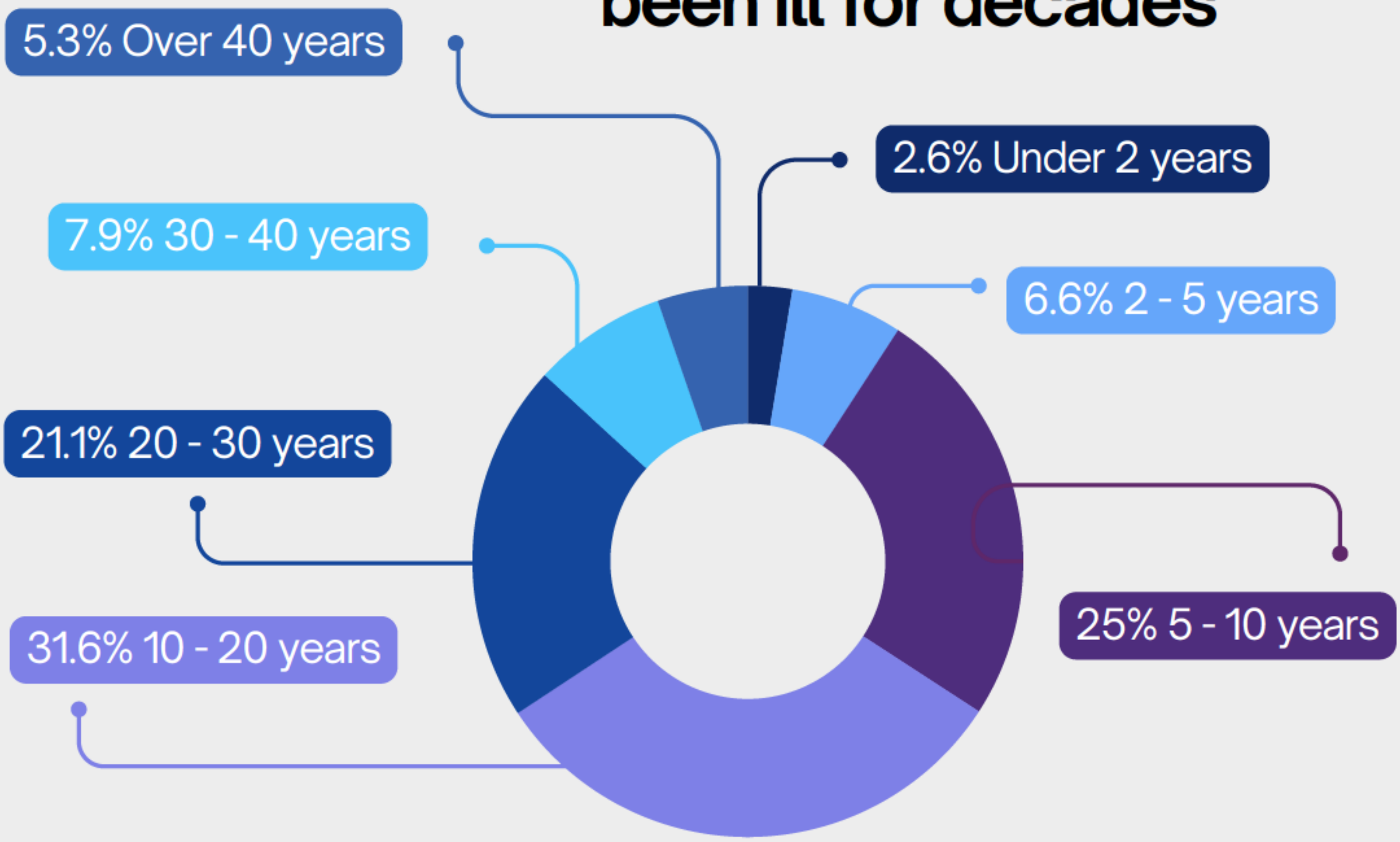
My conditions are improving yet it’s not a linear experience. I sometimes take huge steps back after a mould exposure whilst interacting with the outside world but then I see major advances in my capacity to deal with these extreme distressing allergic reactions. Sanctuary Sessions have helped heal my nervous system and have given me strategies to better cope with my health.

My Conditions are fluctuating, some improvements with recent new medications and others are stable. Others there have been no improvements.

Waxes and wanes a lot but overall declining with age

Timelines for illness

The majority have been ill for decades



We asked how many doctors or practitioners they saw before receiving an accurate diagnosis but many were not able to calculate:

3 or 4 depending on the illness

Ongoing...

Around 10-15

Still waiting

I've lost count

Too many to count

42 practitioners

10 and still searching

Still in progress, have seen 15-20 different specialists, but about all different symptoms.

Difficult to say with multiple diagnoses

Timelines for illness

Of those who could estimate the number of doctors they'd seen in order to finally get a diagnosis, the answers ranged from 1 to over 40

So many conditions - I can't answer this!

I saw over 40 practitioners (GP's, specialists, alternative practitioners, functional and holistic practitioners) before they finally figured out that mould was causing most of my physical and mental health symptoms

Still on waitlists for some doctors in relation to certain conditions.

A few, but I worked it out myself and told the doctor.

6 specialists and still going

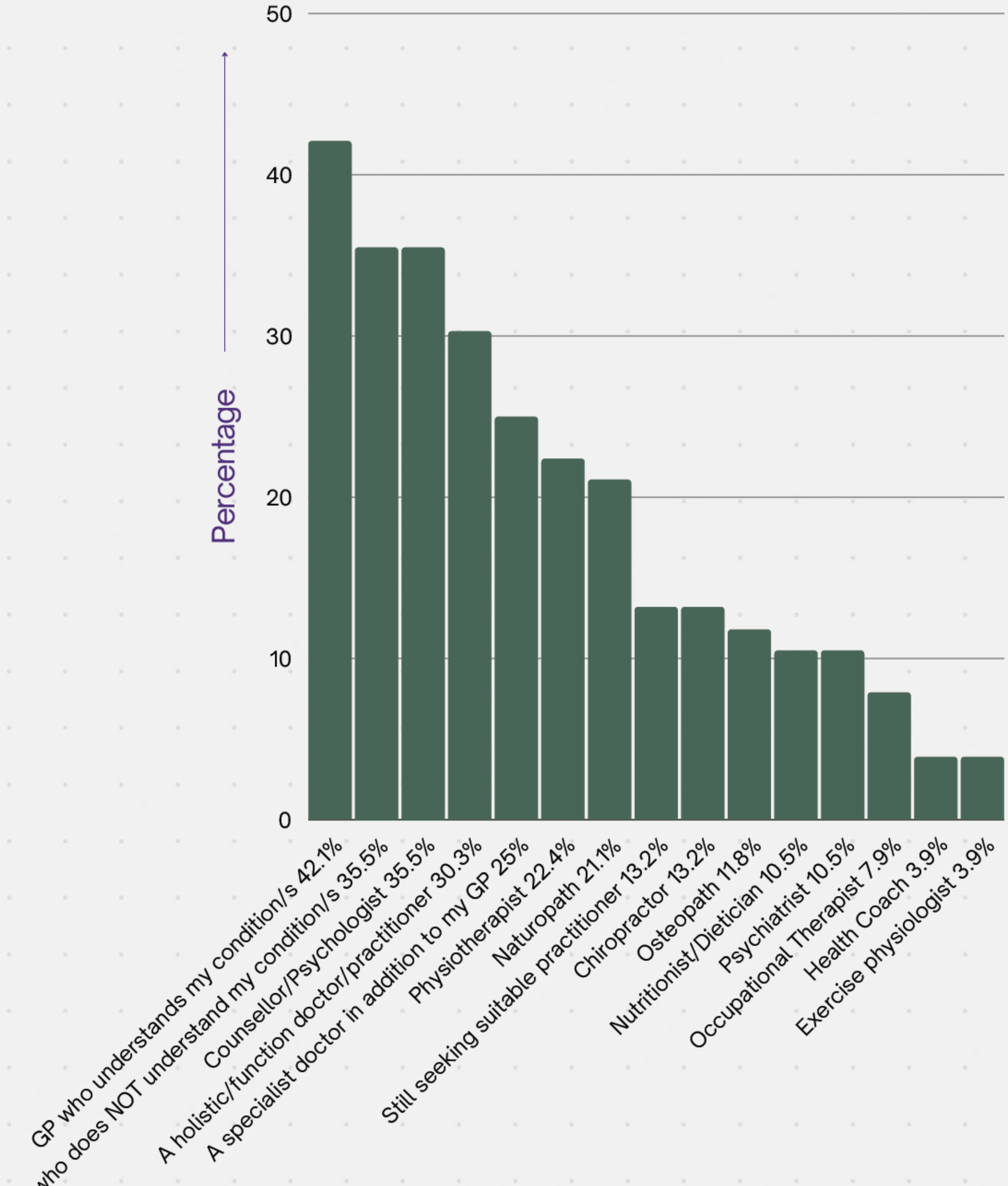
One GP and hospital admissons for when I fist became ill and then many more doctors as I continued to develop illnesses and be in and out of medical clinics and hospitals throughout the last 16 years. You loose track of the amount of doctors.

25 years a few doctors.

At least 15, and still counting.

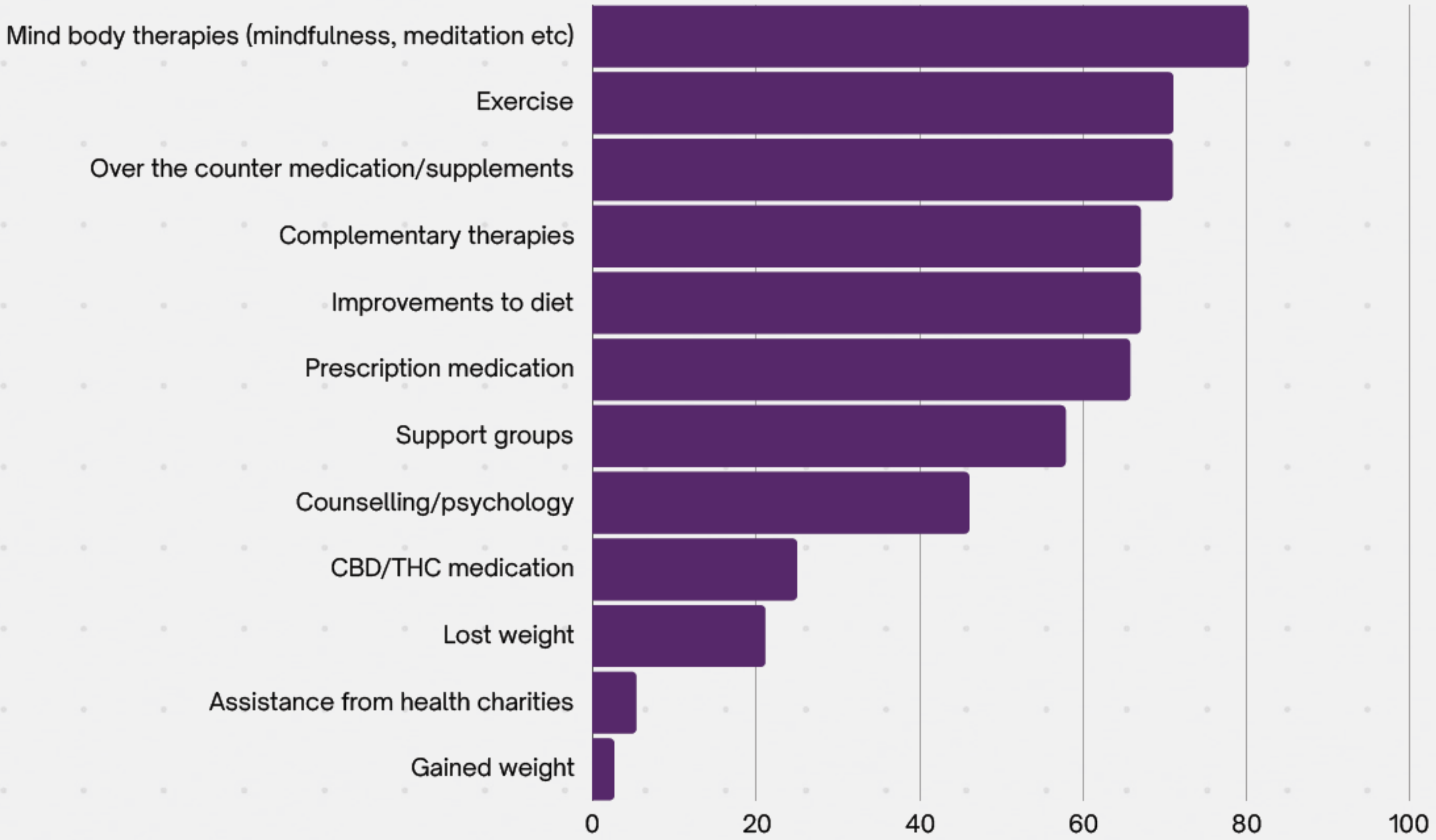
Over 30 years so several dozen. Way too many

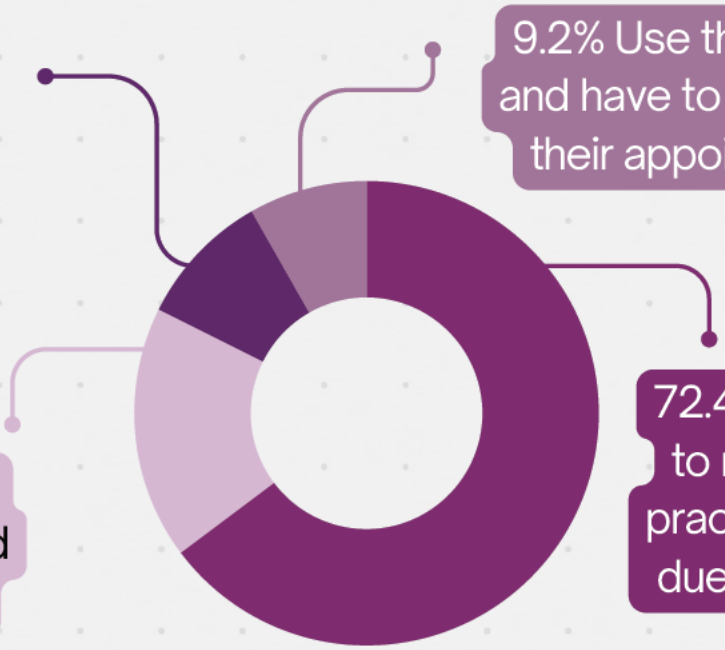
Medical team



Methods of healing/management

Survey Participants have taken the following action towards managing or improving their health in the last year:





10.5% Can always afford appointments

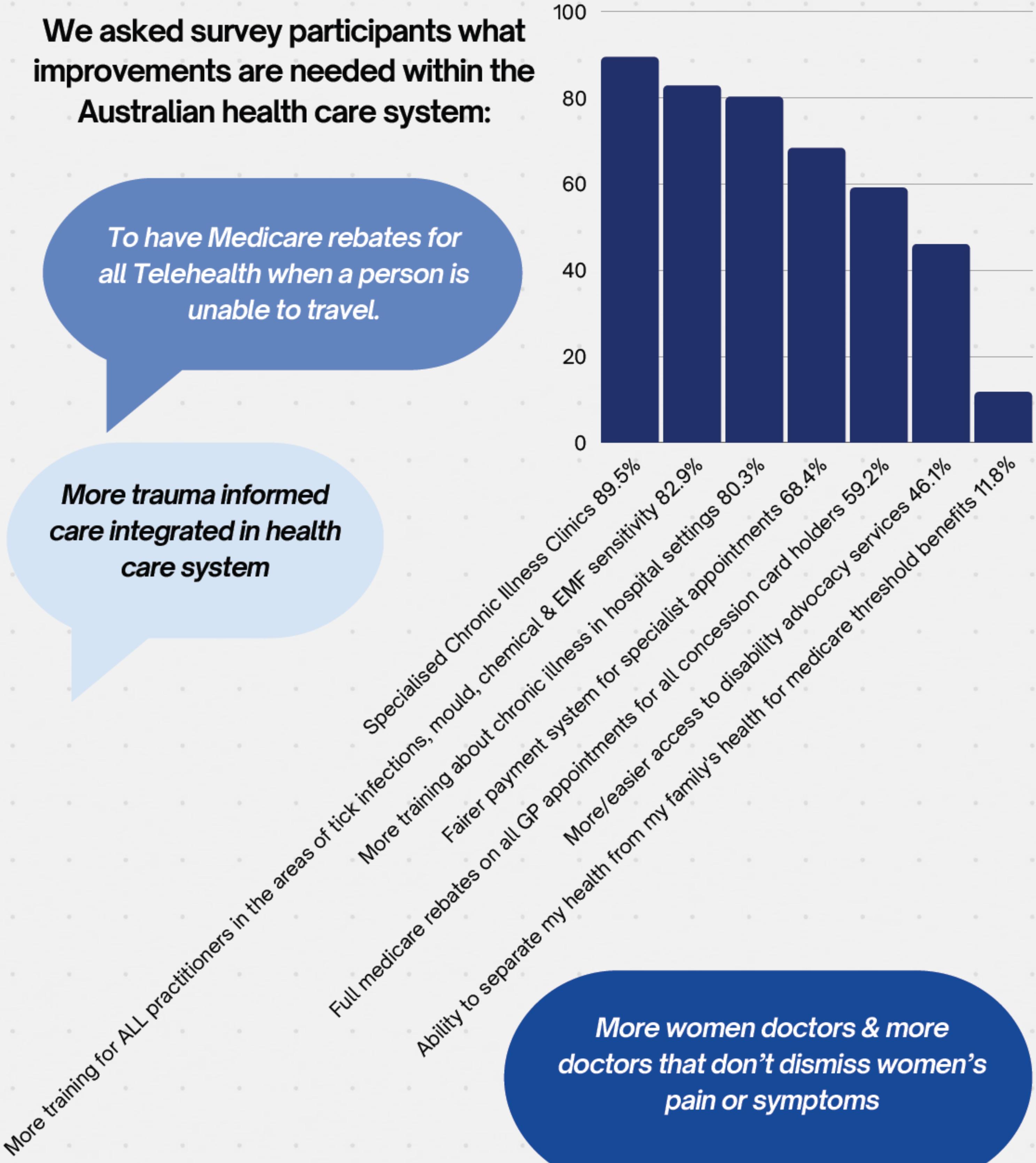
9.2% Use their credit card and have to pay interest on their appointment costs

19.7% Sometimes have to borrow money to attend appointments

72.4% Say they have had to reduce frequency of practitioner appointments due to high costs or lack of funds

Improving the Australian Health Care System

We asked survey participants what improvements are needed within the Australian health care system:



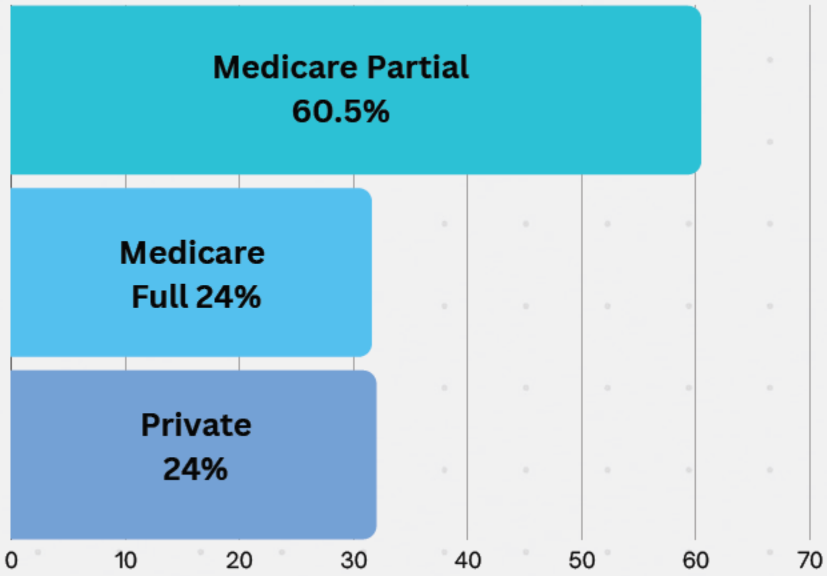
To have Medicare rebates for all Telehealth when a person is unable to travel.

More trauma informed care integrated in health care system

More women doctors & more doctors that don't dismiss women's pain or symptoms

Improving the Australian Health Care System

How do you pay for medical services?



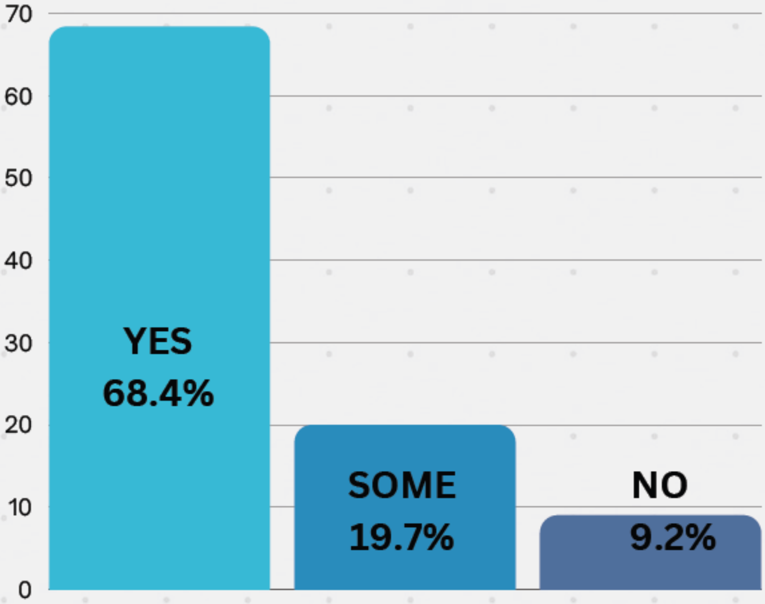
***Dental to be included in Medicare**. Limits on gap payments for specialists and allied health practitioners. Better/ streamlined processes for accessing NDIS and DSP*

***More subsidised treatments** using integrative medicine and alternative health options as often these are all that work and they're mostly out of pocket expenses*

***Mandatory doctor education** about now common chronic diseases and about which GPs and Physicians are ignorant- ME/ CFS, Lyme, Mould, CIRS! They have Specialist clinics for ME/CFS in the UK- so why are we ignored here? Why are these other life-disabling diseases not treated on Medicare?*

***Better rebates for compounding pharmacy** drugs as many patients react to fillers / over the counter drugs, higher rebates for GP specialists, lower private health cover for chronically ill and TBD to be included as a chronic illness*

Telehealth



Telehealth has been crucial to my ongoing care with GP as I have vertigo from long Covid which makes it difficult to get there and wait

Without them, I'd be lost. I had no GP for 2.5 years when I lost access to my GP due to reactions to fragrance

They have meant I don't need to make myself MORE unwell - taking weeks or months to recover, just for a 5 minute consultation.

Without longer telehealth appointments I am unable to access GP services as housebound due to unsafe community housing. Need longer telehealth due to brain injury otherwise become cognitively overwhelmed/confused from trying to cope with multiple short appointments which must have a certain number of hours between for medicare bulk billing codes to be acceptable and there is always risk of GP being accused of overbilling for trying to help me.

I wouldn't be able to access treatment at all without Telehealth

Telehealth is essential for me as I live rurally and am too sensitive to enter most buildings in the current phase of my healing.

Summarising our findings:

The survey of our patient community outlines that the Australian Government can greatly improve assistance in many areas for the increasing number of invisible chronically ill Australians that our patient groups volunteer to support that does not have the usual support of other well known conditions.

We have realised this patient group cannot just wait for research. We need help now.

If provided continued funding, Conquering Chronic Illness, TICNA collaborating with Sanctuary Safe Spaces can help until research provides more answers by **improving social engagement** and **mental health** by **decreasing isolation** for many online Australia-wide.

Plus provide relevant patient-driven support with existing and newly developed classes and programs uniquely tailored to our community quickly, efficiently and directly.

As outlined by this survey, mental health has improved in this growing community with people understanding there are collaborating organisations listening, caring and communicating directly with them. There is a huge need, one which our support is providing and can provide more of, given relevant and continued funding.

PRESENTED BY Peter Owen & Amelie Becher

Conquering Chronic Illness & TICNA in collaboration with Sanctuary Safe Spaces

Improving Health Survey - April 2024 Back Cover

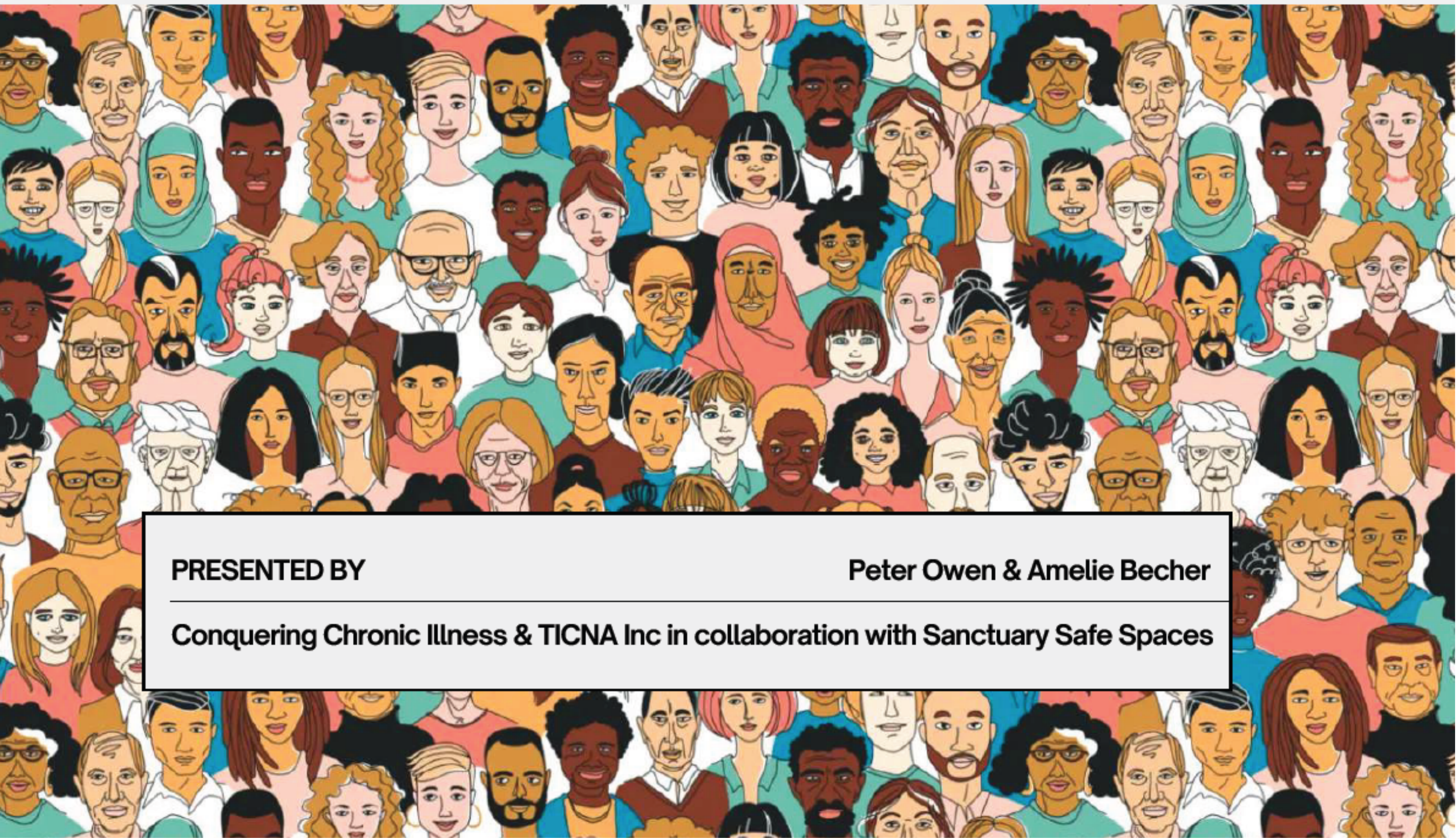
PRESENTED BY Peter Owen & Amelie Becher

Conquering Chronic Illness & TICNA Inc in collaboration with Sanctuary Safe Spaces

Conquering Chronic Illness et al patient survey - April 2024

Meeting the needs of Australia’s growing “invisible” chronically ill population.

CLASS & PROGRAMS TESTIMONIALS



PRESENTED BY **Peter Owen & Amelie Becher**

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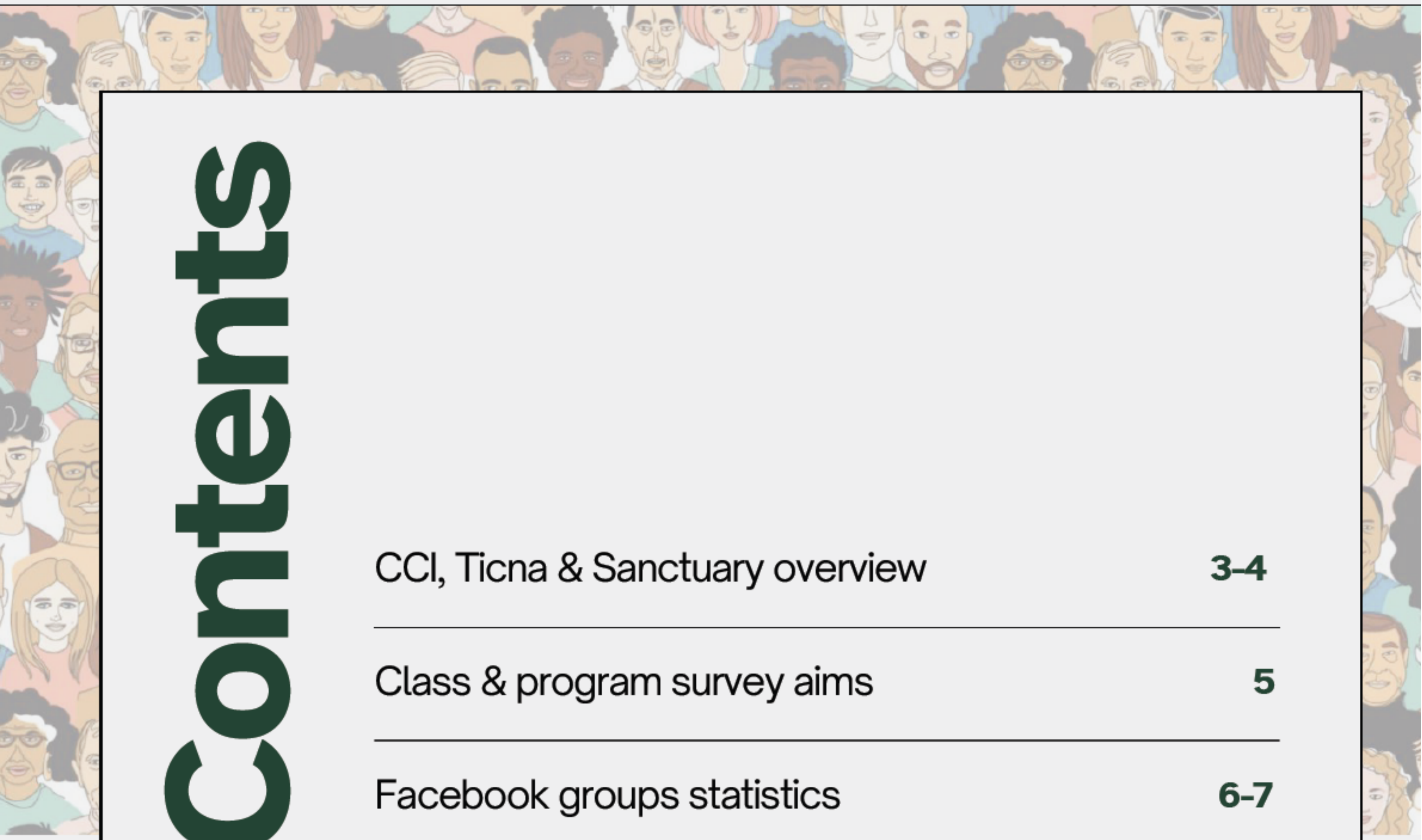

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About Conquering Chronic Illness (CCI)

CCI was conceived over 8 years ago as an online Facebook education & patient support group. The idea of this group was developed by one unwell patient who could see a need for a different all-encompassing group that included people with varying condition names who had very similar symptoms, experiences and needs.

He formed this to help proactive like-minded people with similar overlapping symptomatic conditions of **ME/CFS, Fibromyalgia, Mould/mycotoxin illness, tick (inc overseas Lyme) and other vector infections & Multiple Chemical Sensitivity (MCS) & EMF sensitivities.** It has now expanded to include many with **Long Covid** & other **autoimmune and chronic pain** patients. It has grown from zero without paid marketing and little promotion to help serve nearly 1100 members. It has a public page and a private group.

The principal facilitators volunteer 100% of their time in admin and organisational roles, predominately from their homes and sometimes their bedrooms as they remain unwell. CCI's next step is to become a full DGR-status charity. CCI has a website in development but is waiting for more funding to complete an educational patient community resource.

CCI previously received $10,000 in funding from the Victorian government. With that, it has delivered **FREE** online support to members via **tailored movement, Yoga, Qi Gong & Breathwork classes, many health practitioner presentations and free or significantly financially subsidised education courses.**
The CCI et al volunteers recognised a missing need, so they developed these classes and programs specifically tailored to our community

This has been extremely beneficial for bringing communities together, especially over the Pandemic period and these online classes, in-person cafe catch-ups and email communications have been supportive for many who felt alone in their illness journey. Although started in Melbourne Victoria, it now reaches people Australia-wide and from our recent survey people are keen to continue the hugely beneficial support of classes and programs.

Public Facebook page
https://www.facebook.com/conqueringchronicillness.org/
CCI/Ticna YouTube Channel
https://www.youtube.com/@conqueringchronicillness836
Our free classes and programs are shared and promoted on the Sanctuary Safe Spaces website. **https://www.sanctuarysafespaces.org/**

About Ticna and Sanctuary Safe Spaces.

Ticna Inc. is an acronym for Tick-borne Illness Community Network Australia and became an incorporated body in Victoria in 2018 and is an LTD company. Its primary aim is to factually educate the public about ticks and other vectors and their diseases in Australia and from ticks and other vectors overseas and, secondary, to support currently unwell tick-affected patients. It is also volunteer-run by the same person who volunteers and oversees CCI.

It previously received $10,000 in private funding which enabled Ticna to become established and develop & provide over 40,000 public tick education brochures that before the Pandemic were able to be distributed Australia-wide. We also provided in-person education talks about ticks and their diseases to various groups like Probus, Lions clubs etc, that sadly had to cease due to the pandemic. The Ticna website is still under development as it is waiting for more funding. **https://www.ticna.org.au/**

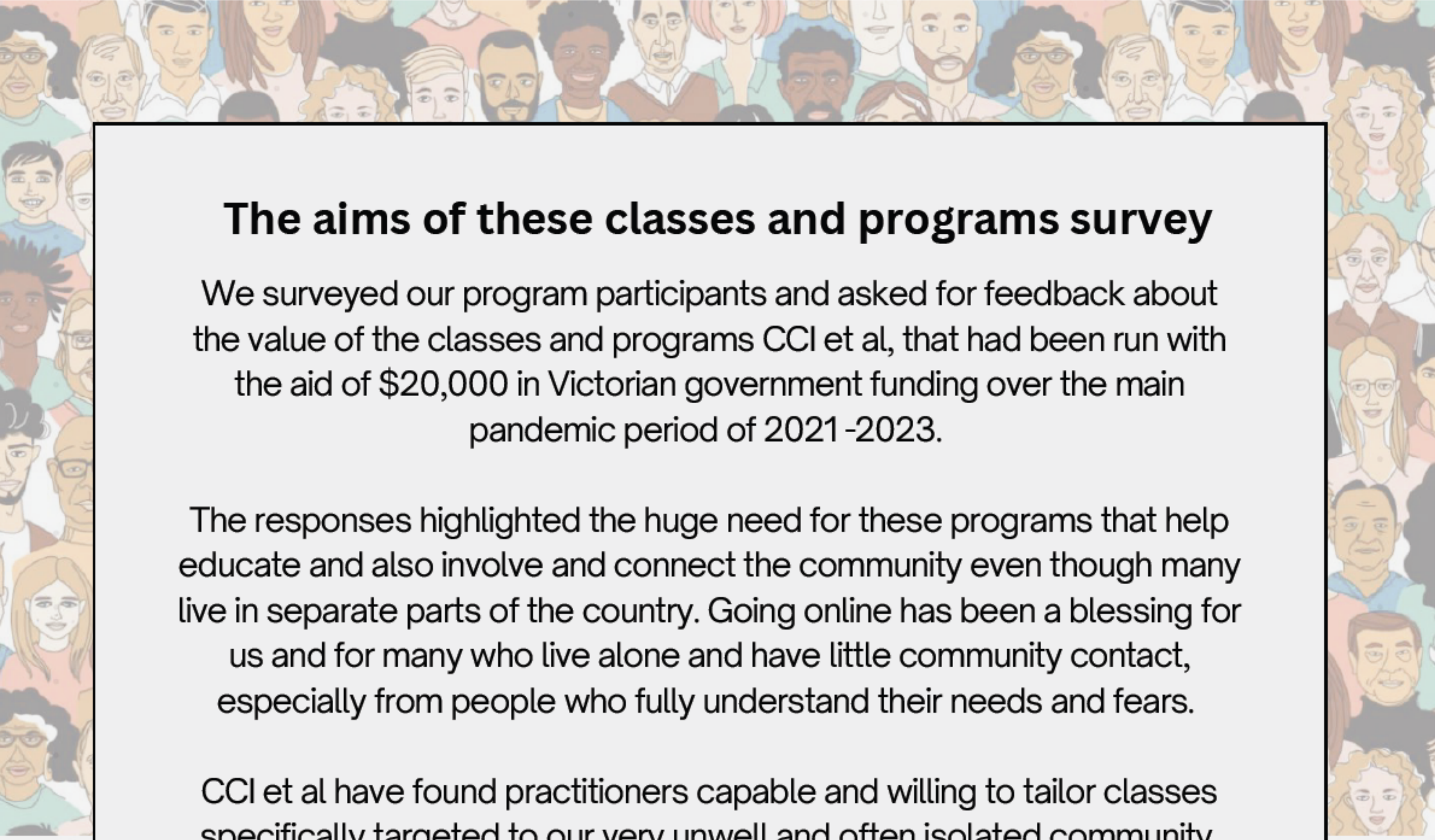
Some of the Ticna private funding was diverted back to support patients during the pandemic. Ticna has a private Facebook group that supports patients and a Public page to educate the public. **https://www.facebook.com/TICNAinc**

Ticna also received $10,000 in Victorian government funding and along with CCI and in collaboration with Sanctuary Safe Spaces organisation, free classes and programs were developed and also shared and promoted by our collaborators on the TICNA, CCI and Sanctuary Safe Spaces social media and website to broaden the audience and get best value from the investments.

Sanctuary Safe Spaces is a perfect fit to collaborate with CCI and Ticna as their facilitator's aim matches our group's goals.

Sanctuary began when the founder experienced a lack of understanding and support for those suffering from chronic illness due to mould & bacteria caused by water-damaged buildings. The existing support groups (Toxic Mould Support Australia & Overseas equivalents) were often extremely triggering to the nervous system so Amelie wanted to create a space that was easily accessible and felt safe for the nervous system. A place where people could turn to for hope and healing. It has grown to welcome anyone struggling with the health of their nervous system, regardless of the initial cause.
Sanctuary is self-funded by Amelie with occasional donations from the participants of the sessions which she hosts multiple times each week.

All CCI, Ticna and Sanctuary free classes and programs are shared and promoted on the Sanctuary Safe Spaces website. **https://www.sanctuarysafespaces.org/**



The aims of these classes and programs survey

We surveyed our program participants and asked for feedback about the value of the classes and programs CCI et al, that had been run with the aid of $20,000 in Victorian government funding over the main pandemic period of 2021 -2023.

The responses highlighted the huge need for these programs that help educate and also involve and connect the community even though many live in separate parts of the country. Going online has been a blessing for us and for many who live alone and have little community contact, especially from people who fully understand their needs and fears.

CCI et al have found practitioners capable and willing to tailor classes specifically targeted to our very unwell and often isolated community. This has been because the volunteer organisers have lived with chronic illness themselves and completely understand the needs and limitations of these patient communities.

CCI et al have allocated funding primarily to be able to support patients directly now and hope this proves the value for the money invested and outlines a huge need by our community for ongoing funding as outlined by this survey and testimonials.

Compared to so many other charities and groups online, our small groups have made a huge impact with little resources and little funding, showing the power of passionate people who know how to target classes and programs to those who need them most.

You will see genuine testimonials from people for the classes and programs we have run, and feedback about the need for and benefit of continuing the classes and programs.

Conquering Chronic Illness (CCI) audience.

Online facebook groups and pages

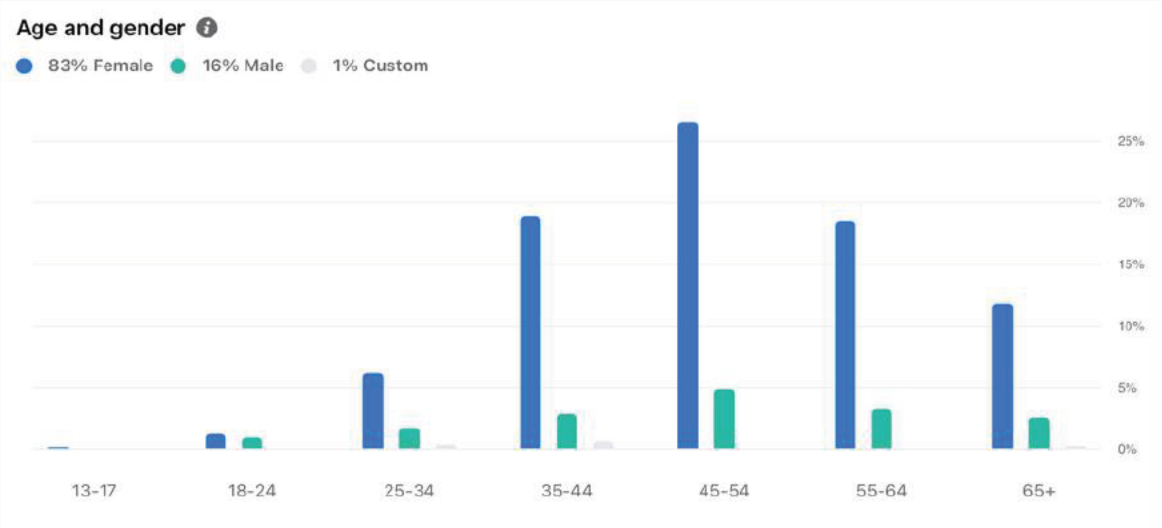
CCI group and page-mixed chronic illness patients

Conquering Chronic Illness

Community, Connection, Care

Providing help & hope for the health of the chronically ill

Conquering Chronic Illness Organisation



Top countries	
Australia	935
United States	48
United Kingdom	12
Nigeria	10
Canada	6
Cameroon	5
New Zealand	4
Sweden	3
Indonesia	3
Romania	2

Top towns/cities	
Melbourne, VIC, Australia	326
Sydney, NSW, Australia	116
Perth, WA, Australia	46
Brisbane, QLD, Australia	46
Adelaide, SA, Australia	31
Gold Coast, QLD, Australia	27
Sunshine Coast, QLD, Australia	21
Newcastle, NSW, Australia	13
Ballarat, VIC, Australia	10
Canberra, ACT, Australia	10

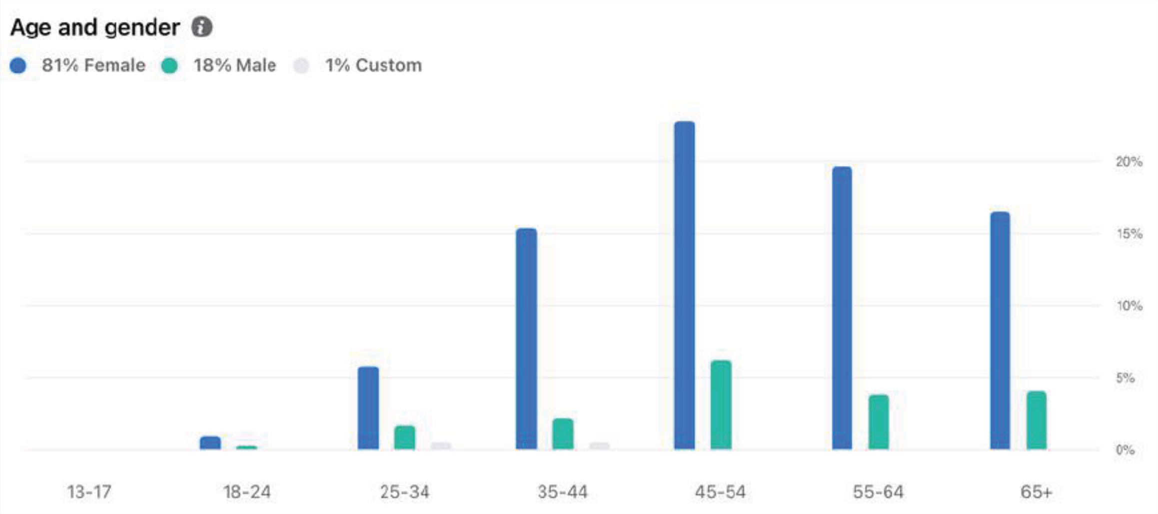
Ticna Inc audience.

Online facebook groups and pages

Ticna group and page-mostly tick affected patients

TICNA Tick-borne Illness Community Network Australia Inc

TICNA Tick-borne Illness Community Network Australia Inc



Top countries	
Australia	331
United States	44
United Kingdom	16
Ireland	5
New Zealand	5
Japan	2
South Africa	2
Canada	2
France	2
South Korea	1

Top towns/cities	
Melbourne, VIC, Australia	78
Sydney, NSW, Australia	67
Brisbane, QLD, Australia	15
Perth, WA, Australia	15
Gold Coast, QLD, Australia	7
Sunshine Coast, QLD, Australia	4
Adelaide, SA, Australia	4
Taree, NSW, Australia	3
Coffs Harbour, NSW, Australia	3
Ballarat, VIC, Australia	3

Online Session & classes overview

The following outlines just some of the free classes and 2 greatly discounted programs CCI et al volunteers have organised for chronic illness patients.

You are welcome to join Conquering Chronic Illness Facebook group or email subscription to be notified of all the free programs on offer.

The online classes & programs are for people with various chronic illnesses such as **ME/CFS**, **Fibromyalgia**, **Tick-Lyme** and other **vector infections**, **Mould/CIRS/Biotoxins**, **Long Covid** & other **chronic pain** and **autoimmune** conditions. All patients and carers welcome.

Want to be proactive about your health? A group run by patients for patients.

WANT ACCESS TO FREE HEALING RESOURCES FOR A VARIETY OF HEALTH CONDITIONS?

This is for bed, housebound & various limited ability people with PEM in mind. The group is also about building community Australia wide.

Free online classes such as
- Qi Gong
- Yoga - Beginners to intermediate
- Simple movement and stretching
- Breath work
- Health coaching
- Trauma program
- Mindfulness
- Meditation
- Health education programs on the gut, vagus nerve and many more planned.

Conquering Chronic Illness jointly with TICNA group have obtained Victorian Government Funding to run these free programs for the community. **Join email list info@conqueringchronicillness.org**
Join Private Facebook www.facebook.com/groups/ConqueringChronicIllness

Pranayama Breathwork-Live Classes
with Dr Paul Holman
Tuesdays
Every Fortnight
FREE ONLINE SESSION brought to you by:

Restorative Sleep Qi Gong
with Adrian Allen
Wednesdays
FREE ONLINE CLASS brought to you by:

Gentle Qigong for Mobility & Relaxation
with Debbie
Tuesdays
FREE ONLINE CLASS brought to you by:

Community Chat ~ Starting A New Habit: Vision, Motivation and Goals
with Health Coach Cat Smit
Join from the comfort of home via Zoom:
Monday
11am AEST
17th April
FREE ONLINE SESSION brought to you by:

2pm AEDT
Fridays
Seated & Reclined Movement Class
FREE ZOOM CLASS

COURSE - IMPROVE YOUR HEALTH
STRATEGIES FOR IMPROVING CHRONIC ILLNESS

Special course for CCI Members!

Learn all about how brain-based healing methods can improve your symptoms

Register at the link below

FREE QI GONG COURSE FUNDED BY CCI SPECIFICALLY FOR SUPPORTING PEOPLE WITH CHRONIC ILLNESS

NOURISHING REST QI GONG - INTRO COURSE

This class via ZOOM is for those new to Qi Gong to support chronic illness recovery or a gentle practice that anyone can do that energises the body & relaxes the mind. Come along and see if these practices can support you, as they do for me and other participants. You can attend any of the classes as an individual stand-alone session, but will gain a greater experience and create momentum for your health committing to them all. Free to all registered participants.

Dates for these five classes with their specific theme:
1. **Wednesday 7th September 2022 - 2.30pm AEST**
   CALM - Nervous system regulation
2. **Wednesday 14th September 2022 - 2.30pm**
   SLEEP - Resetting the circadian clock and optimising sleep
3. **Wednesday 21st September 2022 - 2.30pm**
   INTERNAL DAY SPA - Internal organ support and sound healing
4. **Wednesday 28th September 2022 - 2.30pm**
   NEURAL REWIRING - Healing Brain and Gut
5. **Wednesday 5th October 2022 - 2.30pm**
   DETOXIFICATION - Optimising detox, rejuvenating the liver

To register your interest in this free live practice program email Adrian Allen by Monday 5th September on email: fisheagles@hotmail.com

Please note your email will also register you for the Conquering Chronic Illness email list so they can inform you of future funded programs.

CCI PRESENTS NEW FREE 4 WEEK CLASS

1. RESTORATIVE SLEEP QI GONG

FROM THE COMFORT OF YOUR HOME LEARN TO RESET YOUR CIRCADIAN RHYTHYM, GET A GOOD NIGHTS SLEEP & INCREASE YOUR ACCESS TO THE MOTHER OF ALL MEDICINES & NATURES NO. 1 ANTIOXIDANT

Starting Wed 1st Feb at 7.30pm AEDT (Melb/Syd)

PRACTICAL & LIFE CHANGING RESTORATIVE SLEEP TIPS , TOOLS AND PRACTICES

" THE PERFECT MIX OF MODERN SCIENCE AND ANCIENT WISDOM AND SUCH A GIFT TO WAKE UP REFRESHED AGAIN AFTER STRUGGLING FOR SO LONG."

"IT'S PRICELESS WAKING UP WITH A SMILE AGAIN, THANKS "

LIVE ON ZOOM

ANCIENT PRACTICES NOW BACKED BY SCIENCE

FOR MORE INFORMATION OR TO REGISTER CONTACT ADRIAN ALLEN
EMAIL: RESTORATIVEQIGONG@GMAIL.COM
COMING SOON - RESTORATIVEQIGONG.COM.AU

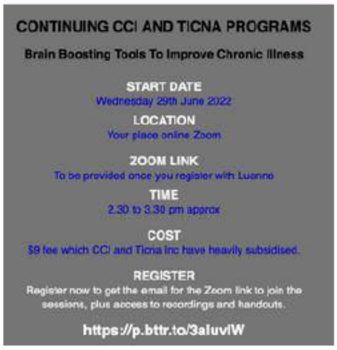
Conquering Chronic Illness

Peter Owen
Admin

Hey @everyone ready to start your week off well?
Hope to see you at this mornings session @ 11am AEST
Join us from your chair, couch or edge of the bed via Zoom link:... See more

Mindful Movement & Meditation
with Amelia
Mondays
11am AEST
FREE ONLINE CLASS brought to you by:

View insights



CONTINUING CCI AND TICNA PROGRAMS

Brain Boosting Tools To Improve Chronic Illness

START DATE
Wednesday 29th June 2022

LOCATION
Your place online Zoom

ZOOM LINK
To be provided once you register with Luanne

TIME
2.30 to 3.30 pm approx

COST
$9 fee which CCI and Ticna Inc have heavily subsidised.

REGISTER
Register now to get the email for the Zoom link to join the sessions, plus access to recordings and handouts.

https://p.bttr.to/3aluvlW

Free Online Yoga Class

DATE & TIME
TUESDAY 31ST JANUARY
3:30-4:15 PM AEDT

FREE LIVE AND ONLINE

PLEASE COPY ZOOM LINK TO LOG IN BEFORE LIVE CLASS

Meeting ID: 826 5018 1260

Note this class will not be recorded

Gentle Yoga & Meditation with Ianthe

Sanctuary Session begins in 2 hours

Start times across the country:
11am AEDT (VIC/NSW/ACT/TAS)
10.30am ACDT (SA)
10am AEST (QLD)
9.30am ACST (NT)
8am AWST (WA)

You are welcome to join ten minutes early for a ...eck in chat with others in our healing communi... or join a little later if that works better for you
just please mute yourself if joining late

Clickable Zoom link in text

This is a free nervous system session brought to you by Sanctuary Safe Spaces

Hey guys I hope you're having a good morning, I'm just jumping

...ama Breathwork-Live
with Dr Paul Holman
SESSION brought to you by:

Gut Health 101
What you don't know

Online Session & classes overview

The following outlines just some other free webinars and extra we did for May awareness 2024 & in person cafe events we arranged in the past.

Your Constitution Presentation

with Dr Paul Holman

Connect. Breathe. Heal.

Brought to you by conquering CHRONIC ILLNESS TICNA TICK-BORNE ILLNESS Community Network Australia Inc. Educating the public about tick-borne illness. Implementing change through knowledge

The Gut Guy-Joshua Williams.

How poor gut health plays a significant role in human disease and how to achieve your best gut health, the right way.

FRIDAY
11.00 am AEST*
3rd May 2024
*9am WA
Check your timezone

Connect. Learn. Heal.

Join on Zoom:
https://us02web.zoom.us/j/87102686021
NO PASSCODE NEEDED

This will be Recorded. Available @ CCI YouTube after.
https://www.youtube.com/@conqueringchronicillness836

FREE ONLINE SESSION courtesy: TICNA TICK-BORNE ILLNESS conquering CHRONIC ILLNESS

Briana Gunn Naturopath - FREE Webinar

Uncovering Root Causes

Join live so you can ask questions. These are recorded.
Available after @ CCI YouTube
https://www.youtube.com/
@conqueringchronicillness836

SATURDAY
9.30 am AEST*
11th May
2024

Connect. Learn. Heal.

Join on Zoom:
NO PASSCODE NEEDED

*7.30 am WA
Check your timezone

FREE ONLINE SESSION courtesy: TICNA TICK-BORNE ILLNESS conquering CHRONIC ILLNESS

Dr Mackenzie Kwak: Paristologist.
Australian Ticks: Neglected Threats To Public Health.

FRIDAY
11.00 am AEST*
31st May 2024

Connect. Learn. Heal.

Join on Zoom:
NO PASSCODE NEEDED

FREE ONLINE SESSION courtesy: TICNA TICK-BORNE ILLNESS conquering CHRONIC ILLNESS

Coping with grief & loss due to chronic illness

with Dr Paul Holman

Thursday
27th July
1.30pm AEST

Connect. Learn. Heal.

FREE ONLINE SESSION brought to you by: conquering CHRONIC ILLNESS TICNA TICK-BORNE ILLNESS

Briana Gunn Naturopath - FREE Webinar

European Treatment Centres & Tick Infection Testing

Join our community live so you can ask questions.
These will be recorded. Available after via
our CCI YouTube channel

FRIDAY
11.00 am AEDT*
15th March
2024

Connect. Learn. Heal.

Join on Zoom:
https://us02web.zoom.us/j/86784295378
Passcode: 725390

*8 am WA
10 am Qld Check your timezone

FREE ONLINE SESSION courtesy: TICNA TICK-BORNE ILLNESS Community Network Australia Inc. conquering CHRONIC ILLNESS

Jess Milroy Naturopath - FREE Webinar

Mould and Mycotoxins

Join live so you can ask questions. These are recorded.
Available after @ CCI YouTube
https://www.youtube.com/
@conqueringchronicillness836

FRIDAY
11.00 am AEST*
24th May 2024

Connect. Learn. Heal.

Join on Zoom:
https://us02web.zoom.us/j/82361876830
NO PASSCODE NEEDED

*9 am WA
Check your timezone

FREE ONLINE SESSION courtesy: TICNA TICK-BORNE ILLNESS Community Network Australia Inc. conquering CHRONIC ILLNESS

MELBOURNE CAFE CATCHUP
Saturday 19th January 2019 at 1 pm
The Rubber Duck
139 Queens Parade Clifton Hill, Victoria

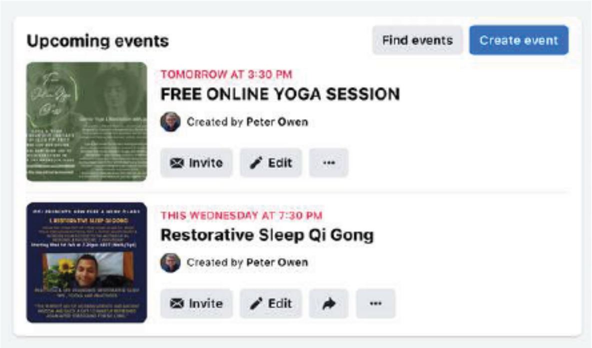
To Book -
info@conqueringchronicillness.com.au

MELBOURNITES-CCI-SOCIAL CATCH UP

KEW LIBRARY Phyllis Home Room
Corner Cotham Rd & Civic Drive, Kew
SATURDAY 2ND DECEMBER 12.30 - 4 PM
BYO LUNCH. Tea/Coffee & Cake supplied. MUST RSVP
by 25th Nov 2023 info@conqueringchronicillness.org

Example of attendance of Qi Gong classes

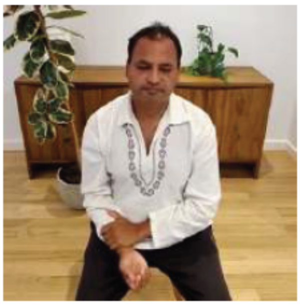
This indicates the popularity of just one of our previous online weekly classes. This is Qi Gong, but sadly we can no longer run due to a lack of funding



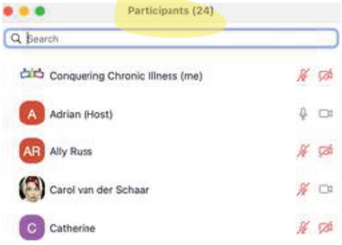
Upcoming events

TOMORROW AT 3:30 PM
FREE ONLINE YOGA SESSION
Created by Peter Owen

THIS WEDNESDAY AT 7:30 PM
Restorative Sleep Qi Gong
Created by Peter Owen



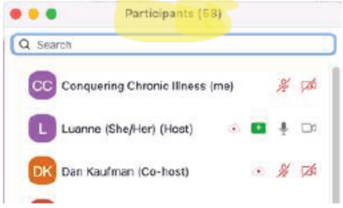
Attendance



Participants (24)

Search

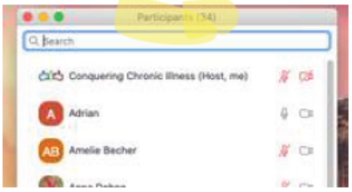
Conquering Chronic Illness (me)
Adrian (Host)
Ally Russ
Carol van der Schaar
Catherine



Participants (58)

Search

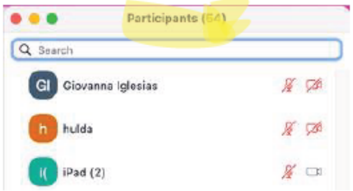
Conquering Chronic Illness (me)
Luanne (She/Her) (Host)
Dan Kaufman (Co-host)



Participants (34)

Search

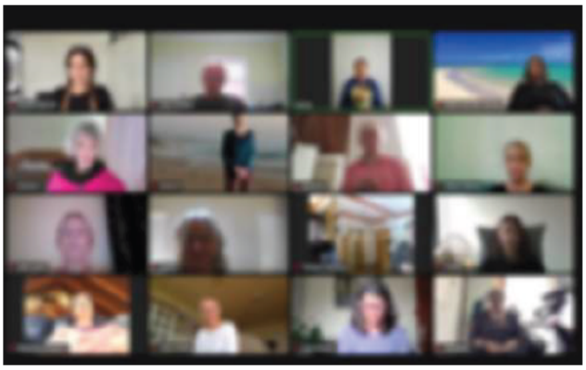
Conquering Chronic Illness (Host, me)
Adrian
Amelie Becher



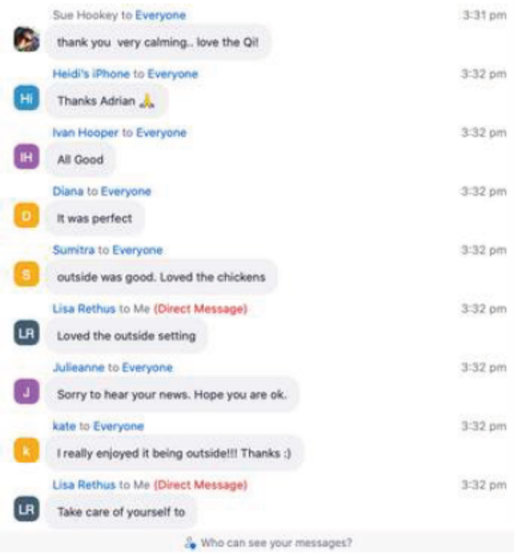
Participants (54)

Search

Giovanna Iglesias
hulda
iPad (2)



The thank yous



Sue Hookey to Everyone 3:31 pm
thank you very calming.. love the Qi!

Heidi's iPhone to Everyone 3:32 pm
Thanks Adrian 🙏

Ivan Hooper to Everyone 3:32 pm
All Good

Diana to Everyone 3:32 pm
It was perfect

Sumitra to Everyone 3:32 pm
outside was good. Loved the chickens

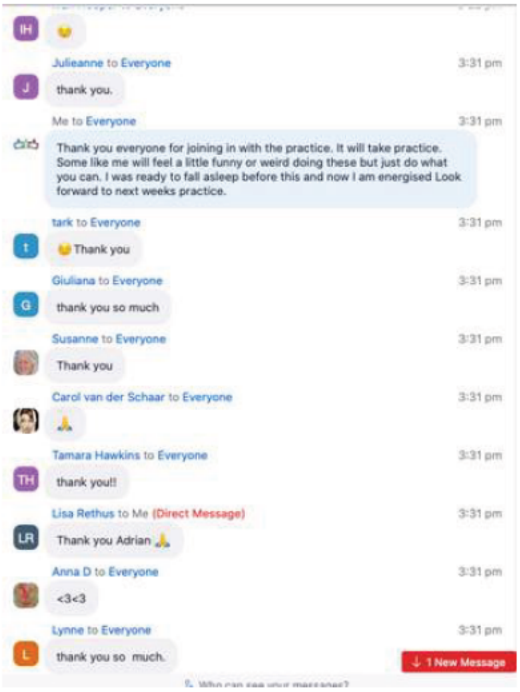
Lisa Rethus to Me (Direct Message) 3:32 pm
Loved the outside setting

Julieanne to Everyone 3:32 pm
Sorry to hear your news. Hope you are ok.

kate to Everyone 3:32 pm
I really enjoyed it being outside!!! Thanks :)

Lisa Rethus to Me (Direct Message) 3:32 pm
Take care of yourself to

Who can see your messages?



😊

Julieanne to Everyone 3:31 pm
thank you.

Me to Everyone 3:31 pm
Thank you everyone for joining in with the practice. It will take practice. Some like me will feel a little funny or weird doing these but just do what you can. I was ready to fall asleep before this and now I am energised Look forward to next weeks practice.

tark to Everyone 3:31 pm
😊 Thank you

Giuliana to Everyone 3:31 pm
thank you so much

Susanne to Everyone 3:31 pm
Thank you

Carol van der Schaar to Everyone 3:31 pm
🙏

Tamara Hawkins to Everyone 3:31 pm
thank you!!

Lisa Rethus to Me (Direct Message) 3:31 pm
Thank you Adrian 🙏

Anna D to Everyone 3:31 pm
<3<3

Lynne to Everyone 3:31 pm
thank you so much.

↓ 1 New Message

CCI/TICNA & Sanctuary Testimonials

The following pages are just some of the testimonials we have received directly and from the recent survey about the classes and programs we have arranged for CCI, Ticna and Sanctuary (CCI et al) members. These are also available to anyone outside our groups as well. For access to the initial real quote names, please ask to see initial survey responses.

Suffering from a chronic, invisible illness is extremely isolating. Having the opportunity to share some time and activities with people who go through similar experiences makes me feel understood and less isolated. The sessions give me something to look forward to.

...I felt part of something much bigger, in a place of understanding for us all...

It is the one platform where I dont feel alone. At that time I have a community that understands and can relate to my feelings of isolation.

My feelings about life with ME are validated. These sessions really help me to feel less isolated and connecting with people in this community is encouraging and so supportive.

They help me connect with others in similars situations when my mental health is low. Helps me remember i'm not alone in this fight of chronic illness and rarely being understood by society.

CCI/TICNA & Sanctuary Testimonials

The online classes are tailored to suit our health conditions and limitations. Other online classes like yoga and QiGong are too fast and too hard but these classes are awesome and easy what to follow. The person running the classes always give other options so you can do the movements whilst sitting or lying down if needed and understand that some days are harder than others

Helps to have a connection with people who have lived experience with chronic health The sessions have helped me learn further, and understand how to better manage my health - both physical and mental.

These sessions have meant so much to me. They have allowed me to feel like a part of a community where I am seen and understood. It's been good for my mental health and has given me something to look forward to and has empowered me as I feel I'm doing something to help my health. I can't attend classes outside the home and can't really afford extra things so these classes are so important to me.

Through discussion with others both in person and online, Conquering chronic illness helped improve my awareness about multiple comorbid conditions and empowers me with information to help me learn how to cope with my conditions.

Thanks to the sessions I'm able to connect with others undergoing similar challenges and I don't feel so alone. I'm also able to access useful supportive practices that are run specifically for those with chronic illness by those with chronic illness so I know they'll be aimed at me and not push me too far so I know I won't suffer negative consequences. I'm also able to access really useful tips and insights through these groups.

CCI/TICNA & Sanctuary Testimonials

Kind Words

☆☆☆☆☆

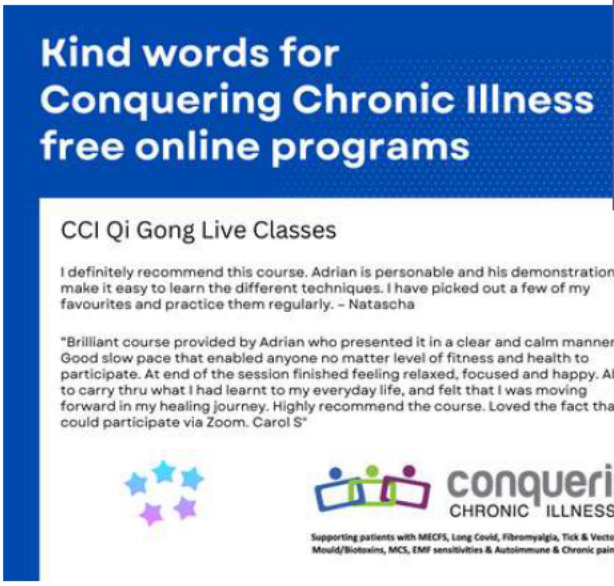
I want to let you know how amazing Amelie Movement class was. I'm in a WhatsApp group that shares resources and a few from my group joined for the first time. We were all saying how much we loved it. I am inspired to change my sleep habits and other habits thanks to your explanations and experience.

We hope we can always come back to your offerings.

So grateful to you.
Best Regards,

Leah

Supporting patients with MECFS, Long Covid, Fibromyalgia, Tick & Vector infections, Mould/Biotoxins, MCS, EMF sensitivities & Autoimmune & Chronic pain conditions.



Kind words for Conquering Chronic Illness free online programs

CCI Qi Gong Live Classes

I definitely recommend this course. Adrian is personable and his demonstrations make it easy to learn the different techniques. I have picked out a few of my favourites and practice them regularly. – Natascha

"Brilliant course provided by Adrian who presented it in a clear and calm manner. Good slow pace that enabled anyone no matter level of fitness and health to participate. At end of the session finished feeling relaxed, focused and happy. Able to carry thru what I had learnt to my everyday life, and felt that I was moving forward in my healing journey. Highly recommend the course. Loved the fact that I could participate via Zoom. Carol S"

Supporting patients with MECFS, Long Covid, Fibromyalgia, Tick & Vector infections, Mould/Biotoxins, MCS, EMF sensitivities & Autoimmune & Chronic pain conditions.

Thank you Ticna for these free online programs

☺ | ☆☆☆☆☆

Qi Gong Live Classes

Adrian did an excellent job introducing the powerful, healing energy of Qi Gong. The space was safe and inviting. I felt very supported and validated. Adrian encouraged us to tune into our bodies and honour what felt right to us. There was no getting it wrong. Everyone was valued and encouraged to respect whatever we were capable of trying. It was also an excellent introduction as far as how to calm the body in real life situations using qi gong. I liked learning about the different healing mechanisms and how they correlated to different parts of the body. I enjoyed the positive energy of the class under Adrian's guidance.

Diana

TICNA TICK-BORNE ILLNESS
Community Network Australia Inc.
www.ticna.org.au • info@ticna.org.au

What People Have Said About CCI Free Programs

☆☆☆☆☆

I've found Ianthe & Amelie's Yoga & movement classes most sympathetic to the needs & restrictions of the chronically ill. They are beautifully & professionally presented by very likeable teachers who both pitch their classes perfectly for those who need/wish to lay/sit/stand for the exercises.
It feels great to be doing this for my health and it's also really enjoyable! It's so uplifting to have access to a class which is suitable for me - finally!

Sheila

SUPPORT GROUP

Supporting patients with ME/CFS, Fibromyalgia, tick & other vector infections, mould/CIRS, MCS, EMF sensitivities and other similar chronic illness conditions.

CCI/TICNA & Sanctuary Testimonials

[These sessions are essential, the support, sharing of experiences and recommendations the group shares makes me feel heard. Seeing others in the same situation makes me feel validated and connected to a very special community where I feel seen and heard.

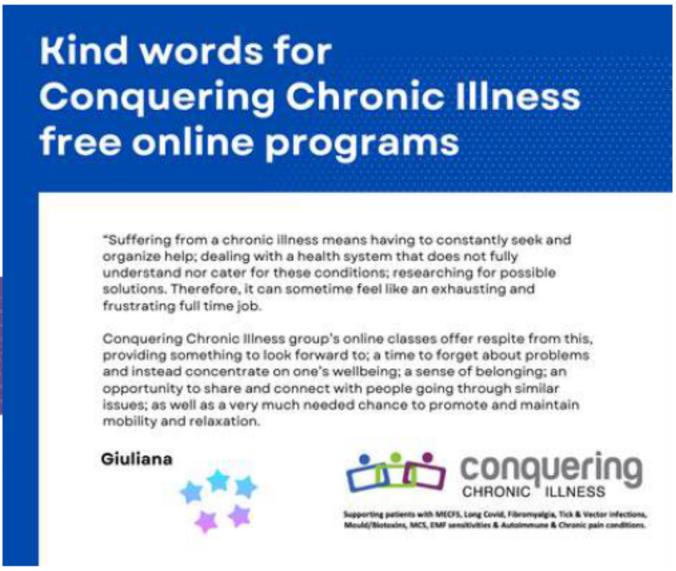
To know that you are not alone and that people understand means so much.

The Sanctuary Group session has been an important part of my healthcare. It has provided me with a sense of community, and a class of movement and nervous systems regulation that offers considered and flexible options throughout to suit differing abilities and needs. The benefits of the gentle movement combined with the practices to calm my nervous system does exactly that -!: leaves me feeling calmer, grounded, and connected after each class. When I have to miss a session due to clashes with other appointments, I notice the impact of increased isolation, and await eagerly for the next class. These sessions are significant and empowering!

Less isolated, have enjoyed Qi Gong particularly, have caught up online. It is reassuring to know that there are some advocates like CCI

An absolutely beautiful community. Provides a unique opportunity to be with others in a similar situation to you - online (which is necessary for unwell people) and with wonderful facilitators that understand

CCI/TICNA & Sanctuary Testimonials



Kind words for Conquering Chronic Illness free online programs

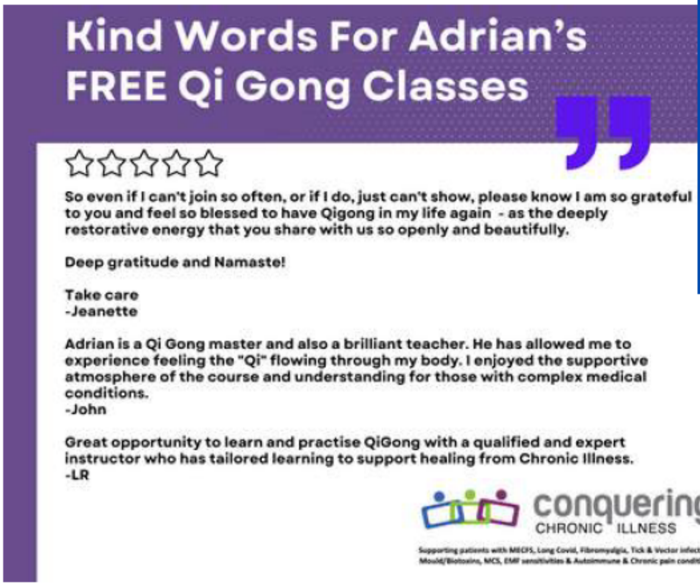
"Suffering from a chronic illness means having to constantly seek and organize help; dealing with a health system that does not fully understand nor cater for these conditions; researching for possible solutions. Therefore, it can sometime feel like an exhausting and frustrating full time job.

Conquering Chronic Illness group's online classes offer respite from this, providing something to look forward to; a time to forget about problems and instead concentrate on one's wellbeing; a sense of belonging; an opportunity to share and connect with people going through similar issues; as well as a very much needed chance to promote and maintain mobility and relaxation.

Giuliana

conquering CHRONIC ILLNESS

Supporting patients with MECFS, Long Covid, Fibromyalgia, Tick & Vector infections, Mould/Biotoxins, MCS, EMF sensitivities & Autoimmune & Chronic pain conditions.



Kind Words For Adrian's FREE Qi Gong Classes

☆☆☆☆☆

So even if I can't join so often, or if I do, just can't show, please know I am so grateful to you and feel so blessed to have Qigong in my life again - as the deeply restorative energy that you share with us so openly and beautifully.

Deep gratitude and Namaste!

Take care
-Jeanette

Adrian is a Qi Gong master and also a brilliant teacher. He has allowed me to experience feeling the "Qi" flowing through my body. I enjoyed the supportive atmosphere of the course and understanding for those with complex medical conditions.
-John

Great opportunity to learn and practise QiGong with a qualified and expert instructor who has tailored learning to support healing from Chronic Illness.
-LR

conquering CHRONIC ILLNESS

Supporting patients with MECFS, Long Covid, Fibromyalgia, Tick & Vector infections, Mould/Biotoxins, MCS, EMF sensitivities & Autoimmune & Chronic pain conditions.

Kind Words

☆☆☆☆☆

I've found Ianthe & Amelie's gentle Yoga & movement classes most sympathetic to the needs & restrictions of the chronically ill. They are beautifully & professionally presented by very likeable teachers who both pitch their classes perfectly for those who need/wish to lay/sit/stand for the exercises.
It feels great to be doing this for my health and it's also really enjoyable! It's so uplifting to have access to a class which is suitable for me - finally!

Sheila

conquering CHRONIC ILLNESS

Thank you Ticna for these free online programs

Qi Gong Live Classes

I am so glad I found you and your wonderful healing classes that are so special for me now - giving me a sense of deep connection and grounding - so I can go on with my life, at least a little! Also start to address my own health issues - put on hold for so long.
The self-care is a hard one for me but your story and practices today really helped me to gain some new insights into my own needs and better ways to support myself as well.

So even if I can't join so often, or if I do, just can't show, please know I am so grateful to you and feel so blessed to have Qigong in my life again - as the deeply restorative energy that you share with us so openly and beautifully.

Deep gratitude and Namaste!
Take care

Jeanette

TICNA TICK-BORNE ILLNESS Community Network Australia Inc.

www.ticna.org.au • info@ticna.org.au

CCI/TICNA & Sanctuary Testimonials

O.m.g. where do I start? Connection with people who are already guaranteed to believe me and understand what I'm going through. The sessions help immensely reduce my pain and relax my reading mind. I feel so much better after the sessions

Recorded sessions are great to be able to do sessions in small increments to suit energy and muscle fatigue

The online sessions are the high point of my week. I am not judged and they appreciate that it is a monumental effort just to be able to attend and that is a huge accomplishment if I can make it. I participate as I can and on a good day I am able to participate and on a not so good day at least I can lie there and cry and not feel so alone.

I think I'd be dead without the online sphere. The information has been invaluable

The information provides hope and sessions are designed to recognise the difficulties that prevent me participating in regular activities and the need to pace myself with these tailored sessions

Amelie's classes are an amazing, weekly energy boost of hope to know recovery is possible!

Attending the sessions improves my mental wellbeing, always feel better afterwards

CCI/TICNA & Sanctuary Testimonials

The sessions create an online community which helps to feel less isolated, and most classes help to regulate the nervous system, which is needed for both physical and mental health issues

My wife and I attend the classes. It's such a positive nurturing environment for people that are unwell. Its the highlight of the week as its free and so inclusive.

Relating to people who are completely well and getting a long in life is difficult...without the understanding of other unwell people i definitely wouldn't have coped.

Thanks to the sessions I feel heard, understood and my lived experience is validated. I don't feel so alone in my experience and this has helped my emotional state immensely

Very helpful for connecting with community and undertaking activities that promote good mental and physical health

CCI/TICNA & Sanctuary Testimonials

I have made some important friendships through CCI and Sanctuary groups, where my experience is acknowledged and I feel respected. When I am less well, having a class or a zoom session or cafe catch up can be a great relief to feeling alone with this experience. Unfortunately, I think most people are unable or unwilling to extend support much past a year or so, and as this condition has been 8 years long. There is understanding about the unique stresses a chronic fatigue/pain condition brings. These groups are also greatly beneficial in terms of sharing information about Drs, experimental treatments etc. Due to loss or work and social/travel/hobby opportunities, these groups fill an important need for social connections.

The experience of connecting with other people who understand has made a huge impact on my overall health. I regularly call a friend I made through this community and we are very strong supports for each other. Being such a rare and also socially challenging illness to navigate, as many people's clothing that has been exposed to mould, makes me reactive. This high sensitivity essentially makes me allergic to most people and buildings. This enormous social barrier has made it almost impossible to have in person friendships. These online communities that focus on nervous system work and connection are essential for people who are so physically impacted by in person connections.

Sanctuary has been a wonderful space of solace and guidance for me. I am very grateful for it's existence!

Knowing that these sessions are FREE, and there is someone there who gets it, even if all I can do is join and be lying down with my eyes closed. It helps when one feels so completely alone. But also the actually movements and breathing and stuff are really helpful

CCI/TICNA & Sanctuary Testimonials

These classes are a staple in my week. Living with chronic illness, every day is challenging and I find that these classes with Amelie allow me the chance to take stock and reset. I find that I am always feeling calmer, more balanced and grounded after the classes which is a welcome reprieve. It is also much more motivating to have a class and community to connect with at as set time each week, than to attempt to practice these techniques on my own.

Helps to connect with others going through the same experience. To feel less alone and to normalise the issues I face. Just knowing that someone cares and that there is support there helps immensely. Also the sessions help me mentally and physically and are adapted to my needs. Having someone empathise and understand my issues helps a lot.

Honestly, I wouldn't be alive today if it weren't for the online sessions. I live alone on a remote island in a safe bubble house and react to the world anytime I go out in it. I was in such a bad way mentally at one point but due to my extreme sensitivities I couldn't present to a psychiatric ward as my physical health would deteriorate. The only way to prevent my psych or parents from having me forcibly admitted was to promise to connect online at least once a week... so I attended the free sessions. It's literally what saved me. All of a sudden I didn't feel so alone in my struggle, I didn't feel cut off from the entire world, I didn't feel quite so hopeless. I felt understood, seen, heard and above all supported. I'm so grateful that these sessions exist and I don't know what I would do if they stopped.

These groups are essential to my mental and physical health, because I am unable to leave my home for social activities due to chronic illness

Feedback findings:

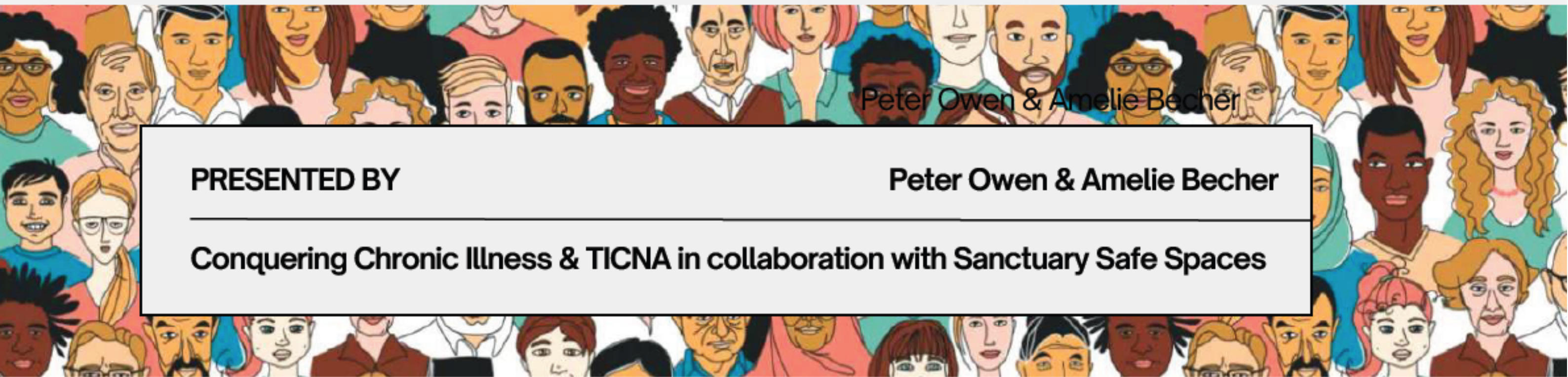
The surveys asked for feedback about the value of the classes and programs CCI et al, ran with the aid of $20,000 in Victorian government funding over the main pandemic period of 2021 -2023 outlining the huge need for these programs. Programs that help educate and also involve the community even though many live in separate parts of the country. Going online has been a blessing for us and for many who live alone and have little community contact especially from people who fully understand their needs and fears. CCI et al have found practitioners capable and willing, most so far from Victoria but want to venture wider, to tailor classes specifically targeted to our very unwell and often isolated community. This has been because the volunteer organisers have lived with chronic illness themselves and understand this patient community completely.

The classes and programs have been appreciated for their mental health alone.

The practitioners for the classes are often run by past and existing patients themselves so they have full understanding of PEM Post-exertional malaise and the often worsening that can occur from overdoing movements. The classes have been arranged so they can be done from bed, couch or the floor. Allowances are made for every person attending and the practitioners check in with people to indicate rest when needed and drop off if they feel too tired. Nothing is pushed or rushed and there is a compassionate calmness about all we do with people. This practitioner approach is unique as there is very little online catering specifically to our patient community with the range of classes and type of programs we have arranged with practitioners and that is now all FREE for people. Why FREE? Because most have lost their incomes and are now on disability so cannot afford the usual $15-$25 per class.

When provided continued funding, CCI et al will continue to improve social engagement and mental health by decreasing isolation for many online Australia-wide. Plus provide relevant patient-driven support with existing and newly developed classes and programs uniquely tailored to our community quickly, efficiently and directly. As already outlined mental health has improved in this growing community with people just knowing there are collaborating organisations listening, caring and communicating directly with them. There is a huge need, one which our collaborative supports are providing and can provide more given continued funding. These classes are NOT limited to just our groups as we endeavour to try and reach other like-minded organisations and also offer these for free to their members as well.

We are not in the same boat as often is said. All of us with many common and overlapping symptoms regardless of our chronic illness condition names are all in the same ocean and these classes and programs help save people from drowning and lift them to safe dry land.



Peter Owen & Amelie Becher

PRESENTED BY **Peter Owen & Amelie Becher**

Conquering Chronic Illness & TICNA in collaboration with Sanctuary Safe Spaces