

# **Bio-toxin and Mycotoxin (mould) related diseases: A challenge for Australian doctors**

## **Submission to the Parliamentary Inquiry into Biotoxin-related illnesses in Australia**

Prepared by the Australasian Integrative Medicine Association (AIMA) in collaboration with the Australian College of Nutritional and Environmental Medicine (ACNEM).

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### **Summary**

Our survey indicates that doctors are seeing an increasing number of patients presenting with the symptoms of bio-toxin and mycotoxin (mould) related illnesses.

Many doctors have indicated that they are ill-equipped and/or trained to properly diagnose **or** treat patients with bio-toxin and mycotoxin (mould) related illnesses.

The lack of standardised guidelines for the identification, testing and treating of these patients has the potential to compromise patient care and contribute to significant ongoing morbidity.

Adequate pathology testing for patients is not available in Australia. When testing is available it is often too expensive for patients as it is not covered by Medicare.

Resources are urgently needed for:

- Clinical Research into the nature of bio-toxin/mycotoxin illness
- Establishment of diagnostic and treatment protocols
- Education for doctors
- Medicare subsidised pathology tests
- Education and testing of possible mould-affected work and home environments
- Funding to facilitate testing and remediation of possible mould-affected work and home environments

## About Us

The Australasian Integrative Medicine Association (AIMA) is the peak medical body representing the doctors and other health care professionals who practice integrative medicine. AIMA is an independent not-for-profit organisation supported by its membership and governed by a volunteer board.

Integrative medicine is a philosophy of healthcare with a focus on individualised patient care. It combines the best of conventional western medicine with evidence-based complementary medicine and therapies.

The Australian College of Nutritional and Environmental Medicine (ACNEM) is an education organisation that offers training to doctors and other health professionals.

Nutritional and Environmental Medicine is an evidence-based practice concerned with the interaction of nutritional and environmental factors with human biochemistry and physiology, and the resulting physiological and psychological symptoms and pathology.

## Methodology

In response to the Parliamentary Inquiry into Biotoxin-related illnesses in Australia, a survey was initiated to understand the clinical experience of doctors in the area of biotoxin related illness and the burden of illness that they are witnessing in the communities that they serve. The survey was sent to doctor members of AIMA, ACNEM or the RACGP Integrative Medicine Special Interest group. The survey asked a series of questions regarding:

- The prevalence of patients presenting with the symptoms of biotoxin and mycotoxin-related illnesses
- Their confidence in diagnosing and treating these illnesses
- Their need for training and support

Respondents were also encouraged to give more detailed feedback regarding their experiences in diagnosing and treating biotoxin and mycotoxin related illnesses. Sixty-one responses to the survey were gathered, 90% from GPs and medical specialists.

## Findings

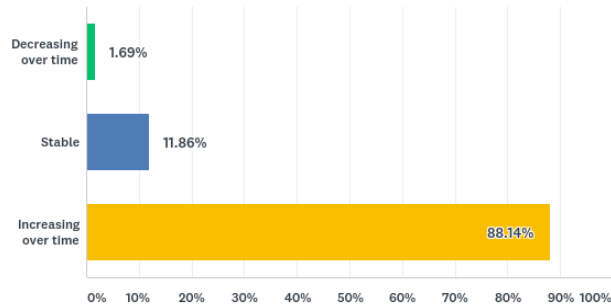
### 1. Patient numbers are growing

Overwhelmingly doctors are seeing an increase in the patients who are presenting with the symptoms of biotoxin and mould-related illnesses (88%).

Doctor's Comment:

*"These patients are so complicated with multisystem symptoms, have been chronically ill for some time, are usually desperate, can't work, testing is expensive, treatment is expensive BUT results can be life changing once they respond."*

Q2 What is the pattern of the frequency of seeing these patients?



(NB question numbers in the graphics relate to survey questions)

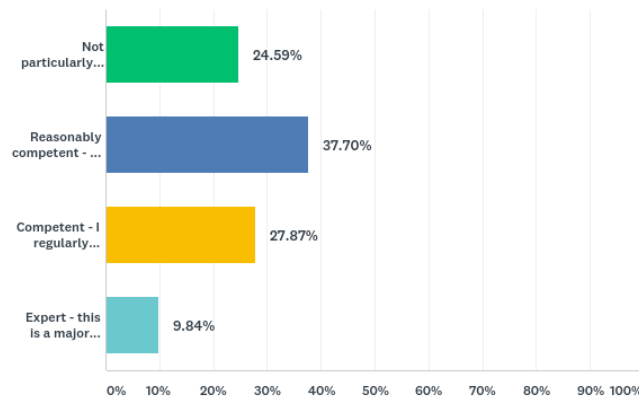
**2. Doctors need more support and training to diagnose and treat Environmentally acquired illnesses**

The survey separated general environmentally acquired illnesses from specific mould and mycotoxin illnesses. This response refers to general environmentally acquired illnesses only.

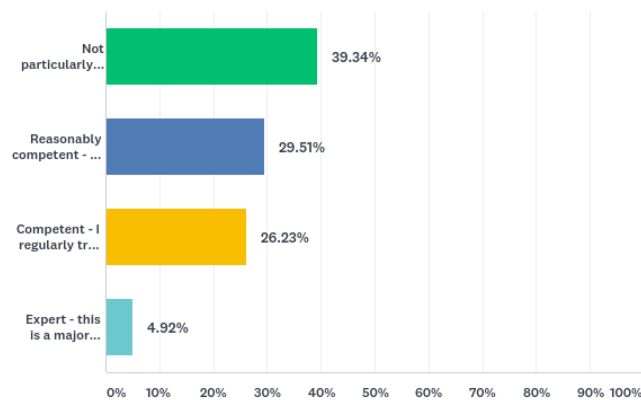
There is an identified need for further training for doctors in recognising and treating environmentally acquired illnesses. Currently many doctors do not feel competent in either recognising or treating environmentally acquired illnesses.

68% of respondents placed themselves in the lower scales of competency in **diagnosing** environmentally acquired illnesses. Likewise 70% of respondents placed themselves in the lower scale of competency in **treating** environmentally acquired illnesses. This included a huge 40% who responded that they were 'not particularly competent - I need more training in this'.

Q6 How competent do you consider yourself in recognising general environmentally acquired illness?



Q7 How competent do you consider yourself in treating general environmentally acquired illness?



### 3. Doctors need more support and training to diagnose and treat specific mould/mycotoxin acquired illnesses

The survey separated general environmentally acquired illnesses from specific mould and mycotoxin illnesses. This response refers to specific mould/mycotoxin acquired illnesses only.

There is an identified need for further training for doctors in recognising and treating specific mould/mycotoxin. Currently many doctors do not feel competent in either recognising or treating environmentally acquired illnesses.

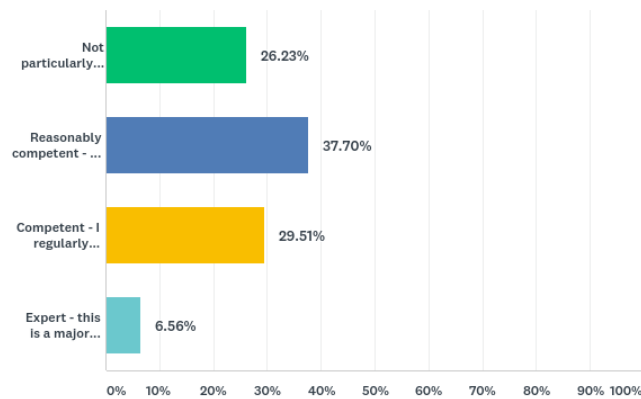
64% of respondents placed themselves in the lower scales of competency in **diagnosing** environmentally acquired illnesses. Likewise 77% of respondents placed themselves in the

lower scale of competency in **treating** environmentally acquired illnesses. This included a huge 43% who responded that they were 'not particularly competent - I need more training in this'.

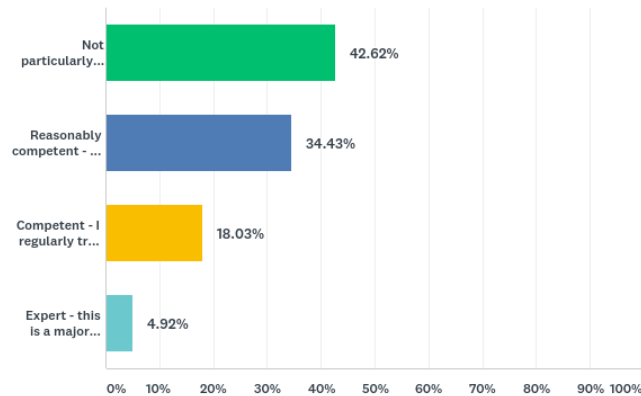
#### Doctors' Comments

*"My main issue is not in recognising mould illness but in the monetary cost to individual patients in terms of getting a diagnosis (such as mould testing)"*

Q9 How competent do you consider yourself in recognising specific mould or mycotoxin illness?



Q10 How competent do you consider yourself in treating specific mould or mycotoxin illness?



**4. Doctors need more advanced education, patient education resources and better referral networks to support their treatment of people with biotoxin-related illnesses.**

This is the aggregated result of the questions around education and support for both general environmentally acquired illnesses and from specific mycotoxin-related illnesses.

The three main areas of education and support which doctors identified as needed to help them recognised and treat both general environmentally acquired illnesses and mycotoxin/mould illnesses were”

- Advanced practitioner education (66%)
- Better referral networks to refer patients to (57%)
- More patient education and other patient resources (56%)

Specifically doctors identified access to testing, the cost of testing and the need for testing to be available on Medicare as major factors impacting their ability to treat patients who present with the symptoms of biotoxin-related illnesses.

Doctor comments include:

*“I need Medicare to reimburse appropriate investigations for these types of patients, and to stop harassing the practitioners who are diligently treating these patients, thus ultimately saving public health costs”*

*“I need testing and treatment to be affordable for patients”*

*“We need access to the diagnostic blood testing and clarity around how best to confirm mould exposure in the home. Currently there are services in the community (building assessments) who do not understand the true impact of mould on health and can dismiss the significance of this. This undermines my efforts in helping patients recognise the impact that mould in the home can be having on their health”*

**5. Doctors need biotoxin-related illnesses to be recognised and treatment guidelines established**

Survey respondents raised the need for these illnesses to be properly recognised in Australia so that doctors can treat these patients in a safe medico-legal environment.

Doctors’ Comments

*“I need recognition of CIRS in Australia so I can work in a safe medicolegal environment.”*

*“I have several patients at the moment who are being treated for either Lyme like illness or mould toxicity that don’t have a good diagnosis or treatment protocol in place. I feel that this is an area that is poorly understood by most practitioners, including myself, that needs public awareness as well as some set protocols for assessment, diagnosis and treatment.”*

*"In my experience, there is a general lack of acceptance by medical professionals that environmental influences may be relevant contributing factors to a variety of chronic disease states. In my experience, many chronic disease states are managed poorly due to a lack of emphasis on attempting to find the underlying causes of the patient's condition. Instead the emphasis is frequently on treating the symptoms only in isolation, often via the recruitment of multiple sub-specialists, each focussing on their domain of interest in relative isolation to the whole. The ideal outcome would be a simple acknowledgement by medical practitioners that these conditions exist, that there is research pointing to their role. This alone would be a positive starting point, that legitimises the patient's experiences and allows a pathway for further exploration."*

## **6. Doctors' Stories of treating biotoxin-related illnesses**

*"In November 2017, I formally diagnosed CIRS in one of my patients, a 14 year old girl who has severe chronic fatigue syndrome, who is under the care of 4 specialists and on a long list of medications that was helping her to 'tread water'. That is, despite the medication, she was developing new significant symptoms leading to more medications and greater disability. Being able to formally diagnose CIRS provided us with an answer and helped to identity a clear strategy to move forward. Unfortunately following this 'win', Melbourne Pathology declined to continue sending blood tests to Quests Pathology in the states. I can't monitor her progress. I can't diagnosis CIRS in my other unwell patients. This has placed considerable pressure and strain on me as a practitioner, as I am identifying a clear risk in my patients who have complex needs and who, quite frankly, the medical system has given up on. The pressure relates to being unable to formally diagnose CIRS and the huge costs (emotional & financial) that is linked to managing CIRS. Recommending to a patient that they need to move home and to get rid of their personal belongings that may be contaminated, whilst suffering from brain fog and exhaustion, without a formal diagnosis, is a heavy weight to bear for any practitioner. And that's just the start of the treatment process! We then need to navigate the difficulties of supporting the individual to recovery, which in my experience requires a very holistic approach. The lack of recognition in the wider medical community can exacerbate the problem and undermine our efforts also."*

Doctor Respondent to the AIMA ACNEM survey, July 2018

*"Very difficult as a GP as hardly any specialists know anything about mould illness and will often not take referrals or dismiss patient concerns, even infectious diseases and occupational health specialists. Many of the tests are expensive and not available on Medicare. Patients in public housing get no assistance with mould infestations and water damage and can't afford to move out. As the mould is making them sick they can't get back into work and so are stuck on benefits and in poor quality public housing, a real vicious circle. .... People just don't realise how dangerous mould is for health and either just put up with it, or face road-blocks if they try to get help due to lack of legislation (on) mould in Australia, lack of specialists and lack of guidelines"*

Doctor Respondent to the AIMA ACNEM survey, July 2018

## Discussion

Our survey indicates that doctors are seeing an increasing number of patients presenting with the symptoms of bio-toxin and mycotoxin (mould) related illnesses. These illnesses are commonly chronic and involve multiple systems and many doctors have indicated that they are ill-equipped and/or trained to properly identify, diagnose and treat these patients. It is also clear that until these illnesses are formally recognised, some doctors are feeling unsupported and at times criticized while they are working with these very unwell patients.

The lack of standardised guidelines for the identification, testing and treating of bio-toxin/mycotoxin patients has the potential to compromise patient care and contribute to significant ongoing morbidity. None of the pathology tests that are being used as indicators to aid in the diagnosis of mycotoxin induced illness are subsidised by Medicare.

Support and training is urgently needed for doctors and other practitioners who treat and support these patients on their therapeutic journey. Support and resources are also urgently required for the patients, who are often quite incapacitated physically, emotionally and mentally and under considerable financial strain.

It is likely that bio-toxin/mycotoxin illness is one of the new and 'emerging' environmental illnesses and thus to date is not recognized by occupational and environmental specialists. It is proposed by many that its emergence is due to a complex interplay of the many changes in our food and environment in addition to a growing number of people with increasing environmental sensitivities (with accompanying complex immune dysfunction).

The outcome of this survey is consistent with a recent study of expert clinicians in the field of environmental medicine in Australia and New Zealand<sup>1</sup>. This study identified the complexities in diagnosing and treating patients with environmental sensitivities and reinforced the need to develop standardised exposure assessment tools such as a comprehensive exposure history survey. This study also illustrates the fact that environmental specialists don't seem to have had training in the recognition and treatment in the new and emerging environmental illnesses such as bio-toxin/mycotoxin induced illness.

Resources are urgently needed for:

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- Establishment of diagnostic and treatment protocols
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<sup>1</sup> Bijlsma, N., Cohen, M.M.: 'Expert clinician's perspectives on environmental medicine and toxicant assessment in clinical practice', *Environmental Health and Preventative Medicine*, May 2018 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5956903/>



## Resources

Further information on biotoxin and mycotoxin related illnesses can be found at:

International Society for Environmentally Acquired Illness <https://iseai.org/>

Bijlsma, N., Cohen, M.M.: 'Expert clinician's perspectives on environmental medicine and toxicant assessment in clinical practice', *Environmental Health and Preventative Medicine*, May 2018 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5956903/>

## Acknowledgements and thanks

AIMA and ACNEM thank the doctors who participated in this survey.

We would also like to acknowledge the assistance provided by the RACGP Integrative Medicine Special Interest Group in distributing the survey to their membership and to Dr Carolyn Ee for her assistance in the survey design.