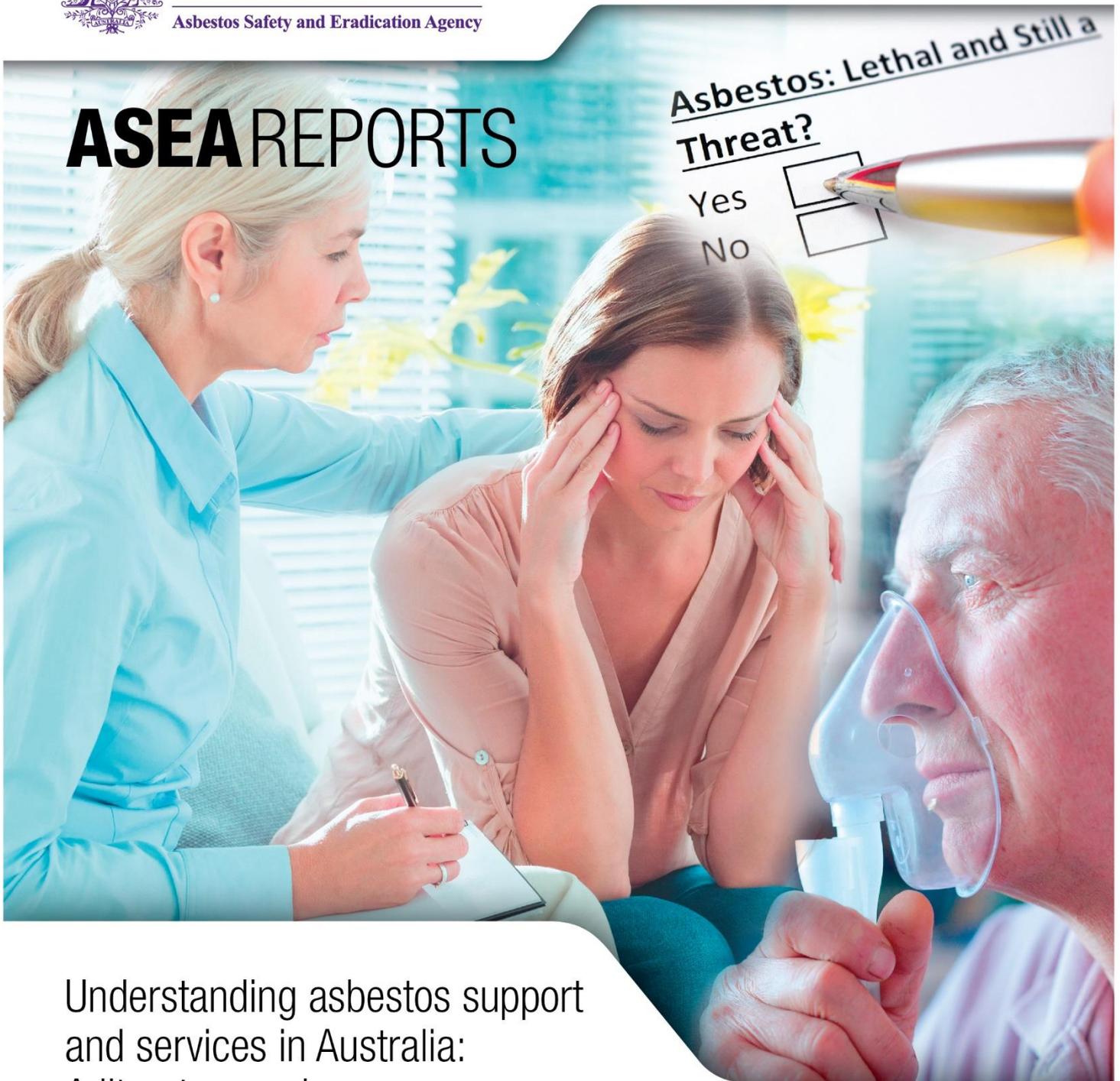




ASEA REPORTS

Asbestos: Lethal and Still a
Threat?

Yes
No



Understanding asbestos support and services in Australia: A literature review

FINAL REPORT



CENTRE
for SOCIAL
IMPACT



As prepared by Julie Tucker, Centre for Social Impact, Swinburne University of Technology

List of acronyms

ACM	Asbestos containing material
ACV/GARDS	Asbestos Council of Victoria/Gippsland Asbestos-Related Disease Support Inc
ADFA	Asbestos Diseases Foundation of Australia
ADII	Australian Digital Inclusion Index
ADRI	Asbestos Diseases Research Institute
ADSA	Asbestos Diseases Society of Australia
ADSS	Asbestos Related Disease Support Society Limited
ADSSA	Asbestos Diseases Society of South Australia
AFTF	Asbestos Free Tasmania Foundation
AMAA	Asbestosis and Mesothelioma Association of Australia
ARD	Asbestos-related disease
ASEA	Asbestos Safety and Eradication Agency
AVA	Asbestos Victims Association of South Australia
BARD	Barrow Asbestos-Related Disease Support
CARDS	Cumbria Asbestos-Related Disease Support Group
CRADS	Canberra Region Asbestos Diseases Support Group
NHADS	Newcastle and Hunter Asbestos Disease Society

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Acknowledgements

I would like to thank the Asbestos Safety and Eradication Agency for proposing and supporting this research into the service and support needs of women and men affected by asbestos related disease in Australia. In particular, I thank Stephen Rochfort for his guidance, support and many helpful comments on earlier drafts.

This research is also the result of a wider collaboration. In September 2016 an earlier draft was circulated to Australia's community-based asbestos support organisations for comment. A number of detailed and very constructive responses were received. In November 2016 the research findings were presented during the 2016 Asbestos Awareness and Management International Conference in Adelaide, South Australia. Both the responses from the community organisations and the feedback from the conference attendees have been incorporated within this final report. This research has been considerably enhanced as a result of this process of consultation and ongoing discussion and I thank, sincerely, the many people who contributed their time and shared their knowledge and experience.

Executive summary

This literature review, commissioned by the Asbestos Safety and Eradication Agency (ASEA) in 2016, evidences the service and support needs of the people affected with asbestos-related disease across Australia. Two sources of evidence inform this research. Firstly, the academic literature, both Australian and international, exploring the service and support need of people affected by asbestos-related disease. Secondly the information available online about the services and supports available to people affected by asbestos-related disease in Australia. Whilst recognizing and acknowledging that valuable services and support for people affected by asbestos-related disease are provided by organisations from a range of different sectors the focus of this research is on the services and support provided by Australia's community-based asbestos support organisations.

The review of the academic literature highlights what is currently known about the impacts of asbestos-related disease on individuals and within different communities and identifies some of the gaps in our collective knowledge. In so doing it provides the context for this research and evidences the complex support and services needs associated with an asbestos-related diagnosis in Australia.

The review of the online resources provided by Australia's community-based asbestos support organisations comprises the first step in documenting how this sector provides services and support to communities across Australia. It is important to acknowledge at the outset that this research does **not** seek to be a comprehensive guide to the services and supports provided by Australia's community-based asbestos support organisations. It is simply not possible to capture the breadth and depth of this work solely via the information that appears online. This is for a variety of reasons, including the difficulties that small, volunteer-based organisations face in maintaining an up to date online presence in the face of the many more immediate demands on their time. Given this reality, this research seeks firstly to make more **visible** some of the work of Australia's community-based organisations and secondly to consider this work in the context of the support and service needs identified by the academic literature.

The research concludes with three recommendations designed to enhance the capacity of community-based asbestos organisations to meet the ongoing need for services and support.

Review of the academic literature

The research commences with a review of the academic literature, both Australian and international, exploring the service and support needs of people with asbestos-related disease, including the needs of specific communities, within this wider cohort. The research includes the following key findings:

Research overview

Research, both international and Australian, has identified the consequences of exposure to asbestos as multi-layered and complex, encompassing the individual (Lee et al 2009), the built environment (Park et al 2013), and the wider community, particularly those communities in which the use of asbestos was previously prevalent (Cline et al 2010; LaMontagne and Walker 2005). Unsurprisingly, given Australia's history of asbestos mining, manufacture and consumption, mesothelioma incidence rates in Australia are amongst the highest worldwide (Kao et al 2013). A report recently commissioned by the Asbestos Safety and Eradication Agency predicts "19,000 cases of mesothelioma diagnosed in Australia between 2015 and the end of the century" (Asbestos Safety and Eradication Agency 2016, p 26).

Implications of non-occupational exposures to asbestos

Exposure to asbestos within the built environment, particularly during home renovations and repairs, has resulted in a new and “third wave” of environmental exposures and asbestos-related disease (Olsen et al 2011; Park et al 2013). Recent Australian research suggests that domestic or non-occupational exposures to asbestos are likely to account for an increasing proportion of all mesothelioma fatalities in Australia (Hyland et al 2007; Olsen et al 2011). Women are expected to form an increasing proportion of non-occupational exposures (Hyland et al 2007). Exposure to the asbestos embedded throughout the Australian built environment continues to present an ongoing challenge to government and policy makers (Asbestos Safety and Eradication Agency 2016; Park et al 2013).

Scarcity of relevant literature

Notwithstanding the importance of support and services for the women and men affected by asbestos-related disease, a review of the literature reveals a relatively small body of international (Arber & Spencer 2012; Hughes & Arber 2008; Moore, Darlinson & Tod 2009) and Australian research (Buultjens et al 2014; Hunter & LaMontagne 2008; LaMontagne & Walker 2005; Lee et al 2009; McCulloch 2007). Much of what is known has been informed by research seeking to inform the delivery of health and allied health services programs and interventions, including palliative care. Significant exceptions exist including research into the community-wide impacts of asbestos-related disease in the Latrobe Valley in regional Victoria (Hunter & LaMontagne 2008; LaMontagne & Walker 2005; Lee et al 2009) and research into the lived experience of men and women with an asbestos-related diagnosis in urban and regional NSW (Buultjens et al 2014).

Asbestos-related disease: complex impact and unmet needs

Two key themes emerge from the current literature, both international and Australian. Firstly, that the impact of an asbestos-related diagnosis is multidimensional, characterised by high levels of unpredictability and uncertainty (Arber and Spencer 2012; Buultjens et al 2014; Clayson 2007; Moore, Darlinson & Tod 2009). Secondly, that the associated needs, at both an individual and community level, are complex and frequently unmet. (Arber & Spencer 2012; Hawley, Monk & Wiltshire 2004; LaMontagne et al 2008; Lee et al 2008; Moore, Darlinson & Tod 2010). Social isolation is consistently reported as one of the “key psychosocial costs of an asbestos-related disease” (Kozlowski et al 2014, p 466 citing Hawley & Monk 2004 and Hughes and Arber 2008). Whilst much of the literature has limitations, participant numbers are frequently small; it also has strengths, generating qualitative data that is rich in detail.

Whilst the literature exploring the support needs of women and men with other types of cancer, including non-asbestos related lung cancer is extensive, researchers like Clayson (2007), Clayson, Seymour and Noble (2005) Hughes and Arber (2008), and Moore, Darlinson and Tod (2009) argue that the circumstances surrounding a diagnosis of mesothelioma add an additional layer of complexity to the needs of patients and require a different policy response.

Carers and bereaved carers

A consistent finding across all of the literature is that the social impacts of an asbestos-related diagnosis are far-reaching including for the carer, usually the spouse and other family members. (Moore, Darlinson & Tod 2009; Hawley & Monk 2004; Clayson et al 2005; Hughes and Arber 2008). The demands associated with caring for someone with asbestos-related disease frequently lead to the social exclusion of the carer.” (Clayson 2007). The literature identifies carers as needing information as well as “practical, social and emotional” support.” (Clayson 2007). The impact of an asbestos-related diagnosis on carers in Australia is also well documented. (Lee et al 2009) The literature suggests that the impact of an asbestos-related bereavement is particularly severe. (Clayson 2007). At the same time the literature notes a general lack of

appropriate support and services and highlights the potential of asbestos support organisations and groups to provide a valuable space for bereaved carers (Clayson 2007; Lee et al 2009).

Regional communities

There are a small number of studies exploring how people living in regional or remote communities experience asbestos-related disease and the support and services required to meet their needs.

Unsurprisingly, much of the literature in this area is Australian (Buultjens et al 2014; Hunter & LaMontagne 2008; LaMontagne & Walker 2005; Lee et al 2009) although there is an emerging body of American scholarship (Cline et al 2010; Cline et al 2014, Kuntz et al 2009; Orom et al 2012). The picture that emerges from the Australian literature is of an experience made more difficult by a range of factors including the additional stress associated with travel to and from major cities for appointments with specialists and treatment, delays in diagnosis due to a lack of available specialist appointments, and a relative lack of local knowledge about asbestos-related disease and local support services (Buultjens et al 2014; LaMontagne and Walker (2005); Lee et al 2009). The literature also notes that locally-based support groups in regional towns can provide both information and place-based support (Lee et al 2009).

Culturally and linguistically diverse (CALD) communities

With the exception of research into the experience of the European migrants who made up much of the workforce at the asbestos mine in Wittenoom in Western Australia (Cappelletto & Merler 2003; McCulloch 2008) there is little Australian literature exploring the impacts of asbestos-related disease in culturally and linguistically diverse (CALD) communities. The cancer literature notes that carers from CALD communities face “language and health literacy barriers” (Otis-Green and Juarez 2012). This in turn makes navigating and understanding information, particularly medical information, more difficult (Devitt et al 2010).

Aboriginal and Torres Strait Islander communities

According to a significant body of Australian research, the incidence of malignant mesothelioma in Aboriginal communities, particularly in those communities associated with the mining of asbestos in the Wittenoom Gorge in Western Australia, as very high, even by Australian standards (Knibbs & Sly 2004; Musk et al 1995; Musk & de Klerk 2006; Musk et al 2006). A recent study (Franklin et al 2016) found that West Australian Aboriginal communities have the highest incidence of malignant mesothelioma worldwide. In addition, there are significant asbestos legacy issues within regional and remote Aboriginal communities throughout Australia (Asbestos Safety and Eradication Agency 2016, p 34).

There is however, a distinct lack of research, international or Australian, into the associated need for culturally appropriate support and services within Aboriginal and Torres Strait Islander communities affected by asbestos-related disease. Research into chronic lung disease in Aboriginal and Torres Strait Islander people in Queensland (O’Grady et al 2014) has identified a number of barriers to effective health care namely: lack of transport to specialist appointments and treatment; fear and distrust of services; and a lack of culturally safe support services.

Women with asbestos-related disease

There is very little research, international or Australian, exploring the service and support needs of women with an asbestos-related diagnosis. At the same time the literature suggests that women are emerging as a distinct community within the third wave of environmental exposures (Hyland et al 2007; Olsen et al 2007).

Recent Australian research (Buultjens et al 2014) notes that women with asbestos-related disease, particularly the younger “third wave” cohort, may experience loss of career and associated financial

independence, recognises the need for peer-to-peer support and highlights the value of asbestos-specific support groups as opposed to more generic cancer support groups.

Strategies of amelioration

The literature identifies three principal “strategies of amelioration” each with the potential to ameliorate the impacts of asbestos-related disease namely: peer-to-peer support; asbestos awareness and education initiatives; and community-based asbestos support organisations.

Strategy one: peer-to-peer support

The literature recognises the value of peer-to-peer support for women and men with asbestos-related disease, particularly as a means of overcoming social isolation (Carbone et al 2007; Hughes and Arber 2008; Kozlowski et al 2014). Insofar as the provision of support to family carers is concerned the literature identifies both the value of peer-to-peer support as a means of overcoming social isolation and the future potential value of virtual/online support models (Clayson 2008). The Australian literature (Bultjens et al 2015; Kozlowski et al 2014; Phillips and Lindgren 2010) identifies the potential digital technology, including the internet to enable other models of peer-to-peer support, including online communities. There is no suggestion that online support can ever take the place of face-to-face support and human contact, instead it is argued that the creation of virtual spaces for peer-to-peer support could enhance traditional support mechanisms. Online peer-to-peer support may be of particular value in regional and remote towns, especially when traditional face-to-face support is not a viable option.

Strategy two: asbestos awareness and education programs

The Australian literature, reflecting the nature and extent of Australia’s own asbestos legacy, particularly the emerging third wave of non-occupational exposures, has identified the ongoing need for asbestos education and awareness raising programs both within the wider community, and for specific cohorts including health professionals, workers at risk of exposure, and home renovators (Bultjens et al 2014; LaMontagne and Walker 2005). In addition to their intrinsic value as a preventative strategy, the literature identifies asbestos awareness raising and education programs as having added value for people affected by asbestos-related disease, providing a valuable channel for positive, life-affirming action (LaMontagne and Walker 2005).

Strategy three: community-based asbestos support organisations

The literature, both international (Arber & Spencer 2012; Flanagan & Whitson 2004) and Australian (Bultjens et al 2014; LaMontagne and Walker 2005; LaMontagne et al 2008, Lee et al 2009), recognises the importance of local, community-based, asbestos-support organisations. Asbestos support organisations typically, though not always, comprise volunteers, women and men with personal experience of asbestos and asbestos-related disease (Flanagan and Whitson 2004), sometimes augmented by the work of a paid support worker. A high level of collaboration with other organisations and sectors is another identified strength (LaMontagne et al 2008).

In addition to providing peer-to-peer support for men and women affected by asbestos related disease, the literature identifies asbestos-support organisations as having the potential to provide a range of different supports and services including: identifying and addressing any unrecognised needs within their community (LaMontagne et al 2008), education and awareness raising, including amongst health professionals (LaMontagne and Walker 2005); providing written, accurate information about asbestos-related disease to people living in regional communities (Lee et al 2009); and providing a space for bereaved carers to meet,

share experiences and support other people affected by asbestos-related disease (Clayson 2007; Lee et al 2009).

Nevertheless, questions as to the long-term sustainability of this particular organisational model remain. Volunteers who provide “24-hour support” are identified as being “particularly at risk of compassion fatigue and burnout (Lee et al 2009). The literature suggests that a combination of volunteers and some funded positions may help build long-term capacity (Flanagan and Whitson 2004).

Review of asbestos support and services: findings

A desktop review of the support and services provided by asbestos support organisations within each state and territory comprised the second part of this literature review. The literature used to inform the review of support and services comprised the publicly available information accessible via the websites of each asbestos support organisation and, where applicable, publicly accessible Facebook pages. No interviews or surveys were conducted as part of this research.

As previously noted this review was not designed to produce a comprehensive guide to community-based services and support rather it was intended to evidence some of the work that takes place every day in communities across Australia, to build our collective knowledge of this work, and to lay the foundations for future projects.

The review of asbestos services and support in Australia has generated three significant findings. Firstly, Australia’s community-based organisations comprise a diverse network of services and support. Within this network each organisation has its own unique area of expertise.

Secondly, Australia’s support and service organisations work collaboratively, with other community-based support organisations and with organisations from other sectors. There is plenty of evidence of successful, cross-sector partnerships delivering real social impact.

Finally, Australia’s asbestos support and service organisations play a very significant role in asbestos awareness raising and education throughout Australia and also internationally. These three themes provide the framework for a wider discussion of service and support strengths, areas of unmet need and opportunities to further enhance the provision of asbestos support and services in Australia.

Finding one: a diverse Australia-wide network of services and support

Strengths

Australia’s community-based asbestos support organisations offer strong and varied programs of traditional peer-to-peer support including support groups, hospital and home visits and telephone advice.

Taken together Australia’s community-based asbestos support organisations comprise a dynamic, nationwide network of support and services. At the same time, it is clear that each organisation has its own area of focus and expertise, bringing both diversity and depth of experience to the wider network. In South Australia for example, ADSSA provides access to free counselling services to individuals and groups. ACV/GARDS in regional Victoria has a long history of providing and enabling education and asbestos awareness training and has worked successfully with a diverse range of partners including training providers, statutory authorities and local government. In NSW the Bernie Banton Foundation, with its strong focus on providing an integrated program of support to people affected by asbestos-related disease has established the Mesothelioma and Asbestos-Related Support (MARS) Network offering peer-based support across Australia, including online support groups.

It is also important to acknowledge that this support is delivered by a network of community-based organisations each of which relies on the work of a small cohort of paid staff working together with a cohort of committed volunteers. Given the nature of this work, particularly the daily contact with women and men experiencing severe trauma and loss, the risk of “volunteer burnout” as identified by Lee et al 2009 should not be underestimated.

Unmet needs

The review of services and support highlights the relative lack of culturally and linguistically appropriate services or support designed specifically for people from CALD communities. There is a similar lack of culturally appropriate services and support for Aboriginal and Torres Strait Islander communities in Australia. In a very positive development the Queensland-based ADSS will provide services and support to communities throughout Queensland and the Northern Territory in 2017, including Aboriginal and Torres Strait Islander communities. The value of this work should not be underestimated, both because of its potential to begin to meet an area of unmet need but also as a possible template for the provision of culturally appropriate services and support in other states.

Future opportunities

Digital technology represents a potential opportunity for Australia’s asbestos support organisations. The online peer to peer support groups established by the Bernie Banton Foundation provide an excellent example of digital technology’s potential to connect people with a wide range of experiences and needs to their peers. Whilst there is certainly no need to replicate already established online support groups digital technology could provide opportunities for collaboration amongst asbestos support organisations. An online community of Australian asbestos support organisations could, potentially, enable member organisations to share information and expertise. Establishing a simple online community would not be difficult. Online collaboration platforms like Basecamp and Slack offer cost effective, easily accessible options and could be used as a means of gauging interest and exploring the potential value of an online community of practice.

At the same time however it is important to recognise that digital technology requires access to a reliable, high speed internet connection. Whilst Australia’s capital cities and major regional centres are well served by Australia’s broadband network, recent research suggests that service provision in parts of regional and remote Australia may be less reliable (Barraket et al 2016).

Finding two: collaboration and partnership

Strengths

It is clear that collaborations and partnerships have enabled Australia’s community-based asbestos support organisations to reach new communities of people at risk of exposure to asbestos. In addition to working cooperatively with each other, particularly when the needs of any one client and their family members require support across more than one state, asbestos support organisations in Australia evidence the ability to manage a wide range of successful partnerships. This research identifies a number of project-based collaborations with organisations from other sectors.

In Queensland for example the ADSS partnership with Queensland Health has led to the creation of a valuable resource for tradesmen and home renovators. In Victoria ACV/GARDS partnered with industry, local government and statutory authorities in order to create another resource, the Asbestos in the Home Removal Kit. The Asbestoswise collaboration with four Melbourne-based councils has enabled the delivery and evaluation of an asbestos-awareness raising program within the wider community.

Unmet needs

Australian research has highlighted high rates of mesothelioma within Aboriginal communities, particularly those connected to the mining of asbestos in Wittenoom Gorge in Western Australia and in Baryulgil in Northern NSW. At the same time there are significant asbestos legacy issues within regional and remote Aboriginal communities throughout Australia.

Currently however there is a relative lack of partnerships and collaborations with Australia's Aboriginal and Torres Strait Islander communities. Similarly, there are currently very few partnerships with organisations representing the members of Australia's many CALD communities.

Future opportunities

Australia's community-based asbestos support organisations have demonstrated the capacity to work collaboratively with partners across a number of different sectors. These collaborations continue to raise awareness within the wider community and amongst targeted communities like tradesmen and women, home owners and home renovators.

The opportunity now exists to apply this sector-wide experience and knowledge in order to establish partnerships with a range of new, non-traditional partners. Building a series of properly funded, long-term partnerships with organisations representing other less visible communities at risk of exposure to asbestos, including CALD communities, Aboriginal and Torres Strait Islander communities and communities of social and public housing tenants would increase both the impact and capacity of Australia's community-based asbestos-support organisations.

Finding three: asbestos awareness raising and education

Strengths

Australia's community-based asbestos support organisations have produced a diverse range of excellent awareness-raising and educational resources including fact sheets, videos and audio files. Stan's Van, an initiative of the Bernie Banton Foundation, is a mobile asbestos-awareness raising unit able to reach new audiences, particularly in regional Australia. Betty the ADRI house, another mobile awareness raising unit and the result of a partnership between the Asbestos Diseases Research Institute and the Asbestos Education Committee also deserves mention.

In addition to providing online materials and resources asbestos support organisations have also employed a number of innovative community engagement strategies, including running information and awareness raising stalls at DIY/Home Shows, producing Asbestos Removal Kits for home renovators and delivering asbestos awareness training to the next generation of tradesmen and women via TAFE Colleges and trade schools. In Western Australia ADSA organises a yearly sponsored walk designed to raise awareness about asbestos and funds for research. The translation of an awareness-raising resource for people living in rental accommodation into eleven other languages by Asbestoswise provides an important example of a culturally and linguistically appropriate asbestos awareness raising resource.

Unmet needs

There is a relative lack of culturally appropriate asbestos awareness raising resources and associated community engagement strategies for Australia's Aboriginal and Torres Strait Islander communities or for the members of Australia's many CALD communities.

Future opportunities

Having already demonstrated the ability to develop the engagement strategies and resources required to reach and educate a wide range of communities at risk of exposure to asbestos, the opportunity exists to reach other, less visible cohorts, including Aboriginal and Torres Strait Islander communities, people living in rental accommodation and the members of CALD communities. The members of these communities are less likely to attend home renovation events or access online materials in English so new engagement strategies and resources will be needed.

The Lung Foundation's partnership with the Indigenous Respiratory Outreach Centre Project in Queensland, whilst not focused specifically on asbestos-related lung cancer, provides one potential community engagement model. This partnership has produced a series of culturally appropriate materials designed to raise awareness about the prevalence of lung disease in Aboriginal and Torres Strait Islander communities and empower community members to seek advice and support. Resources include DVDs, posters, lung disease flipcharts to enable clinicians to communicate clearly with patients and an Indigenous Talking Board to encourage conversations with health workers. This model could provide the foundations for an asbestos specific program of support and services.

The translation of an awareness raising audio file into eleven other languages by Asbestoswise represents a step towards recognising and meeting the needs of CALD communities and could provide the foundation for a further more comprehensive strategy of engagement. Similarly, ADFA's asbestos awareness program targeting high school students in culturally diverse Western Sydney provides another example of engagement with CALD communities.

Recommendations

The research concludes with three recommendations. The recommendations are informed by the review of academic literature and the online information about asbestos services and support in Australia. They are designed to provide a possible way forward, and to stimulate further discussion as to what that path might look. The recommendations are made in the knowledge that the availability of resources, both human and financial will be key to their implementation. Put simply, enabling Australia's asbestos support organisations to respond to the needs of the people most affected by Australia's asbestos legacy, now and into the future requires long-term funding.

Recommendation 1: new collaborations and partnerships

Asbestos support organisations currently provide a wide range of support and services making a significant difference to the lives of all those affected by asbestos-related disease. Lack of resources, financial and human, currently limits their ability to provide face-to-face services beyond their geographic location, a significant issue in a country as large as Australia. Many organisations offer telephone advice, 24 hours a day, seven days a week, however this level of commitment, particularly within small organisations, creates risks of burnout and compassion fatigue.

This research has identified a number of successful collaborations, particularly those with an awareness raising and community education focus, with organisations from a range of different sectors. Collaborations and partnerships enhance the capacity of asbestos support organisations to deliver services and support. When properly funded they can also provide greater financial stability enabling asbestos-organisations to think strategically and to plan for the medium to long term.

Whilst the literature in this particular field is still emergent it is clear that the impacts of asbestos-related disease, and the associated need for services and support, vary from community to community. This

provides both a challenge in terms of the services and support required and an opportunity for new partnerships. To take one example, the service and support needs of the people within CALD communities are likely to differ from those of Anglo-Australians. Partnership with organisations with strong connections to local CALD communities, like the state-based Migrant Resource Centres or the various Tenants Advice and Advocacy Services, could enable the development of culturally appropriate asbestos awareness-raising and education materials and enhance the financial stability of the partnering organisation.

Recommendation 2: create an Australia-wide map of asbestos services and support

This research provides evidence of the very significant role played by community-based organisations, in the provision of support and services to people affected by asbestos-related disease and in the delivery of asbestos-awareness raising and education activities to the wider community. It comprises the first step in documenting how the community-based sector provides services and support to communities across Australia and the foundations for future work.

Further investigation could create a more comprehensive map of services and support, one that fully captures the work undertaken by community-based organisations and identifies all areas of unmet need. Any future mapping of services and support across Australia would, ideally, involve interviews with key people within each asbestos support organisation, including those with frontline experience of service provision. Equally as important would be interviews or focus groups with current and past clients as well as with representatives from other sectors, like for example local government, the trade union movement and industry in order to incorporate a range of different perspectives and insights within the final findings. The research could be undertaken and delivered in stages. Once complete it would comprise the base line for future research and would enable a longitudinal study of services and support.

Recommendation 3: document social impact

The value of any Australia-wide map of services and support would be enhanced by a greater understanding of the social impact of the work undertaken by community-based asbestos support organisations. Social impact is a notoriously difficult concept to measure however evaluations, both quantitative and qualitative, of funded project outcomes and social impacts could provide the ideal place to start. The sharing of project outcomes and key learnings within the wider asbestos support and services community would also help build the collective capacity of the sector. Evaluations of future programs seeking to reach new communities, including CALD and Aboriginal and Torres Strait Islander communities will be particularly important.

In order to facilitate the sharing of this knowledge, consideration could be given to the establishment of an online knowledge space. In other words, a virtual library of projects and their social impact. There are many models which could be used to inform the development of this space. The Knowledge Centre established by the [auDA Foundation](#) provides one such example.

The auDA Foundation was established “to promote and encourage educational and research activities that will enhance the utility of the Internet for the benefit of the Australian community”. Their online Knowledge Centre contains case studies highlighting the outcomes of projects funded by the Foundation and organised according to a number of key themes including “regional and remote” “health” and “migrants”. There is no reason this model, modified accordingly, could not form the basis of a knowledge centre designed to share the knowledge generated by asbestos support and services projects, including awareness raising and education projects.

An Australia-wide evidence base, one that maps the provision of asbestos services and support and makes visible the social impact of this work would represent a valuable resource for Australia’s community-based

asbestos support organisations, for other organisations and for the many communities affected by asbestos-related disease. It would also help inform those policy makers, within Australia but also internationally, seeking to develop the policies and programs needed to meet the ongoing challenge of asbestos in the home, in the workplace and in the community.