The Australian Asbestos Network - how journalism can address a public health disaster

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Abstract

Asbestos is responsible for an ongoing epidemic of asbestos-related diseases (ARDs). While banned in many Western countries asbestos is still being exported to new target markets in the developing world. Asbestos is therefore not an issue of yesterday –in Australia the epidemic of asbestos-related disease through past exposure is not due to peak until at least 2020. However public awareness of the risks from exposure is low. Often companies and governments have been less than forthcoming with information about risks and how to avoid them.

This paper describes a unique collaboration involving journalists, doctors and public health researchers which aims to improve access to public health information about asbestos.   The outcome is a website serving first, as an historical archive of asbestos stories through interviews with asbestos sufferers and their families; second, as a one-stop-shop for public health information about asbestos risk where journalism skills are employed to translate often complex information into accessible language and formats; and third, as an online community where patients and doctors can interact and experiment with more collaborative models of medical and public health interventions. The project demonstrates how journalistic activity can be the subject of legitimate academic research.

Keywords: asbestos; journalism; public health; narrative medicine; online communities

Asbestos presents an ongoing health disaster worldwide. First through mining and manufacturing, and now through workplaces and the home, exposure to asbestos is presenting a public health hazard that will continue well into the 21st century. Yet it is a hidden epidemic with litigation often silencing the voices that could attest to the destructive impact of what was once known as the 'magic mineral'. This paper describes a unique collaboration between journalists, historians, clinicians and public health researchers where journalistic techniques are being used to bring the peoples' stories of suffering and caring to public attention. The process of storytelling where journalism merges with narrative medicine is an empowering event in itself, but the aim is also to increase public awareness of asbestos risks in order to achieve genuine public health outcomes.

The media have always been seen as essential to the dissemination of public health information, but the relationship between the health providers and media practitioners has not always been a happy one. The mass media and public health institutions have conflicting priorities (Atkin & Wallack, 1990, p.16). This has

led to growing frustration with the way mass media covers health issues driven by entertainment or news agendas which often distort the message (Seale, 2002, p.6). There has also been a disciplinary gulf between the media producers and the medical and public health experts – Seale (2004, p.52) refers to the 'two cultures' which creates 'tensions between the worlds of scientists and journalists'. The journalists understand the medium, the clinicians understand the message, but opportunities for collaborating in the interdisciplinary middle ground are rare.

The tensions are even more acute in the new media context. The internet has opened up opportunities which move away from the idea of 'health messages as "hypodermic needle" injections of information into a largely passive audience...to alternative conceptions that imagine a much more active audience role, represented by edutainment, social marketing and media advocacy.' (Seale, 2002, p.7) The audience is no longer a silent passive absence but a vocal, interactive presence, an 'imagined community' (Hine, 2001, p.192) which will be attracted to and constructed around the health topic. Now more than ever health practitioners and media producers need to share an understanding of the potential benefits of internet use, in the case of the former when determining a health intervention, and in the latter when translating this into an appropriate format for dissemination.

Even in the context of old media little attention has been paid to the study of media production in the area of media health studies (Seale, 2004, p.13). This is no less true of the new media represented by the internet. While there has been a lot of focus on the uses and benefits of online health sites (see for example Atkin & Wallack, 1990; Burrows et al., 2000), there has been less attention paid to the mechanics of production and the journalistic thought processes that go into the selection and creation of online health-related content. Burrows et al. (2000) in their review of research and initiatives in the area of 'virtual community care' conclude from reviewing numerous studies that 'there exists a strong and unambiguous relationship between social support and both physical and mental health and well-being' (op. cit., p.99). These virtual networks not only provide peer support but also challenge the 'conception of welfare based upon rationally administered state provision coupled with paternalistic professionally determined needs and bureaucratic organizational delivery systems' (op. cit., p.105).   They can become a site for experimenting with more collaborative models of healthcare delivery and policy development. However as yet this is an under-researched area which currently lacks 'robust evidence on the health benefits of virtual communities and peer to peer online support.' (Eysenbach et al., 2004, p.3)

The Australian Asbestos Network project provided the opportunity to focus and reflect on specific journalistic challenges encountered during the process of compiling a health-related website dealing with a particularly traumatic topic. The analysis reveals how at every step of the way wide-ranging journalism skills are crucial in achieving the main outcomes.

Background: Asbestos Stories Project

The researchers were Chief Investigators (CIs) on an Australian National Health and Medical Research Council (NHMRC) funded project called 'Community consequences of asbestos exposure in Western Australia'. The multi-disciplinary project ran from 2007 to 2009 comprising researchers in public health, epidemiology, medicine, history and journalism from three universities in Western Australia. The journalism component of this asbestos research project was to develop a website called Asbestos Stories featuring audio interviews with people affected by asbestos. A further tranche of funding from 2010-2012 is allowing the researchers to experiment with the community-building capacity of the website which will be launched in November 2010 as the Australian Asbestos Network with Asbestos Stories as one component. The multi-disciplinary collaboration has given journalists access to authoritative historical, medical and public health resources, while experts in those fields have been able to access journalistic expertise to experiment with new and original ways of engaging with a wider public.

Asbestos fence, Western Australia

Australia is especially affected by the legacy of asbestos because of its mining and manufacturing of blue and white asbestos. While the use of asbestos was banned in Australia on 31 December 2003 (Workers Health Centre, 2004) the material is still pervasive in both domestic and work life. The country has the

highest rate of the fatal cancer of the lining of the lungs or abdomen called mesothelioma (Robinson et al., 2005).   Many assume that 'the asbestos problem' has been fixed by legislation and modern handling practices. It is also assumed to be a work-related issue, ignoring the fact that asbestos exposure remains an everyday fact of life for many Australians. With many of the buildings constructed in the post-war asbestos building boom now coming to the end of their lifespan, the issue of exposure through renovation and demolition is a real and present threat. Such current and potential casualties extend far beyond the workplace and future projections of asbestos-related diseases stretch well into the twenty-first century (see for example Leigh et al., 2002). There is therefore some urgency in creating public awareness both by capturing the stories of those affected by asbestos-related diseases (ARDs) and the historical data they reveal before it is too late, as well as by extending public awareness of the asbestos hazards and how to avoid them. The web is a perfect vehicle for providing and sharing this information.

Public awareness can be enhanced in a number of ways:

- Personal stories, which engage listeners and readers in an immediate and emotional way, can provide a more telling warning than impersonal health messages.
- Medical information can be made available in accessible and easy-to-understand ways.
- Public health messages offering practical advice for handling health hazards can be disseminated.
- Most importantly, human networks can be created to put people in touch with each other and to provide a vehicle for their stories to be told.

The web provides an arsenal of creative opportunities in all four areas. By developing a site that exploits the information delivery and networking powers of this multiple media resource it can become a powerful communication tool for the whole community.

Journalism is still evolving as an academic discipline and an important task for journalism academics is to reveal and articulate the theory behind the practice.   While the interviewing skills of journalists are acknowledged by other disciplines to be useful, especially for research projects focusing on recorded interviews, the potential contribution of journalists in multi-disciplinary projects extends way beyond interviewing alone. The Australian Asbestos Network project is an example of how journalism can enhance more traditional academic research, a fact acknowledged by the ongoing investment of the NHMRC in this medico-media collaboration.

Telling the asbestos story

From an editorial perspective the asbestos story is a particularly complex one for a number of reasons. Although the media have reported on asbestos issues for many years, often the voices of asbestos

sufferers are missing because of confidentiality clauses in compensation settlements. As a result many stories of suffering have not been shared with the community.

Asbestos is also a topic that many people don't want to hear about. There is a real sense of denial around asbestos in Australia resulting from the very pervasiveness of the material in the community. In the US an estimated 3000 building materials have been found to incorporate asbestos (ROC, 2005). The legacy in Australia is visible in the suburbs with their fibro homes and asbestos fences. The challenges of 'fixing' the asbestos problem are overwhelming: Should the houses and fences be torn down? Who should pay? Can local authorities quarantine the public from exposure to deadly fibres during the removal process, and if so, how?

This project aims to give the people affected by asbestos the chance to tell their so far untold stories. The benefits are twofold: at the community level this will help to raise awareness of the dangers of the material. At the personal level it will empower people by validating their often traumatic life experiences. The web will be the vehicle for bringing together a community of interest where people can help each other and share their experiences.

The asbestos story is multi-faceted. First it comprises an historical account – encompassing not just the factual information about where, when and how asbestos was mined and manufactured and used in the community, but also the personal accounts of the miners, manufacturing workers, tradespeople, home renovators and their families who came into contact with the 'magic mineral'. The long drawn-out medical struggle for official recognition of asbestos-related diseases and the equally long and painful battles for compensation are also part of the historical narrative. Because many of these stories are unavoidably about sickness and death they are not easy ones for the interviewee to tell nor for the journalist to hear. Here the journalist is in the role of recorder.

Second, the asbestos story involves the current medical and public health aspects of asbestos-related diseases. The medical information encompasses causes, diagnosis, and treatment of ARDs and the ongoing research which is trying, so far with only minimal success, to find a cure for the inevitably fatal asbestos-related cancer, mesothelioma. The public health information focuses on disease prevention. With the instances of mesothelioma not due to peak in Australia until 2020 (Leigh et al., 2002) this part of the site describes modern-day risks from asbestos along with access to protocols and practices aimed at reducing exposure and minimising present and future harm. Here the journalist is in the role of translator.

Third, the asbestos story involves a community. Brought into being through the website on which the patients, their family members, the clinicians and the public health practitioners collaborate, this new social network has the potential to generate its own momentum and to spin off into possibly unforeseen directions. Here the journalist is in the role of facilitator.

Journalist as recorder

Ted Grant and Margaret Page, two Asbestos Storytellers

In this phase of the Asbestos Stories website project the journalists worked with members of the public to show the human face of the asbestos tragedy by collecting the individual stories that all those touched by asbestos have to tell. The storytellers included the workers and their families, as well as the doctors, lawyers and lobby groups who had been on the frontline trying to stem the tide of death, prevent future illness, or ensure appropriate compensation for the victims. The stories were told in a variety of ways: through oral and filmed interviews, radio documentary features, pictorial narratives, and archival material. The historian provided the factual background and context in which to situate the various narrative threads. Finding people who are willing to talk about their life when suffering from terminal illness can be challenging for journalists. Many of the interviewees for this study were referred through a chest physician (a fellow Chief Investigator on the asbestos project) and an asbestos litigation lawyer. Both contacts asked their patients/clients if they wanted to be interviewed for the website. Making contact through the interviewee's doctor or lawyer was helpful as it gave the journalists greater credibility and helped to establish trust more quickly than is usually the case in the process of persuading people to agree to an interview (Adams, 2001, p.17).

Constructing a personal narrative can help people make sense of their experiences, especially experiences that are difficult and traumatic to deal with. Baumeister & Newman (1994, p.688) argue that 'constructing a narrative account may be a vital first step toward understanding an event', with stories of trauma providing a means of 'cognitive coping' (op. cit., p. 682). The value of personal narratives is being increasingly

explored in the area of clinical practice. The discipline of narrative medicine (Kleinman, 1988; Charon, 2006) has grown up around the search for a form of healthcare 'that recognizes suffering, provides comfort, and honors the stories of illness.'(Charon, 2006, p. ix)

This has involved training medical practitioners, social workers and other health professionals in the art of evoking, listening to and empathising with the narratives of their patients.   Charon (2004, p.32) acknowledges that this approach is demanding:

> ...practitioners, be they health professionals to begin with or not, must be
>
> prepared to offer them self as a therapeutic instrument.

For patients this can be an important tool for assisting them to convey what they are going through in an illness: '...without these narrative acts, the patient cannot himself or herself grasp what the events of illness mean.' (Charon, 2006, p. 66) Thomas Newman, professor in epidemiology and biostatistics, while stating he is more comfortable with numbers than stories, argues for the benefits of storytelling as 'a way to extract some meaning and redemption from tragedy, by preventing its reoccurrence' (Newman, 2003, p.1426).

The therapeutic aspect of telling a personal story can be translated into journalism practice. Bell & van Leeuwen (1994), in their analysis of the confessional interview style represented by Australian veteran journalist Caroline Jones, describe this type of interview as belonging to the 'revelatory genre'. Jones's revelatory interviews are explained as vehicles for self discovery where the interviewees get the opportunity to review their own life in a search for meaning (Bell & van Leeuwen, 1994, p. 92). Klempner (2000, p. 70) argues that trauma narratives can be a way of finding closure. As such sharing a traumatic experience during an interview can give the interviewee a sense of completion where the event or the experience can be left behind. This is especially poignant for asbestos victims as for many there has been no single traumatic event as such. Instead the trauma is ongoing as they cope in their daily lives with the ever present threat of diseases which may kill them decades later.

Interviewing traumatised people presents a particular challenge for journalists as it requires different techniques from those of daily news reporting. Informed by recommendations from the DART Center journalism trauma network, the journalists involved in this study used what Kawamoto (2005, p. 9) calls an 'extended personal narrative' technique when collecting the personal stories of trauma resulting from asbestos exposure. This required that journalists develop a relationship of trust with the interviewees so they felt confident to share their very private and personal experiences. Where usually journalists might have a brief encounter with a traumatised person when collecting his or her story before moving on to the next news story of the day, here the researchers established relationships with the interviewees that stretched over a long period of time. They actually had to enter the worlds of the interviewees (ibid). As

pointed out by Kvale (1996, p. 36) this type of personal long-form interview where an attentive and sympathetic listener focuses specifically on the interviewee's life, can be such positive experience for the interviewee that he or she wants to continue the conversation long after the interview event has passed. Indeed contact with the interviewees of this project has been maintained over a long period of time. In one case the relationship continued after the death of the interviewee where the journalists attended the funeral and met the family of the asbestos victim. This ongoing relationship can be beneficial for both parties but challenging from a professional perspective for a journalist-researcher who might do 20 such interviews.

There are also serious ethical issues which journalists have to address in dealing with victims of trauma. As Charon (2006, p. 233) states,

> Whoever listens, from the relative refuge of health, to the ill or traumatized speaker holds a profound responsibility not to exploit, not to expropriate, not to use the other for one's own ends.

The journalist cannot ignore the fact that an interview is a moral endeavour and being interviewed affects the interviewee (Kvale, 1996, p. 109). In this project journalists had to observe not just the journalistic codes focusing on minimising harm but also the revised Australian National Statement on Ethical Conduct in Human Research (National Health & Medical Research Council, 2007) and the stipulation by Murdoch University's Human Research Ethics Committee that adequate psychological support be offered to interviewees who might become upset as a result of talking about how asbestos has impacted on their lives. There is another aspect of interviewing victims of trauma which cannot be overlooked: the impact on the journalist of *listening* to traumatic stories. In the discipline of oral history the social encounter and its impact on both parties of the interview is continuously explored: Thompson (2000, p.238) reminds us that during an interview we enter into the lives of others in an attempt to understand their values. Oral historians tend to take the question of social mixing much more seriously (Feldstein, 2004, p.18) whereas there is still a culture of detachment amongst journalists. Or as Feldstein (2004, p.19) suggests, journalists are less reflective about their practice. The journalists in this project found access to a counsellor as important for themselves as for the interviewees to help them deal with the stress of interviewing distressed and dying people. It was also helpful to bear in mind the potential benefits for the individual of telling his or her story. Dworznik (2006, p. 540) refers to a study where American television journalists use the 'motive of goal attainment' as a coping strategy. By setting the goal as 'telling a good story about a victim' it helped them deal with their own emotions;   for the journalists '...the experience was not remembered as traumatic, but was instead remembered as an opportunity to offer a grieving family a chance to feel better.' (ibid) And for the trauma victim in addition to the personal benefits already described there is an additional sense that their sacrifice will be of public benefit.

Journalist as translator

An important function of the Asbestos Network is to serve as an information hub, a site by means of which medical and public health experts can expand community awareness of asbestos risks and how to avoid them.

While the web can be a boon for information dissemination it can also compromise health education by circulating misleading or erroneous information. The sort of criteria to use to assess the quality of online health information has been an ongoing topic of discussion. Eysenbach et al. (2002) provide a comprehensive review of methods being used (see also Kim et al., 1999; Kunst et al, 2002; Purcell et al., 2002; Robinson et al., 1998). According to Dutta-Bergman (2004) 'completeness and credibility' are the two critical criteria for the health information consumer (see also Hu & Sundar, 2010). In 2002 the EU established a set of criteria (Commission of the European Communities 2002) and this has been translated into a code of conduct by the Health on the Net Foundation. The principles articulate key standards for the provision of health information online such as authoritativeness, accuracy, authenticity, issues of confidentiality and independence and conflict of interest (Health on the Net, n.d.)[i].

The eight principles of this code have informed the approach to content development on the Asbestos Network website. The research collaboration made available to the journalists a group of leaders in the field of ARD research and public health. Through the journalists the health professionals would be able to add the web as a customised resource to suit their public education purposes. A key feature of the site was therefore the authoritativeness of its information and its independence from commercial influences (HoN Principles 1,2,4,5,6,7,8).

The journalistic challenges were many. It was not just reworking often difficult information for a general audience – on the web this also requires making decisions about language, format, multimedia enhancements, links, etc. The integration of these materials into a coherent and integrated online format involves complex judgements about audience usage (Potter, 1998; Wicks, 2001); the appropriate media for different information (Cover, 2004; Deuze, 2003; Gregory, 2004), and methods for achieving greatest effectiveness in the communication of complex health messages (Atkin & Wallack, 1990; Byde, 1995; Fishbein & Capella, 2006; Hillier, 2006).

And it must be remembered that the site was intended to be more than a simple transmission of information to passive recipients – the aim was to welcome the audience, to invite their involvement, and to work towards a collaborative partnership with the health practitioners that could open the way to new forms of research facilitated by the web network. It required moving away from the idea of a purely biomedical outcome to one that empowers the recipients (Dixon-Woods, 2001, p.1417. See also Burrows et al., 2000; McMurray, 2007).

The journalists in the role of translator therefore serve two masters. As Benkler (2006, p.170) notes, 'filtration only enhances the autonomy of users if the editor's notions of relevance and quality resemble those of the sender and the recipient.' To the doctors, health professionals and historians the journalists bear the responsibility of maintaining the authoritativeness, accuracy and credibility of the information they adapted for the web. This inevitably involves an editing process and the professionals are vetting all material before it is published online. But the journalists are also serving their designated audience and have to be no less cognizant of their needs. The vetting process must extend to them as well and feedback will be elicited from all lay contributors prior to the site going live, and will be maintained as a feature of the site subsequently.

Journalist as facilitator

Sharing traumatic stories has potential benefits beyond the individuals who talk about their personal experiences. In a review of award-winning articles for the DART Center, a journalism network with focus on journalism and trauma reporting, Kawamoto (2005) outlined best practices in trauma reporting. One aspect of reporting trauma in a sensitive, ethical and thoughtful way, according to Kawamoto (2005, p.10), is the impact of such stories on the community. He argues that by sharing stories of trauma the '...personal tragedy of strangers becomes a communal concern.' This can lead to real change within society:

> A connected community of empathetic people is more likely to want to change something, such as legislation, demand accountability and speak out against personal and social justice. (Kawamoto, 2005, p. 9)

Charon (2006, p.230), talking in the context of clinical medicine, also notes the community benefits to be derived from story sharing:

> ...narratively obtained knowledge of the other, especially the other who has suffered pain or trauma, can serve to improve health in the widest, most global frame by harnessing narrative as a force for freedom.

In this way personal illness narratives gain what Morris (2002) describes as a 'biocultural' dimension. The act of individual empowerment through storytelling can extend to empowerment of the community as a whole, as McMurray (2007, p.16) describes:

> The concept of empowerment is based on the premise that if people are prepared for events or circumstances with both information and community support systems, they can become empowered and chart their own course of action.

The journalists in the role of facilitator are the bridge between the medical professionals and the general public. They are responsible for activating the online community – for creating a site so compelling that it will attract and retain a targeted group of users. The web is perfect for this sort of niche market: '...attention in the networked environment is more dependent on being interesting to an engaged group of people than it is in the mass-media environment, where moderate interest to large numbers of weakly engaged viewers is preferable.' (Benkler, 2006, p.13)

However the asbestos website is also being constructed to have wider appeal as a go-to resource on asbestos. While its uniqueness lies in its role as a repository for Australian research and information, as Benkler (2006, p.19) notes 'The actual practice of freedom that we see emerging from the networked environment allows people to reach across national or social boundaries, across space and political division. It allows people to solve problems together in new associations that are outside the boundaries of formal, legal-political association.' There is worldwide concern about asbestos and the site will be able to contribute to both national and international communities of interest.

When the site goes live it will provide the opportunity for 'peer production of information, knowledge, and culture' (Benkler, 2006, p.5) in an open sharing environment. In this context the journalists will occupy the role of moderator to maintain the integrity of the site and ensure ongoing compliance with the HON code.

Conclusion

The Australian Asbestos Network has provided the opportunity for a special collaboration between the widely different discipline areas of medicine, public health, history, and journalism and communication. As such the project illustrates the value of interdisciplinary collaboration as well as demonstrating how journalistic activity can be the subject of legitimate academic research. It has foregrounded the role of journalists in medical communication and has thereby provided a case study for much reflection and analysis. This paper has explored some of the journalistic challenges that have been faced in assembling the website during the pre-launch phase. These have covered not just production issues but also research issues around storytelling and trauma, effective web information delivery techniques, and community building. Once the site is launched the collaborative model will be extended to involve the targeted audience. The research focus will shift to the dynamics of the online interactions in order to tailor the website's functions and information to the community's explicit and specific needs.
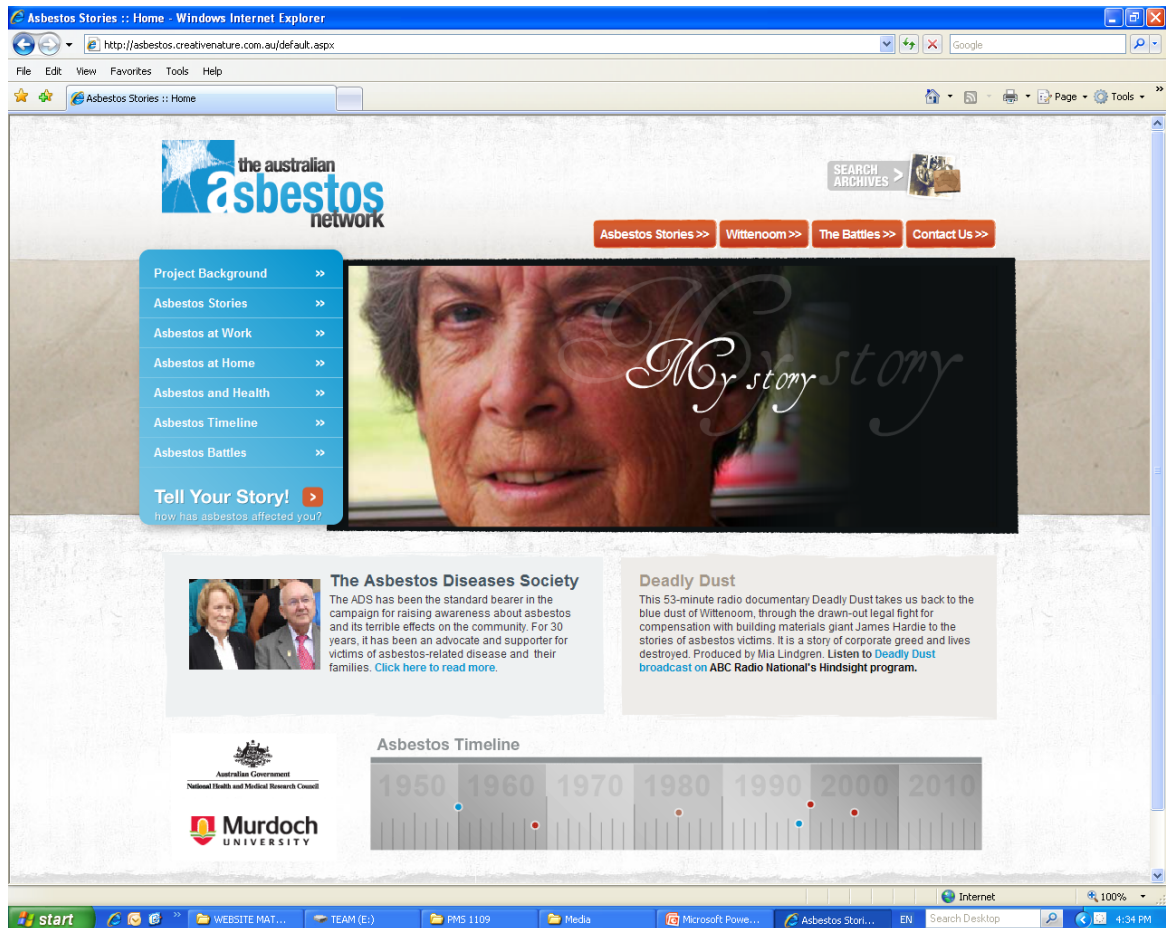
Australian Asbestos Network website under development

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[i] **Heath on the Net HONcode Principles**

Principle 1 - Information must be authoritative. This includes attributions for all information, qualifications of authors, qualification of web information providers, whether platform is moderated and credentials of moderator, standards of acceptable behaviour.

Principle 2 - Purpose of the website. Clear articulation of mission, purpose and function of the site making clear information is not meant to replace the relationship between a patient and physician.

Principle 3 – Confidentiality. Clear articulation of privacy policy and how information will be treated.

Principle 4 - Information must be documented: Referenced and dated. This includes details of all sources and when information was last modified.

Principle 5 - Justification of claims. All information must be truthful and claims relating to benefits of treatments, products or services have to be backed up with scientific evidence (medical journals, reports or others). All medical information must be balanced.

Principle 6 - Website contact details

Principle 7 - Disclosure of funding sources

Principle 8 - Advertising policy. How the site distinguishes between editorial and advertising content and which advertisements are accepted. Any conflict of interest has to be explained.