Informed consent project

Literature review and guidelines for community-based arts projects

Reducing race-based discrimination and promoting diversity

Cultural Development Network

VicHealth

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Prepared for VicHealth by Cultural Development Network

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Section 1

Introduction

VicHealth recently established the *Promoting Diversity through the Arts* program in recognition that the arts have a long history of supporting diversity, contributing to intercultural understanding and exploring and dealing with issues resulting from discrimination (VicHealth 2009). In their funding guidelines for the program, VicHealth cites community surveys which demonstrate that people from Indigenous, migrant and refugee backgrounds continue to report unacceptably high rates of discrimination and that despite support for cultural diversity in Victoria, intolerant and discriminatory beliefs persist (VicHealth 2009).

Media, arts and popular culture in Victoria do not adequately reflect and represent the cultural diversity of the community, and the *Promoting Diversity through the Arts* program provides an opportunity to address this through its target communities and audiences. However, given these processes may involve disadvantaged groups who have historically been misappropriated, misrepresented or exploited, for example by the media – including young people or people from Indigenous or refugee backgrounds – and potentially sensitive or personal issues and stories, this presents a range of challenges and ethical concerns.

The brief

According to brief consultations carried out by VicHealth, there are no formal guidelines or protocols to guide practice for artists working in communities. Based on the concerns outlined above, around giving appropriate consideration to ethical issues when working in communities, VicHealth contracted the Cultural Development Network to carry out a short research project on the development of guidelines for obtaining consent for use of personal stories and images in the public domain. The project involved the preparation of a report, including a review of literature and guidelines around obtaining consent, and a presentation to funding recipients of the *Promoting Diversity through the Arts* program.

The aim of this project is not to formulate a prescriptive set of guidelines for how practice should take place in communities. Rather, it has drawn on the experience and expertise of professionals in the sector to develop principles and considerations that bring together underlying ethics, issues and practical considerations around obtaining informed consent.

The area of informed consent in the community cultural development context emerged from this research as important and complex. Most people interviewed saw it as something that ideally needed to be based in the ethical foundation of a project, but also something that could create significant issues – damaging relationships; unnecessarily taxing scarce resources – if not sufficiently addressed through all stages of a project. This report captures some of that complexity, as well as providing pragmatic suggestions for giving due consideration to the importance of obtaining meaningful informed consent from communities and individual participants amid the resource pressure and shifting ground that is so often part of doing creative work in communities.

Methodology

The project was deliberately small and limited in scope to enable timely review and implementation. The methodology had two key parts: a desktop literature review, including creation of a short annotated bibliography; and stakeholder interviews.

Section 2

Literature review

There is a range of literature or material on informed consent across different areas of relevance (health and medical research and clinical trials, social research, arts). This project looked at some literature from areas other than arts – for example, health and social research. Informed consent has been considered in these fields for a long time, and specific definitions of and processes for achieving consent, as well as underpinning values, are articulated in this material. However, the literature review undertaken for this project confirmed VicHealth's belief that there is very little material available relating specifically to community-based arts practice. This brief only allowed for a desktop literature review to be conducted; however, it is the researchers' belief that a more extensive search would confirm this. Some valuable documents are available (for example, 'Copyright, Moral Rights and Community Cultural Development,' Australia Council 2003), and are utilised by stakeholders interviewed for the project, but there is a gap in terms of detailed study of the issues around obtaining consent in the context of Community Cultural Development (CCD).

Documents were sourced from a range of areas including professional arts practice, Indigenous organisations, academic research and health. There are a significant number of protocols available for working with Indigenous communities – for example, in various artforms and in research – which give good focus to protocols of consent and consultation.

Annotated bibliography

Arts Access Victoria, Obtaining consent from participants in artistic and craft-based community workshops – a model of best practice
http://artsaccess.com.au/accessing-the-arts/raw-law/consent-forms/ *accessed 15 February 2010*

> This document is a model of best practice for obtaining consent from people with disabilities participating in creative workshop programs. It aims to address issues regarding the protection of people's rights relating to intellectual property, and the usage of their image or the art that they produce in workshop settings. It also emphasises that consent forms produced by workshop facilitators need to be made truly 'accessible and understandable to all participants, no matter what the disability'. It suggests having various versions of the consent form document, introducing it to participants in a way that suits their needs, and allowing sufficient time for the process. It goes on to suggest reviewing consent in ongoing projects, notifying guardians of intended public outcomes well in advance, and other guidelines for ethics practice, such as protecting the identity of participants who produce sensitive or personal material.

Arts Law Centre of Australia (2008), Children in the Creative Process: Information for artists and arts organisations – Australia
www.artslaw.com.au/info-sheets/info-sheet/children-in-the-creative-process-act *accessed 15 February 2010*

Arts Victoria/VicHealth (in press), Making Art with Communities: A Work Guide
Developed by Arts Victoria with assistance from VicHealth (final edit)

> This work, currently in press, is being produced by Arts Victoria and VicHealth to provide comprehensive advice on setting up arts projects with communities. Compiled from a series of worksheets, it also provides snapshots of the history of the sector and contemporary practice. Topics range from a brief history of the field, the value of community-based art, principles of working with communities and artists, developing a

community arts project, and managing the project, budget, people and resources through to completion. A range of experienced practitioners have contributed to this collaboratively and consultatively produced document. The chapter 'Working with Communities' includes a discussion of copyright, intellectual property and moral rights. This chapter suggests having a code of conduct by which to work and outlines ethical considerations when working with participants, such as 'respect, honesty, good manners and confidentiality'.

Australia Council for the Arts Community Cultural Development Board (2003), Copyright, Moral Rights and Community Cultural Development www.australiacouncil.gov.au/__data/assets/pdf_file/0011/33977/Copyright_Moral_Rights_and_Community_Cultural_Development.pdf *accessed 10 February 2010*

> This document was produced in 2003 by the now-disbanded Community Cultural Development Board of the Australia Council. It aims to assist CCD practitioners in planning around agreements, copyright, moral rights, intellectual property and so on. Because this document specifically targets the CCD sector, it is more focused in its application than the broader artform documents. Issues of consent clearly cross over with those of moral rights and copyright, but are in a different territory. However, all involve a process of explanation, understanding and communication that varies according to the conditions of each project, i.e. the participants and the medium. It suggests holding a workshop at the start of a project to discuss issues of copyright and getting new agreements for subsequent manifestations of work.

Australia Council for the Arts (2007), Protocols for producing Indigenous Australian media arts www.australiacouncil.gov.au/__data/assets/pdf_file/0003/32358/Media_arts_protocol_guide.pdf *accessed 10 February 2010*

> This is one of several artform-specific protocol guides produced by the Australia Council. It explains how media arts present specific issues for Indigenous cultural production, but that it is a form that is being increasingly used by Indigenous artists. It asks questions like 'can a particular item of Indigenous cultural production be adapted or altered?' and mentions how important it is to 'acknowledge the complexity of Indigenous culture when negotiating the use of Indigenous heritage for a media art project'. It emphasises the importance of Indigenous people being in control of their cultural expression, especially given a legal framework that does not protect or promote their rights to own and control representation and dissemination of their cultural expression (p.7). There is much discussion about obtaining free and informed consent from traditional owners before using traditional cultural expressions, and a useful section on consent. It emphasises four points:
>
> - allow time for the communication of a proposal and for a decision to be made, maybe more than one meeting;
>
> - remember that other internal factors will influence the decision, not just knowledge brought in from outside;
>
> - be prepared to take 'no' for an answer: different kinds of knowledge operating in Indigenous communities may conflict with the requirements of a project;
>
> - respect the views of all factions within a community and make sure consent comes from the appropriate quarter for a particular aspect of a project.
>
> This section emphasises the importance of communication in gaining consent, and that this is an important first step. Also that a project should not be fully formed or designed until this process of communication and gaining consent is taking place (p.14). A later

section raises the point that no matter whether material produced is sensitive or not, in the context of Indigenous people reasserting/claiming control over cultural heritage material, it is the right of the person contributing it to have control over its interpretation in an ongoing sense. This is reinforced as important in the context of groups who have had, in the past (or current) media, little control over how their material is represented or interpreted. There is discussion of the *Copyright Act*, and its increased legal complexity when it is not necessarily one individual artist's rights, such as the Indigenous context and some CCD contexts.

In discussions of 'authenticity,' this document highlights examples where some Indigenous languages, words or phrases should only be used where their proper meaning is known and where they are used in the proper context. Therefore as well as getting copyright to use material in a variety of forms it is also necessary to get permission and to make sure it is the appropriate context – therefore the process of consent may be ongoing. It further states that adapting, editing or altering materials may not be suitable for some Indigenous material, and specific permission should be sought form the appropriate individual/traditional owner group.

The last section has summaries, including a summary of the requirements for gaining full informed consent. It reinforces the points made above, such as being prepared to take no for an answer, allowing time for communication and negotiation, finding out who the relevant people to speak with are, considering the potential impact of the work on the individuals and/or communities involved, and the nature of the material. The point is made that it should not be taken for granted that the structure of a project that might look good from the outside will suit community members. This is why meaningful consultation is important in this context, before or in order to obtain consent.

Australia Council for the Arts (2007), Protocols for producing Indigenous Australian visual arts
www.australiacouncil.gov.au/__data/assets/pdf_file/0004/32368/Visual_arts_protocol_guide.pdf *accessed 10 February 2010*
(Only new media protocols were summarised for the purposes of this bibliography)

Australia Council for the Arts (2008), Protocols for producing Indigenous Australian music
www.australiacouncil.gov.au/__data/assets/pdf_file/0003/32367/Music_protocol_guide.pdf *accessed 10 February 2010*
(Only new media protocols were summarised for the purposes of this bibliography)

Australia Council for the Arts (2008), Protocols for producing Indigenous Australian performing arts
www.australiacouncil.gov.au/__data/assets/pdf_file/0016/32353/Performing_arts_protocol_guide.pdf *accessed 10 February 2010*
(Only new media protocols were summarised for the purposes of this bibliography)

Australia Council for the Arts (2008), Protocols for producing Indigenous Australian writing
www.australiacouncil.gov.au/__data/assets/pdf_file/0018/32373/Writing_protocol_guide.pdf *accessed 26 February 2010*
(Only new media protocols were summarised for the purposes of this bibliography)

Australia Council for the Arts (2008), Protocols for working with children in art
www.australiacouncil.gov.au/about_us/strategies_2/children_in_art *accessed 26 February 2010*

This document is a set of protocols around the depiction of children in works, exhibitions and publications that have received government funding. The aim is to outline the legal and ethical obligations around the safety of children amid great changes in media and technology that have greatly increased access to written and visual material. Obligations

are spelt out for artists working with anyone under the age of 18, as are protocols around applying for funding, nudity, exhibition, distribution, written depictions and online media. As well as abiding by state and federal laws, the Australia Council requires that artists or arts organisations obtain consent from parents or guardians of all children under the age of 15. The artist must also explain aspects of the work such as full or partial nudity.

Australian Copyright Council (2006), Indigenous Artists Information Sheet
www.copyright.org.au/publications/infosheets.htm *accessed 15 February 2010*

Australian Copyright Council (2006), Moral Rights Information Sheet
www.copyright.org.au/publications/infosheets.htm *accessed 15 February 2010*

Australian Copyright Council (2009), Creative Commons Licences Information Sheet
www.copyright.org.au/publications/infosheets.htm *accessed 15 February 2010*

Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS), Guidelines for Ethical Research in Indigenous Studies (2000)
www.aiatsis.gov.au/research/ethical.html *accessed 15 February 2010*

> The AIATSIS Guidelines for Ethical Research in Indigenous Studies emphasise the importance of Indigenous people being participants in any research involving them, and that they share an understanding of the aims and methods of the work, and the results. The principles of the guidelines are founded on a respect for the inherent right to self-determination of Indigenous people, and that the guidelines are not only guidelines for ethical research practice, but are human rights. The first principle of ethical research is that 'consultation, negotiation and free and informed consent are the foundations for research with or about Indigenous peoples. Further, responsibility for this consultation is ongoing'. A range of principles are outlined for obtaining consent, including: identifying the appropriate individuals and communities with whom to consult; allowing the topic to be indentified from within the community; observing appropriate behavioural norms and protocols; and communicating by appropriate means. Clear principles are spelt out for ensuring consultation is transparent and ongoing and that the benefits to the communities are clear and results are shared.

Australian National Health and Medical Research Council and the Australian Vice-Chancellors' Committee (2007), National Statement on Ethical Conduct in Human Research (updated 2009)
www.nhmrc.gov.au/_files_nhmrc/file/publications/synopses/e72-jul09.pdf *accessed 15 March 2010*

> The National Statement is intended for use by researchers conducting research with human participants, any member of an ethical review body reviewing that research, those involved in research governance, and potential research participants. It is in five sections, and section two looks at consent in the research context. Principles and guidelines provide instructions to researchers as well as criteria according to which ethics committees can review research. The discussion on ethics covers how it might be waived or withdrawn, but states that it is a key theme of all human research. Chapter 4.7 (Aboriginal and Torres Strait Islander Peoples) outlines the six core values identified by the NHMRC as being of importance to Aboriginal and Torres Strait Islander peoples: reciprocity; respect; equality; responsibility; survival and protection; and spirit and integrity.

Hurley, A. (2003), Respect, Acknowledge, Listen – Practical protocols for working with the Indigenous Community of Western Sydney. Community Cultural Development NSW
www.wipo.int/export/sites/www/tk/en/folklore/creative_heritage/docs/ccdnsw_indig_westsydney.pdf *accessed 15 February 2010*

Janke, T. (1998), Our Culture: Our Future – Report on Australian Indigenous Cultural and Intellectual Property Rights, http://frankellawyers.com.au/media/report/culture.pdf *accessed 15 March 2010*

Janke, T. (2009), Pathways and Protocols: A filmmaker's guide to working with Indigenous people, culture and concepts (2009), Screen Australia www.screenaustralia.gov.au/filming_in_australia/Indigenous_protocols.asp *accessed 10 February 2010*

> Produced in May 2009, this is an essential guide for filmmakers working with Indigenous content and communities. It includes advice on legal and ethical issues, implementing protocols, copyright law, and information for Indigenous communities on their rights. Chapter 4 (Communication, Consultation and Consent) explains how consultation and consent are interrelated: consultation is defined as 'a two-way process of exchange and sharing knowledge and opinions resulting in understanding', while consent is 'a process whereby permission is given, based on a relationship of trust' (p.51). Consent needs to involve a transparent process from all parties, using clear explanations and interpreters if necessary. The chapter outlines where consent is legally required (eg, filming in certain locations, filming Indigenous people, filming at Indigenous festivals) and where it is recommended (eg, a documentary about a living group, a drama about an identifiable person or group, a drama depicting real-life events). It outlines issues that need to be canvassed in obtaining consent (eg, what are the benefits for participants?) and emphasises transparency and giving enough information so that everyone clearly understands what is being asked and what will occur.

National Association for the Visual Arts (NAVA) (2001), Valuing Art, Respecting Culture, D. Mellor, ed. www.visualarts.net.au/advicecentre/valuing-art-respecting-culture *accessed 15 March 2010*

National Association for the Visual Arts (NAVA) (2004), NAVA Code of Practice for the Australian Visual Arts and Crafts Sector (2nd Edition) www.visualarts.net.au/advicecentre/codepracticeprofessionalaustralianvisualartscraftanddesignsector a*ccessed 10 February 2010*

> Produced as a national best-practice standard, this document provides a set of practical and ethical guidelines for the conduct of business across the visual arts and crafts sector. It states that the principles outlined are voluntary, not mandatory, and that they aim 'not merely to describe how things are done, but how they should be done' (p.10).

> The code was necessary because of the perception that those working in the sector tended to rely on individual knowledge and experience in the absence of a set of broadly accepted guidelines, resulting in a process of learning through trial and error and, sometimes, painful experience. It aimed to clarify the conventions of the sector, and provide a 'primary access point' (p.11). There is discussion of the Indigenous art market – stressing consultation and prior consent for use of materials – although there is also a companion document about Indigenous art and crafts. There is some advice for basic online transactions, such as copyright security. Discussion of community arts suggests that a sound community arts process be implemented in public arts projects aiming to have community development outcomes. It further notes artists need to take note that copyright and moral rights issues may not be as straightforward in the community context as when dealing with the creation of works by individual artists.

National Cancer Institute (USA) (2006), A Guide to Understanding Informed Consent
www.cancer.gov/clinicaltrials/conducting/informed-consent-guide *accessed 10 February 2010*

> This is one of a number of documents on the National Cancer Institute's website about informed consent in the context of clinical trials. It spells out very clearly that informed consent involves two essential parts – a document and a process. The document summarises the trial and begins the informed consent process; the process provides ongoing explanations to help a patient make educated decisions about whether to begin or continue participating in a trial. In very plain English, a series of myths are debunked around informed consent, such as: informed consent is designed to protect the interests of the research team (rather, it is to provide access to information for participants to make a decision and know their rights), or that the most important part of the process is the signing of the document (the heart of the process is the interactions with the research team and medical professionals – the form is just to start that process).

National Cancer Institute (USA) (2009), Simplification of Informed Consent Documents
www.cancer.gov/clinicaltrials/understanding/simplification-of-informed-consent-docs
accessed 21 February 2010

New Zealand Health and Disability Ethics Committees (2006), Operational Standard for Ethics Committees, Appendix 2: Research Involving People with Intellectual Disabilities – Issues of Informed Consent and Participation
www.moh.govt.nz/moh.nsf/pagesmh/4703/$File/operational-standard-for-ethics-committees-updated-edition.pdf *accessed 21 February 2010*

Oral History Association (USA), General Principles for Oral History and Best Practices for Oral History
www.oralhistory.org/do-oral-history/principles-and-practices *accessed 10 February 2010*

Royal College of Nursing (2005), Informed consent in health and social care research. RCN Guide for Nurses
www.rcn.org.uk/__data/assets/pdf_file/0010/78607/002267.pdf *accessed 10 February 2010*

Saskatchewan Visual Arts Sector Best Practice Development Project (2010), Aboriginal Arts Industry Standards and Best Practices: Saskatchewan Visual Arts and Craft Sector
www.bestpracticestandards.ca/docs/1_standardsdrafts/Aboriginal_Industry_Standards_and_Best_Practices_REV_2010_02.pdf *accessed 15 March 2010*

Saskatchewan Visual Arts Sector Best Practice Development Project (2008), Aboriginal Arts Industry Standards and Best Practices: Saskatchewan Visual Arts and Craft Sector, Draft for Discussion
www.bestpracticestandards.ca/?s=underavier.edu/ *accessed 15 March 2010*

> There is increasing participation of Aboriginal artists in the sector and they face cultural, language and geographic barriers for self-representation. This best-practice document discusses issues of cultural exchange and approaches to practice in the visual arts and crafts sector in Saskatchewan. It aims to promote awareness of intercultural protocols and to encourage respect, communication, perspective and moral support for individuals and the sector. Points for discussion include cultural misappropriation, traditional knowledge, communal intellectual property and copyright.

Simon Fraser University, Social Networking and SFU
https://wiki.sfu.ca/socialnet/index.php/Main_Page *accessed 15 March 2010*

Social Sciences and Humanities Research Ethics Special Working Committee (2008), Research Involving Creative Practices: A Chapter for Inclusion in the TCPS
www.pre.ethics.gc.ca/policy-politique/initiatives/docs/Creative_Practice_Chapter_Jan_2008_-_EN.pdf *accessed 21 February 2010*

United States Department of Health and Human Services (1998), Informed Consent Checklist
www.hhs.gov/ohrp/policy/consentckls.html *accessed 15 February 2010*

University of the Arts, London (no date) , Guidance Note on Informed Consent
www.arts.ac.uk/research/304.htm *accessed 10 February 2010*

Xavier University Institutional Review Board, The Informed Consent Process, General Requirements
www.xavier.edu/IRB/forms.cfm *accessed 11 February 2010*

Section 3

Key themes emerging from interviews

Researcher Pia Smith conducted 13 stakeholder interviews either in person or via telephone. The aim was to capture the views of a range of professionals (including artists, researchers and representatives of larger arts-based organisations) working in community-based environments (primarily but not solely arts) with diverse communities and groups, such as Indigenous communities, new arrivals from refugee backgrounds, and young people.

We are very grateful to, and acknowledge the contribution of, the following people: Cymbeline Buhler, Michelle Chiller, David Crofts, Jorge de Araujo, David Everist, Vincent Lamberti, Bree McKilligan, Priscilla Pyett, Shahin Shafaei, Majid Shokor, Helen Simondson, Bo Svoronos and Katie Symes. We also acknowledge the invaluable contribution and assistance of Marnie Badham and Kim Dunphy in shaping the focus, themes and methodology of the project, and suggesting potential interview subjects and literature.

Several key themes emerged from the interviews, along with some accompanying tensions. No single approach emerged from the interviews as being 'best practice' for gaining informed consent in community cultural development work; however, the overarching idea on which all interviewees agreed is that it is important to think about informed consent at the outset of a project, i.e., in the planning stages. This can help avoid problems further down the track and build informed consent into a process in meaningful ways at appropriate times.

Many of the ideas raised in relation to consent were broader ethics or values, such as the importance of creating trust in a project, or that consent is based in the relationships forged. Considering consent as part of the ethical framework of a project, rather than a bureaucratic, formal imposition incompatible with the creative process, emerged from the interviews as a way of ensuring informed consent fulfils its intention of giving the participant agency in their own representation.

Rapid changes in multimedia and multiplatforming (the repurposing of material from one medium to one or several others) raises significant issues around obtaining consent, such as being clear about what will happen to material once it is put online. Who will access it? Could it be altered? How could it be used? These are especially important with increased use of new technologies. Not all interviewees had experience with these contexts, but these questions need to be considered throughout the process of achieving consent as discussed below, and in the use of the Initial Assessment Matrix.

Ethics and values

The authors of *Making Art with Communities: A Work Guide* (Arts Victoria and VicHealth, in press) emphasise that even though every community arts project will be different, 'those that are successful tend to share a number of core values and attributes'. Several people interviewed spoke of the importance of establishing a set of values or protocols for a project, and of consent being woven into these values. CCD practitioner Shahin Shafaei, in planning the ongoing Arts Partnership Project between the Horn of Africa Communities Network and the Centre for Cultural Partnerships, Faculty of the VCA and Music (Melbourne University) stressed the importance of establishing a set of protocols via negotiation between elders and young people from both partner communities – a process that took two or three months of negotiation and consultation. Shahin believes this 'ground for respect and trust … a playground to tap into, run around, come out and be strongly reliant on' provides a mutually respectful framework or 'container' within which the informed consent process takes place. As well as the protocols

themselves, the process of negotiation and dialogue that creates the 'container' sets the model for exchanges around the use of participants' images or materials. For Shahin, 'informed consent is the whole process of negotiating ethically with a person and letting them make a decision'.

Discussing consent alongside broader values such as empathy, reciprocity and respect highlights that there are different layers to the informed consent process, as discussed in some of the literature. There is the 'paperwork' element (discussed below), but there is also an ongoing negotiation of consent. According to actor, filmmaker and CCD practitioner Majid Shokor: 'it's not about filling out forms, whether you agree with this or not – it's about engaging on the human level, and trying to be open to the other person, and be genuine about their problems, their stories that they are sharing. Not just waiting for the other person to tell their story to you, but also sharing your own story with them. By this kind of human interaction you get a better consent than with a formal methodology or form'. Social researcher Priscilla Pyett also spoke of making sure values like trust and reciprocity are not treated as cynical exercises, but are genuine processes within the community, for example by taking time to share skills and 'hang out' in a community before even beginning a project.

Planning

As mentioned above, while there is no prescribed way to obtain consent in community-based arts work, foregrounding consent in the planning process can go a long way towards preventing missteps later in a process. The informed consent matrix tool (see Figure 1) is a way of gauging how the choice of artform and the potential audiences impact on the degree of potential complexity in the consent process for a project.

Bree McKilligan, David Crofts and Michelle Chiller all spoke of the importance of thinking issues of consent through early in a project. For Bree, managing the Homelands Multimedia project with the Centre for Multicultural Youth raised several issues, including: working with young people from a refugee background and needing parental consent; protecting the safety of participants whose 'homeland' was under a military dictatorship, while asking them to upload material onto a publicly accessible website; and ensuring that the necessary resources were on hand to translate, interpret and communicate consent materials to participants and their families. The Homelands project, according to Bree, aims to empower the young people to be media makers and manage their material, and to empower them to determine the possible risks and consequences of putting their material and images into the public domain. Achieving this – negotiating permissions, copyrights, risks and benefits – requires that the consent process is clearly thought through and sufficiently resourced. As part of this, the Centre for Multicultural Youth has hired a part-time support worker who is the same age and culture as the participants and who speaks their language. Also, the project has an advisory group to review content before it is uploaded.

Speaking primarily about community-based storytelling projects, writer David Crofts also spoke of the importance of spelling out a transparent process at the start of a project, including providing examples of the kind of work that will result, explaining the editing process and offering a time for the participants who contributed their stories to see a draft of his work. He explains the whole process to people before they consider participating, because 'consent is part of the journey you are taking people on: storytelling is a journey of trust'. David also emphasised the importance of spelling out protocols for practice – but also of sticking to them: 'don't promise something you don't intend to do – don't fool yourself that people won't remember.'

Michelle Chiller, Executive Officer of The Torch Project, said that the Torch had been on a 'learning curve when consent has come up,' and that the organisation was trialling a new approach to consent that pulls it 'right up front' – not putting it off until later in the process. This approach involves several aspects, including: involving the steering committee in each target

community to administer or communicate aspects of the process; a two-stage consent form process, depending on the nature of the contribution; and a revisiting of consent prior to the culmination or performance of a project. For Michelle, their aim is 'making it more meaningful, so we build it into the creative process, so people feel good when they sign it, empowered because they understand the process and their ownership in it. By embedding it in the first committee meeting, it's setting up all those organisations and community members to take that learning back to their other projects.'

Not all interviewees agreed, however, that thinking through consent at the beginning of a project necessarily means that it has to be obtained at the start. Both Majid Shokor and Shahin Shafaei spoke of not presenting forms until later in a process, once trust was established and participants had experienced the work. Further, while it is easy to speak of 'foregrounding consent,' it may not be easy to carry this out. Cymbeline Buhler, Artistic Director (in Communities) of Western Edge Youth Arts, spoke of the tensions around getting consent from young participants: 'If it all goes according to schedule, it could be built into the first session, in a straightforward way. But not everyone comes on the first day, and under-18-year-olds tend to put the form in their bag and forget about it. Young people are not interested in that.' The duty of care then falls on the artists to pursue it – artists who, Cymbeline emphasised, are already overworked and underpaid. If consent is not gained straight away and a young person makes a contribution and then leaves the project, their contribution may be un-usable; however, in Cymbeline's experience, starting a process with a form to sign can be an 'officious beginning.'

Projects do not always go according to plan, and not all outcomes can be predicted at the start. However, thinking at the beginning about where consent sits in the timeline and nature of a project may not only prevent issues later on (having to re-contact participants; not being able to use fantastic material), but also allows due consideration to be given to the resources necessary for participants to achieve the understanding implied in truly informed consent.

Consultation

According to David Everist, Senior Arts Officer at Arts Victoria and experienced CCD practitioner, it is critical to seek guidance from the support or advisory committee of a project on the appropriate use of materials; however, while projects 'should' have a committee, a lot of them may not – or it may be difficult to make a committee meaningful in an ongoing way throughout a project. The majority of interviewees spoke of the significance of a steering committee, community reference committee, or project advisory committee in relation to aspects of the consent process. Further, many of the documents included in the annotated bibliography (Section 2) discuss the importance, or imperative, of consultation with an appropriate community representative group in negotiating all aspects of a project, including the consent process, along with project design and approach. Further, David Crofts spoke of potentially using steering committee members to translate and interpret when there is no budget for interpreters, and Priscilla Pyett emphasised that someone local is a much more appropriate contact person for withdrawing consent from a project than someone whom a participant may not know or feel comfortable with. While Priscilla's comments were primarily in relation to the university research context, where the usual contact person for 'revocation' (withdrawal) of consent is a member of the university ethics committee (whom a community member is unlikely to feel comfortable contacting), a community member or committee can also remain the contact through time for withdrawal of consent, or if consent needs to be revisited.

As discussed above, the Torch Project are trialling a model where the first steering committee meeting on a project will discuss consent, copyright and ownership of material. Each partner community has a steering committee, and two working groups sit beneath that: a creative development working group and a social change working group. Using a member of the steering

committee to communicate about consent means the responsibility is lifted from the artist, and also that it is a local person sitting down with the participants.

Early consultation and connection with a representative group can also set the foundation for the established dynamics and relationships from which consent comes. Speaking of working with Indigenous communities, Bo Svoronos, festival director and Indigenous Arts and Projects Officer at the City of Port Phillip, emphasised the importance of being aware of the sensitivities around recognising the appropriate spokesperson for a particular group. Further, he suggested that a group be approached with an agreement, but an agreement that contained real reciprocity, 'some kind of symbolic exchange'. Rather than just 'whitefella talk' or a 'white man's agreement', an agreement could be created that included 'things outside western understandings', ie, a more spiritual agreement. Similarly, when Shahin Shafaei described the first meeting of the range of groups negotiating the Horn of Africa Project protocols, he described bringing his guitar and singing a Persian song then translating its meaning: 'I gave something that is very dear to me.' That first meeting was about creating trust; the following session turned to the project.

While prioritising the importance of getting consent from a community, at times this may cause conflict for individual participants. Bo Svoronos and David Everist both spoke of the potential for individuals to be rebelling against the community of elders, or to not want to define their identity according to the particular community group.

Understanding and education

Underpinning all definitions and literature on informed consent is the idea that it is an ongoing process of empowering the participant to understand what they are being asked to contribute and to do, and what the risks, benefits and consequences of that may be. This applies to clinical trials and academic research projects as well as community cultural development projects. However, in understanding what they are being asked to do and the context in which they are doing it (for example, to contribute original material that will then be covered under Australian copyright law), participants are also gaining an education in aspects of society they may not have previously understood.

Documentary filmmaker Vincent Lamberti, who has worked extensively in the town camps in Alice Springs, stated that 'If a person understands clearly what they are agreeing to, it's informed. Obstacles need to be addressed; concepts need to be communicated.' One approach Vincent takes is to roll the camera in an initial meeting about a film, to show people what being interviewed might involve. Vincent has invested many years building relationships with local researchers in the town camp communities. They act as interpreters and help to consult with the communities on the kinds of projects that might be developed.

In relation to education, Majid Shokor spoke about working with young people from a refugee background in a digital storytelling process. He needed to find a balance between explaining their rights (for example, owning and giving consent for the use of their material) and other people's rights (for example, being aware of what music they could use), but also maintaining the excitement of the process. 'They come from a very different background and don't have a concept of copyright. The main thing they have dealt with is the abuse of their human rights … so it's a kind of educational process about aspects of Australian society, so they engage softly and more smoothly with society here … A lecture about rights and responsibilities: they won't comprehend it. But practicing with art, they will engage not just on a theoretical level but also on a human level.'

Moral responsibility and relationships

All interviewees agreed that even once consent had been obtained, the moral responsibility lay with the facilitator of the project to anticipate the present and future interests of the participant, for example if they want to use personal material. In her role as Screen Events Manager at the Australian Centre for the Moving Image (ACMI), Helen Simondson developed ACMI's digital storytelling program. The digital management system at ACMI is designed to protect the storytellers rights and allow them to limit/determine where their story is shown. However, sometimes a participant, particularly a young person, 'might not be aware of the potential impacts' of what they include in a story: 'we have licence agreements with a guardian signed, but it's our responsibility … if there is disclosure … they're young feisty adolescents who think it's all about freedom of speech, but it's our responsibility to protect them.' Ideally, this can be addressed at the story development stage and built into the creative process.

Moral responsibility is also a consideration if the consent process does not fit the legal procedure. David Everist spoke of instances where consent may have been communicated, for example via an elder to parents, but the legally signed form may be 'tricky.' Or, he spoke of projects where participants who were minors continued to turn up without their parents' permission, or brought along younger siblings. Cymbeline Buhler noted that she does not want legality or the parents' lack of involvement to be the decider as to whether someone participates or something goes ahead. This creates extra responsibility for her to chase the paperwork.

As mentioned above, consent is often based in the relationships within a project. For example, Vincent Lamberti – having spent a long time building trust and working in the same small town camp communities in Alice Springs (some of the most disadvantaged communities in Australia) – spoke of the trust placed in him that he will use material appropriately. He finds that often people will not read the consent material once it is explained. For Vincent, this makes it very important that you understand your intentions. In his experience, Indigenous people are very sensitive to intention, and 'that is more important than the written agreement … how you speak, and perhaps more importantly, how you listen.' The understanding of the nuances of responses and relationships built, with trust, over time, is key to the consent process, alongside (or over and above) the formal paperwork.

East Timorese photographer Jorge de Araujo also spoke of the relationships built with his subjects as key to his consent process: 'In Timor it's different. It's about your word rather than a piece of paper: the connection, the relationship. They knew what he was doing and why, and just said "yes."' For Jorge, the consent paperwork can get in the way of the process: 'once you bring out the paperwork, it becomes official, and people may become standoffish. Among the Timorese, it's all about the connections, the relationships – suspicion might arise with the forms.' He also noted that signing a form might not necessarily mean consent. This is also a concern for Bree McKilligan who feels that if they were dealing only with her, the Karen refugee participants would 'just say yes' to what they were asked to do. Thus, the importance of having the support worker there to give them someone they could trust and relate to as a peer.

Leaving a legacy; addressing existing legacies

David Crofts spoke of working on an Indigenous justice publication and how it has taken four years of building trust and relationships in order to address 'a long history of poor practice from government departments in terms of getting consent.' As Bo Svoronos put it, 'you're working for the next person,' and it is important to 'set up a good legacy.'

The next section recommends an approach to gaining consent from participants so that they are truly informed and empowered and do not contribute to the poor history of misappropriation, misrepresentation or exploitation of some disadvantaged groups.

Section 4

Guidelines for informed consent in community-based arts projects

1. **Consider consent as part of the project's ethics and values**

   - What are the underlying values of the project?

   - How are those values reflected in the informed consent process?

   - Have relevant protocols for obtaining consent been consulted?

2. **Negotiate consent in early consultations**

   - Incorporate discussions on informed consent into early consultations with the project steering committee, community reference group or committee of elders as part of the discussions around project design.

   - What role can this group play in the consent process? Assist with communication of consent? Be a contact point for withdrawal of consent?

3. **Include consent in project planning from the outset**

   - What implications for consent does the form of the project have, according to the values on the matrix tool? (see Figure 1)

   - What is the plan for obtaining informed consent throughout the project? What resources are required: interpreter? time? Does the project have them?

   - How sensitive is the material being shared? How personal? Is it communally or individually owned?

   - What happens with the material into the future? Storing, archiving, etc: who holds it?

4. **Ensure consent is clearly communicated and understood**

   - How do you ensure each participant understands what they are consenting to?

   - What resources will help?

   - What are the particular needs of this group?

   - Does the understanding of what will happen with the material extend into the future (e.g., with web-based material)?

   - Has the whole process been fully explained to each participant in a way they understand, including creative processes, editing of participant's work, and so on?

   - Will consent be revisited at any point during the project? How will participants be re-contacted should consent be required for future use?

5. **Be aware of the moral and relational responsibilities in ensuring ongoing informed consent**

   - Be alert to the potential implications of the work produced for each person and discuss/negotiate any potential concern with the participant.

   - Even if consent has been given, 'if in doubt, leave it out'.

- Honour the trust placed in you by participants in the consent process.

6. **Create a positive legacy of informed consent in a community**

   - What is the history facing this group in regards to controlling their representation? How does this project address that?

   - What have these participants gained from this process in terms of having agency in their own representation, in this project and in the future?

Paperwork

Initially, as part of this brief, we had intended to prepare a template consent form for community-based arts projects. However, because every project is different and would require adaptation of a form there is probably no 'ideal' consent form and instead we have compiled a list of key features of an effective consent form as identified through the research (see next page). Most interviewees said they either had their own consent template on file, or they adapted one from the organisation running the project or a resource organisation related to their artform (for example, CAAMA). Several people raised the possibility that a form might be worked on with the participants and/or the community reference group prior to being finalised, to ensure it is accessible, appropriate, and meaningful.

Approaches to presenting the consent paperwork varied among interviewees. David Crofts, Priscilla Pyett and Michelle Chiller spoke of presenting the paperwork early on, but making sure it is explained and accompanied by support materials, and that there is no expectation to immediately respond to it. Majid Shokor and Shahin Shafaei were reluctant to present the forms until the process had been experienced by the group, so they could experience what they were being asked to sign consent for. Cymbeline Buhler and David Everist had experienced the tension between what they considered an 'ideal process' (getting all consent forms back uniformly, early in the piece) with what would *actually* happen in a project, which was often much less straightforward.

Consent forms should be no longer than one page, but should be accompanied by support materials on the project. These might include examples of similar work, a description of the process, or more detail on the project itself. If there are other things for which permission will be sought (for example, evaluation), these would ideally all be on the one form. Above all, every effort should be made for the consent form to be a simple yet meaningful *part* of the informed consent process.

Finally, several interview subjects spoke of how the presenting of a form – while necessary – is an experience that may evoke different responses in people from different cultures. Working in disadvantaged communities or communities from cultural backgrounds other than English, David Crofts found that 'too much in the way of official forms and paperwork can really scare people – their experience of government is very different to our experience of government. The simpler, and less scary, the better.' Bree McKilligan stressed that presenting a form is a kind of enacting of a power relationship, and tries to find ways to do it in a friendly way, without making them 'other'. She asks: 'How are forms, bureaucracy and power enacted in their own country?' Priscilla Pyett emphasised that if someone cannot read or write, receiving a form can create anxiety and someone who is illiterate is unlikely to say so straight away. These possibilities can be anticipated in the design and presentation of the form so that individuals and communities do not feel intimidated or excluded by an impersonal, bureaucratic procedure.

Features of an informed consent form

1. Form should be no longer than one page.

2. Work, if possible, with the local committee or elders to establish the appropriate tone, language, and things to offer and ask.

3. Make the form immediately accessible to the group, in appearance, tone, and via the support resources (e.g., interpreter) accompanying it. Does it need to be translated into other languages?

4. Make it clear *who* is asking for *what*, and what the process will be.

5. Ask for all necessary details (name, contact details, parent/guardian details, what is being consented to, etc) but only ask those questions that are necessary for the project. If questions not directly related to the project (such as religion or diet) are included, use an 'opt-in' option rather than multiple choice.

6. Are the values underpinning the project reflected in the form? For example, reciprocity and community ownership? Has the group had an opportunity to adapt the form according to their needs?

7. How is this form appropriate to the specific group? For example, if it is an Indigenous group, can a question be inserted offering options for the use of images should a participant pass away?

8. Make it clear whether, when and how consent can be withdrawn for the use of materials, and provide an accessible and approachable contact person for withdrawing consent.

9. The form needs to be 'talked through' (with an interpreter if necessary), and understanding established verbally with each person.

10. Negotiate and communicate what will happen with the forms after the project. Where will they be stored? Who will keep them secure?

Initial assessment matrix

It is evident through the literature and the interviews that the earlier the scope of required consent is defined the smoother the development of the right consent form. Below is a suggested visual cue for the project managers and participants to use when defining the scope of consent that is required or tailoring the project to match the available achievable level of consent.

Imagine where your project sits on two axes.

One axis is a continuum from a single 'private' screening or exhibition outcome for participants or immediate community/family members through to a fully 'public' presentation over the internet, and unlimited reproduction of the content.

The second axis is the continuum from a 'personal' story or created artwork by an individual through to a full 'community' owned story or production with multiple rights owners and different levels of community 'permissions'.

When these two axes are crossed it forms four distinct quadrants. Positioning your conceived project in any of these quadrants will suggest different levels of consent.
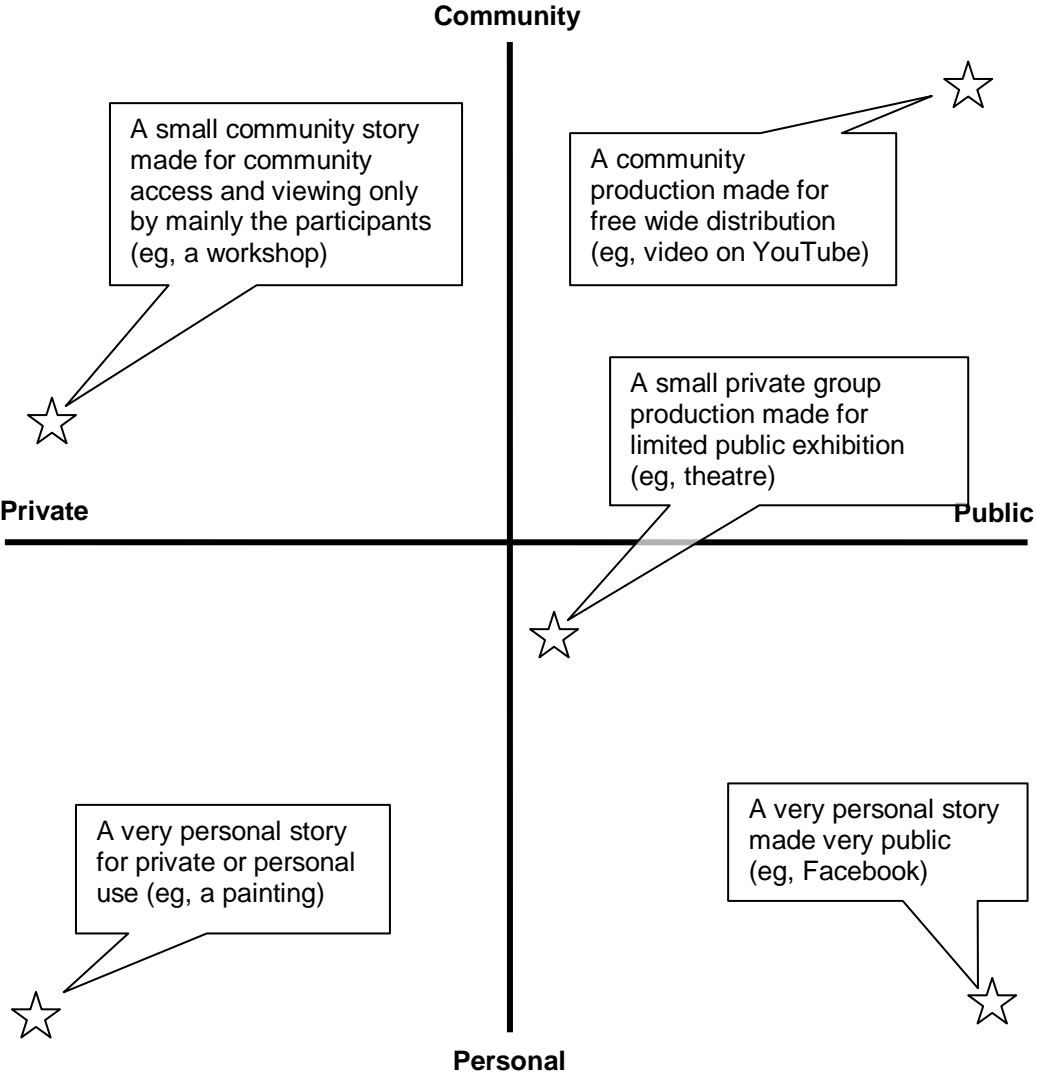
Community

A small community story made for community access and viewing only by mainly the participants (eg, a workshop)

A community production made for free wide distribution (eg, video on YouTube)

A small private group production made for limited public exhibition (eg, theatre)

Private

Public

A very personal story for private or personal use (eg, a painting)

A very personal story made very public (eg, Facebook)

Personal

Figure 1. Initial assessment matrix

Conclusion

The literature review and interviews for this project indicate that to be truly informed consent is a dual process involving a form to be signed, and an ongoing process of communication and negotiation. Many people interviewed emphasised the importance of the communication and negotiation process over the importance of the form itself; however, the consent form does offer an opportunity to spell out and incorporate clear thinking about issues of consent at the beginning of the project development process. Given the rapid development of online media, social networking and so on, opportunities to share and disseminate images, stories and information are increasing at a rate that often outstrips most people's comprehension. What foregrounding consent offers is an opportunity to make time to consider the implications of a chosen media in the context of the community involved, and involve the community in consideration of those implications.

Given that online media and multiplatforming are, as mentioned, rapidly growing, there is certainly scope for further work towards the development of specific templates and tools to use as guides for practice. The specific risks and nature of that environment are not spelled out in this report, partly because it was a small project, and it was not the focus of the practice of many of those professionals interviewed. This rather small project emphasised the parallel between consent and ethics, which strongly emerged from the interviews. With further research, perhaps in partnership with creative, multimedia and legal organisations, more work could be done towards the development of standard forms or templates in a way that was in accord with the media, values and resources of a project. This would need to facilitate an understanding of the potential of all media involved, now and into the future (keeping up with rapid change). Keeping a strong focus on values, protocols and issues of working with diverse groups, including disadvantaged groups or those with a history of misrepresentation and misappropriation, needs to be intrinsic to this process.

A tension emerged in some interviews that creativity, spontaneity and risk may be smothered or subsumed by too much focus on bureaucratic processes aiming (in part) to mitigate that risk. It must always be remembered that there needs to be space for unpredictability and risk in creative work. This project indicates that, ideally, processes of informed consent and creativity are not conflicting but may be holistic and interwoven.

References

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VicHealth (2009). 'Promoting Diversity through the Arts – Funding Guidelines, Arts Venues and Organisations Grant', VicHealth, Carlton South.

VicHealth

State Government
Victoria