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# Culture, science and bioethics: Interdisciplinary understandings of and practices in science, culture and ethics

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## Introduction

This paper presents insights from four years of interdisciplinary discussions and analysis focusing on the complex and multidimensional character of the relationship between culture and ethics[1]. This work started off with a clear perception of the present and cross-disciplinary importance of culture and ethics, in areas such as analysis of quality of life and familial and organizational cultures, as well as in bioprospecting, epidemiology, research ethics and clinical ethics. For example, we see the influence of culture in how contentions arise within bioprospectinglinked to calls that values associated with traditional knowledge and benefit-sharing be recognised. While in studies of organisations, including healthcare organisations, we see culture explored as a tool of change and communication, and at other times as an intrinsic part of how organisations set norms, boundaries and hierarchies. This paper explores a number of ways in which understanding and responding to areas of bioethical concern benefit from a consideration of culture.Itencompasses some of the ways in which each of us is engaging with those relationships in order to make the case for the necessity of thinking through how culture, science and bioethics *do* and *should* intersect.Our discussions have deepened our understanding of how interdisciplinary knowledge operates within our individual projects. They have also highlighted for us howanalyses of culture, whether examining bioprospecting, epidemiology, quality of life, or perceptions of the culture-nature divide, in addition to representing particular knowledge claims, are also always challengesto present social and economic power structures that influenceintellectual and academic approaches and recognition. In the following we present some of the projects discussed and developed within our emerging research network. From theseexamples we generate a new understanding of present challenges in on-going analyses of culture, science and ethics in today's globalized society.This is supported by the broad areas of work our individual projects represent: analysis of quality of life, medical and cultural understandings of family, bioprospecting and biopiracy, epidemiology, research ethics and clinical

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[1] The development of our network has been supported by a research funder: The Swedish Foundation for Humanities and Social Science.

ethics, the retention and handing back of materials gathered by archaeology (repatriation), and the quality of life and knowledge of indigenous peoples.

Multiple disciplines across the social sciences study culture. Our approach to culture is one which seeks to understand how values we know as cultural – that is embedded in and emergent from particular locations and groupings of people who develop shared understandings over time – are part of how groups are recognised (or denied), how knowledge is produced and understood, how people understand their position in the world and how history and change influence the boundaries between cultures and the differential valuing of cultures.While some of us are interested in the cultural values of particular groups, this does not mean we consider some groups to be more cultural than others (and subsequently less modern than others). Likewise, while some of us are interested in objects or disputes, which seem more obviously cultural than others, we do not think that culture can only be found in such things. Instead, our overall claim is that cultural dynamics are embedded in all areas of cultural analysis and bioethical or ethical debate (bioethical we use to denote questions that revolve around medicine, healthcare and biology, while we use ethical to refer to the broader landscapes of concern some of us work in). Our theoretical approach draws mostly from work across anthropology, sociology,folklore, ethics and philosophy.In particular we draw from perspectives that engage with the significance of culture to social practice, identity and meaning, includingpost-colonial and native theory/indigenous peoples' study. This last area of influence is very important because of the ways in which it has deconstructed the cultural underpinnings of dominant cultures` claims to reason and rationality, alongside explorations of how the cultural values of dominated or marginalized groups,locations (centre versus periphery, colonial versus colonialized areas), traditions (folk traditions and livelihoods), certain academic methods or fields of studies that have been in conflict to dominant science discourses have been comparatively framed as the other to modernity and to civilisation.[2]

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[2] Our focus on post-colonial and native theory/indigenous peoples' study emphasizes the relation between location, position, and how power is tied to history and particular worldviews. It also emphasises meaning as contextually defined, i.e. not only that we perceive differently, but that hard facts like resources, health, quality of life and sustainability are context dependent.

The structure of the paper is based around individual accounts of how we draw cultural analyses into our varied approaches to studying bioethics, ethics, science, knowledge and cultural and social lives. The aim of this structure is to provide insight into the multiple ways we can engage with the significance of culture as integrative to all areas of science and ethics.As culture is all-embracing, it represents resources intervened or inseparable from power relations, and as such, cultural analysis demands new ways of approaching areas of research interest that are reflecting inter-/trans-disciplinary analysis and competence.

What the paper produces is a case for seeing culture as a vital component to how we debate science and ethics and indicates several ways this can be done analytically and methodologically.

## Nature and culture or, the culture of nature

A fundamental debate in the field of culture and ethics concerns the relationship of these concepts to what we, often unreflectingly, call ‘nature’ (the physical world and everything in it (such as plants, animals, mountains, oceans, stars, etc.) that is not a manifestation of human activity). One aspect of this relationship - that of the ethical use of the products of nature - is dealt with elsewhere in this paper. In this sectiona related, but in a sense opposite concept is considered: the conservation of nature.

Recent events in the field of conservation have seen a major division develop between ‘realists’ and ‘utopians’ (my terms, with no relative value implied). This has in part come about due to a lecture and a provocative article by Paul Kareiva, Chief Scientist for The Nature Conservancy (see www.youtube.com/watch?v=4BOEQkvCook and thebreakthrough.org/index.php/journal/past-issues/issue-2/conservation-in-the-anthropocene). In these position statements, Kareiva argues that large-scale conservation as it has commonly been carried out, by setting aside large tracts of land as ‘wilderness’ (Nash 2001), protected from humanity’s physical and cultural influence, has failed and must be replaced by a new paradigm that focuses on multiple uses of land, as both ‘natural’ and ‘cultural’. Although the idea of setting aside pristine protected areas has been dying a slow death in the past decades and in many countries was never a fundamental tenet of conservation legislation, nevertheless this represents a fundamental shift in perspective from a major conservation body and has caused a major uproar among proponents of the protected areas concept (e.g., Soulé 2013; response by Marvier 2014). At the same time, the so-called re-wilding movement, which aims at re-introducing animals to places where they have become locally extinct, has gathered momentum, thus setting up a contrasting pole to that represented by Kareiva and colleagues.

From the perspective of our work in culture and ethics, this debate is interesting for several reasons. First, there is an ethical issue at stake. Is it more ethical to work towards the long-term survival of 'natural' habitats and ecosystems, or is it more ethical to consider the well-being of the people already living in the areas in question (as there almost always is a prior population) to be of primary concern. Arguments for both sides were presented in the papers cited above and the answer is not obvious. Second, and more interesting from the perspective of our discussions, is that this debate within the conservation community is both one between conservation cultures and between the classical nature/culture dichotomy. Understanding the different cultures of conservations and their implications, as well as their relation to the classical nature/culture dichotomy, demands interdisciplinary knowledge and also insights into the way these cultures not only represent areas of knowledge but also politics.

The two conservation cultures are clearly in evidence. One is based on a utopian view (hearkening back to Rousseau) of the existence of a pristine nature, unaffected by modern man, or to use a more current phrase, a pre-Anthropocene nature (the Anthropocene being a new term for the time during which human activities have had a significant impact on the planet, which is between 250 and 5000 years, depending on perspective (Steffen et al. 2011; Ruddiman 2008). In its modern formulation, this goes back to the views of 19th century North American philosophers such as Emerson and Thoreau. This philosophical underpinning found its first practical outlet in the activities of John Muir (e.g., 1998), who was a key figure in the development of the US National Parks network, the world's first. The second culture is the more pragmatic one, having developed over the relatively recent past, as it has become clear that protected areas, while valuable, are protectedat the cost (if that) of the environment outside them. This occurs because those areas outside the protected areaare therefore seen as not in need of protection and suffer greater environmental damage via the activities that occur on them. In addition, some successful re-wilding of large carnivores has had negative environmental impactson surrounding land, particularly on the continuation of customary land use, for instance, grazing by domestic animals. The unintended consequence in these situations, according to practicing conservationists working in the areas, is an overall decline in biodiversity.

Overprinted on this debate between ‘realists’ and ‘utopians’ is the question of nature or culture (physical or intellectual manifestations of human activity). The ‘realists’ accept the presence of culture in nature and seek to reconcile the two. The ‘utopians’, on the other hand, see a fundamental separation between nature and culture, and seek to maintain it. This is a debate that has raged for centuries and it is beyond the scope of this brief communication to delve into it. However, it is worth noting that Descola (2005) in his exhaustive treatise on the topic identified the dichotomy as one specific to ‘western’ cultures, and showed that it is largely or completely absent in other cultures. Thus, in the rest of the world, no distinction is made between nature and culture, and therefore it would be completely natural for these cultures to develop conservation practices that embrace cultural, human-dominated landscapes. In the UN Convention on Biological Conservation (CBD) the need for increased involvement of indigenous peoples and local communities in the conservation of biodiversity, i.e. traditional perceptions on the surrounding environment, is a central point. With this in mind, perhaps the existence of the current debate among conservationists can be resolved or at least mitigated by taking into account perspectives on the nature-culture dichotomy from cultures outside the ‘western’ world, which dominates conservation today.This could be considered an important inter-/trans-disciplinary move in the way issues of conservation are being approached and understood. It holds out the promise of an ethical approach that incorporates dynamics and relations excluded from the current two options of conservation practise and from ways of thinking that are sustained in the nature/culture divide. One outcome would be that narrowly framed conservation practices could not be used as an excuse to destroy surrounding areas or lead to the removal of native peoples from the locations to be protected.

## Perspectives on bioprospecting and sustainable use of biodiversity

Biological diversity and ecosystem services are prerequisites for human life and our attempts to reach sustainable development and sustainable societies. There are several perspectives on the term *sustainability*. A common definition is that one at the same time needs to reach long-term *ecological*, *economical* as well as *social sustainability* to achieve sustainable development. The last part *social sustainability* also includes the need for cultural sustainability and a sustainable health situation, i.e. quality of life.[3] From a realistic point of view ecological sustainability determines the possibilities to achieve the two others, which could be exemplified by the fact that no matter how much money you've got you can still not buy more fish than is available in the sea. There are planetary boundaries that determine our possibilities, and there are social and economic perceptions that hinder a change in epistemology when it comes to our consumption patterns. Equally, for some of us at least, social sustainability is higher ranked than the economical; health and well-being is more important than money, but if you can't afford food it is hard to stay healthy (Hassan, Scholes & Ash, 2005).

A general perception is that nature and resources are to be considered as common goods and freely accessible for academic and/or business endeavours. This is probably a conceptual view originating from historical explorers and a past colonial world and not much questioned in the Western world. However, developments in bioprospecting during the last decades has revealed conceptual and cultural differences in this respect (Tunónand Paulsen under review). What resources are to be considered as common goods? What ethical considerations do we have to make when prospecting biological diversity? The UN Convention on Biological Diversity (CBD) clearly establishes the sovereign rights of states over their biological resources, and the authority to determine access to genetic resources (www.cbd.int, article 15).

Within the CBD bioprospecting is described as: 'the scientific research of biological resources for commercial or other purposes. Bioprospecting may also include research into the knowledge associated with the biological resources' (UNEP/CBD/WG8J/4/7,

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[3] Cultural knowledge has become an important theme in the fields of medical research, pharmaceutics, biodiversity and bioprospecting. Traditional medical knowledge, in particular knowledge of plants and insects, has been of interest to pharmaceutical companies for decades. In addition, traditional medicine has become an important strategy to achieve sustainable and available medicine for a variety of diseases in for example Africa.

p. 22). The formulation of the issue is framed by approaches from within the pharmaceutical sector.Even if this kind of venture has a long history it is only during the past decades that the discussions concerning rights and ethics have evolved. Consequently, the CBD process has developed the *Nagoya protocol on access to genetic resources and the fair and equitable sharing of benefits arising from their utilization to the Convention on biological diversity* (CBD, 2011) – a protocol of general guidelines for the development of bi- and multilateral agreements concerning the access and benefit-sharing of biological diversity (see also our reflection on ethical codes of conduct, Tunón et al., *forthcoming*). However, should genetic resources be recognized as a national property or a property belonging to a specific local community? The same is relevant for traditional knowledge systems and their elements, but the international regimes regarding intellectual property rights are not developed to cope with collective ownership or customary traditions in knowledge-sharing. Consequently phrases, like *free and prior informed consent/approval, mutual agreed terms* and *fair and equitable sharing of benefits*,are frequently used in the discussions concerning bioprospecting and the rights of local and indigenous peoples as well as governments in developing countries.

We are today facing several significant changes that will influence the way our human society have been functioning, e.g. climate change, unsustainable use of ecosystems services, collapsing ecosystems, accelerating species extinction, growing world population (Hassan, Scholes & Ash, 2005). There is consequently a need for a sustainable development for food production as well as policies for continued food security. This development has to be fair, equitable and ethically acceptable to all parties.

Furthermore, it is generally conceived that there is a correlation between high biological diversity, high cultural diversity, and a high linguistic diversity. A multitude of ethnicities and local cultures gives rise to a variety of different ways to use the present biological diversity (UNEP 2003 and Maffi 2005). There are also often mutually agreed terms on how local resources are to be shared to try to avoid unsustainable use. Lessons to be learnt from the experiences of such communities might give us valuable knowledge for the global transition to a sustainable development.

When academic scholars meet local cultures it is also often a meeting between natural sciences or social sciences on one side and local and traditional knowledge and customary practices and perceptions on the other, i.e. a meeting of conflicting worldviews and different views on ethical norms. From a natural scientific point of view there is almost always a will to validate the knowledge of the other part. If it is representatives of pharmaceutical companies or academic researchers studying the knowledge of a particular group there will be a cultural/conceptual/perceptual gap between the researching side and those who are researched. Indigenous peoples and local communities are often deeply cynical about the capacity, motives or methodologies of Western research to deliver any benefits to them and it is often seen as disempowering (Smith 2012). This cynicism often goes unnoticed by researchers. It is therefore extremely important to specify on what terms research and/or bio prospecting is to be done, and what the expected local benefits are. Even with clear mutual terms and agreements, real results and benefits may fall short of expectations and the local communities are likely to be frustrated in the end (Tunón and Paulsen *under review*).

In the field of bioprospecting and pharmacy, culture is approached as a resource and is regulated by national as well as international laws and conventions. From another angle, plurality and diversity is an asset that increases the possibilities for identification of knowledge, materials (substances) and ways of living (livelihood).New ways to use and apply this knowledge to support the development of a sustainable global society can be developed. In this context ethics is, in particular, related to questions of ownership and governance, and the most important guidelines and binding regulation are international/transnational, e.g. UN, ILO, Nagoya treaty etc. In bioprospecting and pharmacy, culture is defined and used in ways that emphasise the relation between history and sustainability, the importance of including and understanding history, i.e. tradition as well as political and economic relations to achieve sustainability. These priorities are influenced by the ways in which international policy and political statements speak of the ‘global society’ and its needs. An outcome of these analyses is the visibility of conflicts between majority and minority groups, and between global as well as national market based interests and sustainability, and the urgent need for inter-/trans-disciplinary knowledge to assure ethically relevant evaluations that can facilitate ethical research in these areas. Before research in this area can produce the intended bearing on society, society itself, government as well as the public and involved stakeholders, need to understand and implement a new contextually defined understanding of the relation between value and culture, priorities and outcome.

## Ethics of research practice

Medical sciences have had a continued interest in culture and ethnicity that is important to detect and reflect upon, particularly in the use of bio-banking and genetic research directed at particular ethnic groups, including indigenous populations. Medical research on bio-banks have for a long time been interested in genetic research as a key to history, in particular migration paths and tracing human kind's beginnings all the way back to Africa. One of the challenges entailed by this research is tied to the way the relation between biological heritage, culture and ethnic belonging has been pushed forward, in particular when such research has been used in ways that interfere with questions of social relations, personal identity, and also juridical rights, as has been seen in disputes relating to Native Americans (TallBear and Bolnick 2004).

Epidemiological research, which has a long history of investigating the relationship between groups/populations and diseases, today focuses on common complex diseases (CCD, i.e. Alzheimer, Parkinson, cancer, heart and cardiovascular diseases, diabetes). CCDs are complex diseases not generated from one single cause alone, but from a complex interaction between inner (in particular genetic) as well as outward (behaviour patterns, social and economic contexts, natural contexts or influences etc.) causes. Groups, thought to be geographically isolated, have generated new interest in ethnicity as significant in CCD prevalence and its investigation. Studies are developing in this area, made possible by large bio-banks and new technology that can handle large data collections and also combine information from different types of demographic, medical and environmental data from multiple data sources.

Sámi people (the Sámi people is the only official indigenous people of Europe) is one such group who have been drawn into genetic research on CCDs. The first phase of modern genetic research on the Sámi people was developed by Lars Beckman in Sweden(Svalastog 2013). Beckman, and the researchers attached to his 50 years plusof genetic research, had a particular interest in samples from those Sámi individuals who where directly involved in traditional livelihood, i.e. reindeer herding families. Given most of the Sámi population were not included in reindeer herding, they were absent from scientific accounts about 'Sámi genetics'. In the early research the justification was that individuals involved in traditional livelihoods were the authentic Sámi. Due to a historic past of interaction amongst the peoples of northern Europe, and due to a colonial past where segregation was a late and final outcome in the 20th century, the distinction between authentic and not authentic Sámi people reflects a political expedient definition, rather than appreciating the complexity of history and family ties, generating a problematic mix up, in later genetic research, of biology and culture.

If Beckman's era represents a first phase of genetic research on the Sámi people, a second phase has occurred in the aftermath of the Human Genome Project (HUGO) and the Diversity Project. The Diversity project, which focused on indigenous peoples and tribal groups, generated a harsh public debate and fragmented into a variety of different projects (Reardon 2005, TallBear 2007). The interest in 'homogenous and isolated groups' did not vanish; instead we have seen a transformation in the focus of investigation from groups associated with a particular ethnicity, to groups associated with a specific geographic location characterized by relative isolation. One example of such a study is the EU funded European Special Populations Research Network. In the Swedish counterpart of this project a traditional Sámi location was chosen by one of the researchers who had previously conducted research on the Sámi people in Sweden. Despite the explicit lack of interest in ethnicity, ethnic identifiers were used, which reproduced former definitions of Sámi peoples as mountain reindeer herders. The ethical problematics created by such ways of defining ethnic boundaries in indigenous populations appear to require further consideration, yet are rarely considered in such large scale genetic research programmes (Svalastog 2013).

An additional area of concern in research involving indigenous populations relates to the ways in which laws and guidelines relating to research participation, ownership and governance operate. For example: because indigenous peoples' rights tend to be understood as group rights, is it sufficient to use individual informed consent contracts or does one also need acceptance from, for example, the Swedish Sámi parliament? What is the bearing of this question for present epidemiological and bio-bank research? Research ethical committees (REC) are local, and research ethical applications are sent by the PI of a project to his/her local REC, i.e. the one that covers the area where the PI has his/hers university affiliation. There is no particular REC that has Sámi representation, and there is no archive system that makes it possible to easily trace medical research projects, accepted and declined, including or designed to study the Sámi people, thus making transparency as well as the relation between governance and native representation decision making processes a far more complex ethical situation than at first glance (Svalastog 2013).

Culture is deeply embedded in all aspects of the practices and operation of bio-banking and associated genetic research, including their ethical and legal regulation. Appreciating culture helps us reposition ethical principles as context related, and replace an understanding of science as neutral with one that emphasises its politics and interrelatedness to history.

## Genetics and family as cultural objects of changing and disputed meaning

Genetics has been recognised as a cultural phenomenon in both medical sociology and anthropology. What is of interest is how the notion that genetics can say something about who we are, what makes us sick or well, now and in the future, becomes not just a tool of healthcare, but also a tool in the shaping of identity. This is both at the individual level as people think of themselves as ‘biocitizens’ (Rose 2006), and at the social level as inequalities emerge around knowledge gathered about people’s genetic makeup. A key question being examined across anthropology and sociology is whether genetic technologies that identify inherited conditions have become or will become an imaginary through which difference and similarity within family and kinship relationships are framed (Carsten 2007; Strathern 1992). There is a tendency to assume that the ever expanding scope of genetics will confirm the cultural ascendency of biology as the foundation of kinship (Edwards 2005; Rapp and Ginsberg 2001; Sachs 2004). For example, Finkler(2001) contrasts genetic representations of biological relatedness and contemporary contexts of chosen family relationships and boundaries. She warns of genetics being used to restate ‘traditional’ biologically defined family boundaries as the authentic model of family life: ‘the ideology of genetic inheritance tends to inform people’s experience of memory and time/space and to structure a new kind of sociality’ (2005: 1065). Likewise Sachs sees kinship increasingly being narrowed to ‘the molecular family’ (2004: 27) via genetic pedigrees, which will be able to not only identify those individuals who are damaged, but families as a whole will be collectively framed as pathological.

However, in understanding how genetics may inform understandings, we also need to understand family as also a cultural object of changing and disputed meaning. It is evident that family is a cultural concept that varies over time and has different meanings and shape within different historical and geographic locations (Strathern 1992). What such work emphasizes is that kinship is secured in social and cultural values and understandings, rather than being a fixed entity produced by nature and biology (Carsten 2000; 2004). When thinking about the interaction of genetics and family, what is valuable to explore is how these cultural entities inform each other. So how people think about family, will inform how they think about genetic inheritance, and likewise new genetic information about patterns of inheritance can become a factor in how people think about family (Fitzgerald 2008). For example, both the photographs and family stories of kinship past and present are drawn into genetic diagnostic processes (Atkinson et al. 2001; Bouquest 1996; 2000). Using family photos in a clinical context has the potential to change their meaning and significance as the cultural contexts within which it is read (and by whom) changes the meanings it generates. The same photograph, which in one context represents the connections people share as love and memory, in another, comes to represent an alternative version of a shared history, one of genetic peculiarity and faultiness. Can the original meaning attributed to an image sustain itself through the genetic framing, or once it becomes this ‘clue’ to a shared fault, will it lose its ability to project and produce the shared humanity within a family?

Answering these kinds of questions is what qualitative research examining the interactions of different cultures can explore.Such an approach is inherently inter-/trans-disciplinary in the way it work across genetics, sociology, anthropology, cultural studies, and science studies. This drawing together of multiple approaches enables the analysis of the cultural construction of biology, and the interaction between biological knowledge and cultural identity that occurs in social, economic and historic contexts informing the meanings we create from and give to disease, parental responsibilities, childhood and inheritance. The inclusion of culture in analysis of how genetics becomes part of a construct of biology, reveals the depth and width of culture. The analytical insight is not restricted to culture as a symbolic system or pathway for interpretation. On the contrary, cultural analysis opens up to the detection of relations and processes that expresses power inequality, social processes of marginalisation and exclusion, and economic inequalities. As such the ethical challenges that can be detected in these types of cultural studies of scientific practice in medicine represent key questions for a democratic society.

## Quality of Life and Indigenous populations

Quality of life, or the conditions which foster human thriving have been long considered in Nordic countries, with the first Swedish surveys taking place in 1968. This focus has included Indigenous and minority populations (Hansen et al, 2010, Crondahl and Eklund, 2012).Australia has not paid nearly as much attention to quality of life issues, or the measurement of quality of life (particularly outside of a medical frame). This is particularly true for studies of the quality of life Indigenous populations in Australia (a problem also found in other societies with significant Indigenous populations). It is frequently postulated, however, that quality of life may be a more appropriate and meaningful measure than indicators such as health status to capture the experiences and to explore the expectations of Indigenous populations (Taylor 2008).

Research by 2 of the authors of this paper (Chenhall and Senior) examines the ways in which the inequalities between Indigenous and non-Indigenous health are viewed in Australia; the push to close the gap between Indigenous and non-Indigenous experiences, the recognition of the complex interrelationship of the social determinants of health and an emerging focus of the factors which pre-determine adult susceptibility to disease during pregnancy and early infancy. They examine what scope each of these approaches allows for Indigenous people to position their own values and beliefs about their health and well being, how people's knowledge about the predetermination of some conditions may affect their beliefs and behaviours and the contribution that a focus on life quality may make to addressing some of these issues.

## Closing the Gap

The lives and living conditions of Indigenous populations in Australia are most usually defined by their deficits in comparison with the non-Indigenous population. This is most powerfully stated in terms of the 'gap' in experiences, for example the gap in life expectancy between non-Indigenous males and Indigenous males is 11.5 years and 9.7 years for females (ABS 2012). Closing the Gap is the key platform of the Indigenous Reform Agenda in Australia, agreed from the Council of Australian Government, the peak inter-governmental forum in Australia (FACHCSIA).

Although Chenhall and Senior recognise the importance of reducing inequality across a wide range of social determinants of health and well being, their research is framed by a concern with what it means to Indigenous people, when their lives are continually described in terms of their deficits. Authors such as Pholi et al. (2009) comment that deficit based approaches may contain the potential for further harm through the way that people and populations are labelled, defined and perhaps stigmatized.

## The lived experience of health and well being

Chenhall and Senior's focus is on how people live and experience the complex social determinants that affect their lives and health as well as how their knowledge of the inequalities affects their aspirations and life course planning. For example what decisions do young people make about their future lives when the statistics remind them that their lives will be predictably shorter than the Australian average? For example, Senior commented that her contemporaries in the community assumed that she would outlive them, saying things such as: 'but we won't be around when you are old, we will die a long time before you, Blackbella always do' (Senior field notes 2000).

Their methods combine ethnographic community based research with the use of formal quality of life measurement using the Schedule for the Evaluation of Individual Quality of Life Tool (Hickey et al 1996). This tool, which does not presuppose categories are important to quality of life, allows the individual to generate their own categories.In the studies which they have conducted (Chenhall et al 2009, Chenhall& Senior 2012) they have found that a focus on quality of life as defined by the individual provides an opportunity to talk about future aspirations as well as the supports and resources required to meet these aspirations. The results from this approach alert us to the fact that life quality for Indigenous Australians may have different elements to those of non-Indigenous Australians, and that some facets of a person's life may take more priority than other areas, such as physical health.

Interestingly, despite the emphasis on health as a key indicator of quality of life from a Non-Indigenous perspective, it is rarely mentioned in the interviews which Chenhall and Senior have completed. Their analysis of interviews with 74 Indigenous Adults in the Northern Territory, found that family was by far the most important category mentioned, followed by work, culture and education. This is by no means unique to the Indigenous population, Crondahl and Eklund (2012) recently presented similar results for Balkan Roma adolescents in West Sweden.

In conclusion, although Chenhall and Senior consider that continuing efforts to reduce inequalities between Indigenous and non-Indigenous people is essential, they also see the need to consider how these inequalities are understood and experienced by Indigenous people. Perhaps as important is a recognition of the things in people's lives which contribute to their own life satisfaction, as working within these parameters may offer the most acceptable and meaningful avenue for change. In consequence, the culture of research practice and Dominant culture should both be included in analysis of health and well being, and by doing so the broader context of health and well being and power-relations will be visible and changeable. As in the other areas of focus we have discussed in this paper, such an approach is best facilitated by an inter/trans-disciplinary research approach.

## Cultural challenges at science museums: blending different languages and approaches to build up 'a good story to tell'.

Traditionally conceived as places for collection, study and preservation, science museums have been recently recognized as crucial settings for scientific culture diffusion through informal education and lifelong learning about science and technology innovations, targeted to both schools and broader society (Falk &Storksdieck, 2010). Their mission is being reconfigured to be about disseminating knowledge about new science and technology to the public(s), focusing especially on sustainability issues implied or entailed by science and new technology. This is a change within the museology field, moving from providing science to visitors in the form of definite truths, to providing a context aimed atsupporting the publics' consideration and evaluation of contemporary reality and problems(Quistgaard&Kahr-Højland, 2009). By knowing how science informs everyday lives and how science can be used as a part of people's decision-making processes, visitors are stimulated to gain consciousness of their rights and responsibilities concerning technology transfer into their lives (Árnason 2013). MUSE, the new science museum of Trento[4], Italy for instance, with its sharp profile echoing the surrounding mountains and the eco-compatible criterion concerning its facilities and accessibility, has been projected to be a model of sustainability for the green economy and energy saving, a center of cultural interpretation where nature, science and innovation intermix.

### Ideas and tools for building up 'a good story to tell'

Biotechnology innovations, especially when involved in questions of health and well-being are challenging topics. Creativity is an imperative tool for achieving the new mission for science museums and to conceive innovative approaches that draw from other fields (literature, philosophy, arts etc.) (Lanzinger, 2007). The interdisciplinary approach that blends different languages and approaches is a cultural effort capable of producing 'a good story to tell'. Scientific theatre has become a key approach at MUSE, due to its ability to generate questions and produce deliberative experiences in ways that are both provocative and sensitive (Cox et al., 2009). In 'science lecture-

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[4] http://www.muse.it/it/Pages/default.aspx

performance' scientific concepts and artistic representations (including multimedia and music) are presented in an enjoyable interaction between the science expert and the actor/actress. Particularly intriguing for its scientific, social and symbolic impacts was the case ofthe first immortalized cell line (*HeLa*) established in the late '50s from Henrietta Lacks' rare cervix adenocarcinoma from which scientific knowledge and commercial value have been generated (Svalastog and Martinelli, 2013). The invasive (an aggressive lethal cancer) immortal cells of marginalised origin (a poor, black woman) stimulated the public to reflect on the meaning of important concepts in our society, including the significance of social and material power inequalities to the practice of science.

## A meeting point for fruitful dialogues, public engagement and science showcase

Science museums can operate as a venue that brings culture and science together in a deliberative space, i.e. an 'agora' hosting dialogues between science and society where the various stakeholders can meet (Svalastog et al 2014). They are suitable locations where multiple forms of dialogue between scientific groups and publics' deliberation on controversial science innovation can occur in an open and informed way. The goal is to enable citizens to acquire the necessary capability to face the complex issues of our society, necessary for building-up the democratic possibility to choose among the offers of biology and biomedical innovations entering in their lives (Greco, 2007). However, one benefit of the interdisciplinary approach of contemporary science museums is it requires a rethinking the relationships between science and publics, for example moving away from a 'deficit model' which implies that people need to understand science better and this is what museums can support. Social science approaches can enable more critical agendas that question hierarchies between lay (read as cultural and subjective) and expert (read as scientific and objective) knowledge claims, which can become the basis for new partnerships between scientists and publics searching for sustainable futures(Durant and Legge 2005).

Science museums offer particular spatial locations where culture and science come together in explicit attempts to generate opportunities for public dialogue and deliberation. At their most fruitful the boundaries across disciplinary understandings merge, enabling the science of culture and the cultures of science to become visible.

As such these spaces are deeply political, both in the ways in which they do (and also perhaps do not) enable citizens to become participants in decision-making around science.

## Conclusion

Today we have to approach culture as transgressing the false dichotomies of culture-nature or science-culture. Each is embedded in the other, related in meaning and jointly productive in the creation of claims to knowledge, identity, rights and injustice. Power relations are also present within the ways in which such claims are read and validated by different academic fields of research. The authority structures of institutions such as regulatory ethics procedures and practice or public depositories of knowledge such as museums or science centres inform how we evaluate and define culture in ways that often preclude more critical engagement.Alongside, some actors seek to gain commercial benefit through cultural activity (the marketization of ‘traditional’ knowledge, ways of living, artefacts and locations, or the manipulation of culture by organisations as a mechanism of change). Such neoliberal approaches instrumentalise our understandings of culture and reduce its value to what outcomescanbe manufactured through it.

The value of the interdisciplinary analyses captured in the domains discussed above, is that they draw out the interrelated nature of the practices associated with ‘culture’, ‘ethics’ and ‘science’ in a much more meaningful way. Drawing out such interrelationships is an important stage in thinking through the questions of justice, rights and power, that each of us in our different fields see as vital to our research practice. What we share is a conviction of the need for inter-/trans-disciplinary evaluations of our own disciplines, in order to make visible the culture of Dominant research that resist forms of analysis that question how things are done and why. We also recognise the need to constantly question our own cultural positionings within our disciplines and our society and how we are located within power relations from which we may receive benefit.

**Authors' contributions:**

All authors have read and contributed to the text.

Janice McLaughlin and Anna Lydia Svalastog have co-ordinated the work and shaped the structure.

Main authors for the different sections are:

- Nature and culture or, the culture of nature – Lars Werdelin
- Perspectives on bio-prospecting and sustainable use of biodiversity – HåkanTunón and BeritSmestad Paulsen
- Ethics of research practice – Anna Lydia Svalastog
- Genetics and family as cultural objects of changing and disputed meaning – Janice McLaughlin
- Quality of Life and Indigenous populations – Kate Senior and Richard Chenhall
- Cultural challenges at science museums: blending different languages and approaches to build up 'a good story to tell' – Lucia Martinelli

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