

**Public policy, discourse and risk: Framing the xenotransplantation
debate in New Zealand (1998-2013)**

By

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"But Mr Dent, the plans have been available in the local planning office for the last nine months."

"Oh yes, well as soon as I heard I went straight round to see them, yesterday afternoon. You hadn't exactly gone out of your way to call attention to them, had you? I mean, like actually telling anybody or anything."

[...]

"But look, you found the notice didn't you?"

"Yes," said Arthur, "yes I did. It was on display in the bottom of a locked filing cabinet stuck in a disused lavatory with a sign on the door saying 'Beware of the Leopard'." Ever thought of going into advertising?

- Douglas Adams, [The Hitch-Hiker's Guide to the Galaxy](#)

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Introduction

This thesis focuses on the evolution and framing of xenotransplantation (XTP) policy debate in New Zealand from 1998 to 2011. Its aim is providing a better understanding of both the science-society interface and the importance of issue framing policy debate in understanding of the scientific debate in New Zealand and its relationship with the public. A qualitative study, this thesis draws upon a variety of public science commentary and debate and poses the research question: How did xenotransplantation's introduction and explanation to the New Zealand public inform its current status as a Restricted Procedure under New Zealand law; and what ethical implications arise from this public policy debate for public participation in biomedical research in New Zealand?

Chapter 1 explains the significance of framing in biomedical public policy discussions as seen through the lens of the xenotransplantation debate in New Zealand. This involves a brief examination of xenotransplantation in New Zealand, the regulatory response observed from 1998-2013, and how frame theory can be used to illuminate public policy debate.

Chapter 2 examines relevant literature on xenotransplantation and public engagement. The chapter begins by describing how smaller nations have engaged with biomedical research and how cultural variance has informed this process. Then, how the human element within this public policy discussion can introduce factors such research or audience bias and that this undermines the results of discussion, and ultimately what significance can be attached to public engagement programmes.

Chapter 3 is titled Xenotransplantation: History and Context. While this thesis is exploring public engagement of science in New Zealand, the case study being used is

xenotransplantation. This chapter then will give the reader essential history and context to a relatively obscure medical procedure and the ethical considerations that have arisen from its actual and potential usage.

This is followed by Methodology in Chapter 4; outlining the methods used within and examining frame analysis as a method for examining public discourse and how it has been applied to the xenotransplantation discussion within New Zealand.

Chapter 5 is Presentation and Data Analysis. This chapter presents the observed data and explains the context to specific frame salience, decline or other notable incidences such as event specific frames.

Chapter 6 is the Discussion chapter. It will consider how factors such as key stakeholders and public cultural perceptions influenced discussion on xenotransplantation in New Zealand, but also the discussion itself. This chapter will take a broader look at the debate than what is seen in Chapter 5 by arguing that the result of the salient frames produces a meta-framed cost/benefit analysis. This process and its implication for the public engagement of science in this country will be explored and critiqued.

Chapter 7 includes conclusions and final remarks. This will provide a summary explanation of the thesis and its results. It will discuss the current state of xenotransplantation in New Zealand, the key stakeholders and a reflection on this thesis, its approach to this issue and areas for future research.

Chapter One – XTP and Framing

Xenotransplantation is the transplantation of living animal organs, tissue or cells into the human body.¹ The word, xenotransplantation, has its origins in the Greek word ‘xenos’ - meaning foreign; and it is this foreign nature that is central to the biological and societal issues with this procedure. The central drive for using xenotransplantation (XTP) is the shortage of usable tissue or organs for transplant, though recently, cellular xenotransplantation has been promoted as a cure or relief from chronic conditions and degenerative diseases.

In October 2009, Living Cell Technologies© (LCT) performed a xenotransplantation procedure in New Zealand by successfully injecting porcine pancreatic cells into Type One diabetics with the expectation that the need for insulin injections would be substantially reduced, and with time, eventually eliminated.

It had been eleven years since the New Zealand Government had imposed restrictions on clinical trials of XTP as a measure for public safety. This measure was designed to give the New Zealand Government time to evaluate and legislate for what was effectively, an unregulated risk - while discussing cultural and spiritual concerns with the New Zealand public. How the issue was framed to New Zealanders is significant because of how controversial policy is debated in the public arena informs notions of public trust, informed consent and basic democratic principles.

This study argues that debate framing assigns authority and rationalises certain policy solutions, while minimising other points of view. This allows for support to be mobilised while

¹ Toi te Taiao: the Bioethics Council, *The Cultural, Spiritual and Ethical Aspects of Xenotransplantation: Animal-to-Human Transplantation, A discussion document*, January 2005, Ref. BC 11, Bioethics Council website harvest, mefe.govt.nz

reducing concerns in large sectors of New Zealand society not frequently engaged in the political process. The research will show public debate was rationalised down avenues of conversation that rarely engaged with issues outside of xenotransplantation's uncertain risk of infection; and because of this, substantive policy debate was effectively reduced to be along lines which scientific opinion and business interests had outlined. This meant that authority in discussing XTP ultimately rested with key scientific viewpoints held by stakeholders.

This has large implications regarding how controversial science policy is marketed to the general public, ethnic minorities, social movements and organisations. Both inside and outside New Zealand, public policy debate takes place regarding the advancement of biomedical technologies, such as genetic testing or modification; yet, public input to policy discussion is often relegated to an individual's emotional response, personal story or cultural interpretations that are set apart from industry or government viewpoints or analysis presented as fact.

These are important considerations as XTP is an emerging technology that presents issues with respect to animal transgenics, the expansion of the biotechnology sector and a worldwide tissue shortage that will be expanded on in the next section. As Chapter 2 will include literature that argues the public is able to participate actively in these discussions and able to critique processes that frequently present scientific information to the public without context and evidence. These are considered essential in scientific and academic arenas and show how the separation of expert and lay discourse undermines the significance of public engagement with science. For this reason such public involvement is indicative of public consultation more so than participation.

Context

The success of human organ transplant surgery has increased the life expectancy, and benefited the lifestyles, of those with previously life-threatening illness. However, this now routine procedure called allotransplantation has become a victim of its own success; where organ donation falls short of the need for organs, tissue and cells. Solutions such as XTP have been sought to provide a new source of these materials for the ever growing need as life expectancy grows as well as aging populations in many developed countries.

As of late 2014 there are over 123,000 people waiting for organs in the United States of America and many of those will require more than one transplant.² In New Zealand there were more than 400 people waiting for organ donation at the end of 2011, while the number of deceased organ donors for that year number 38.³ Donors per million of population are 16.4 in the UK, 13.5 in Australia, in New Zealand 8.7.⁴ Even Spain, with its notary presumed consent for organ donation, experiences significant bottlenecks of supply and demand.⁵

Xenotransplantation may also aid in solutions to degenerative illnesses associated with an aging population - such as Parkinson's disease or Alzheimer's, by providing alternative cell and tissue sources. XTP of organ transplants has not succeeded in the long term because of issues that include, but are not limited to: preventing hyper acute rejection, preventing acute vascular rejection, facilitating immune accommodation, inducing immune tolerance and

² U.S. Department of Health and Human Services, Organ Procurement and Transplantation Network, URL: <http://optn.transplant.hrsa.gov/converge/data/>

³ Organ Donation New Zealand, *Waiting List Times*, URL: <http://www.donor.co.nz/index.php/about-transplants/waiting-list-times>

⁴ Organ Donation New Zealand, *ODNZ Annual Report 2013*, URL: http://www.donor.co.nz/files/Annual_Report_FINAL_2013_online.pdf

⁵ Gil-Diaz, Carlos, *Spain's Record Organ Donations: Mining Moral Conviction*, Cambridge Quarterly of Healthcare Ethics (2009), 18: Cambridge University Press, DOI: 10.1017/S0963180109090410, p.257

preventing the transmission of viruses from xenografts into humans - otherwise known as xenosis or zoonosis.⁶

With a worldwide aging population, the issue of organ shortage will only continue to get progressively worse. Xenotransplantation has shown limited but significant success - such as the 1964 transplant of a chimpanzee kidney in a school teacher, who survived nine months before dying of an acute imbalance of electrolytes.⁷ This is compared to the allotransplantation of a heart incurring a 90% survival rate after three years, 70% survival rate of five years and half living ten years or more with a donor heart.^{8,9} More recently, xenogeneic liver perfusion has been used successfully as a bridging technique where the xenograft is attached outside the body until a human organ is available.¹⁰

There also has been proven success in the transplant of cells despite concerns of immune accommodation, but perhaps the most significant concern with XTP can be described in general terms as xenosis. Xenosis is the transference of viral, bacterial or any other type of infection passed from the source animal to human. Some of the most famous examples include the HIV virus - that mutated from chimpanzees' Simian Immunodeficiency Virus (SIV), likely passed to humans through bush-meat cultivation, and the H1N1/09 influenza more widely known as 'Swine Flu' since its 2009 pandemic. In the context of XTP a known virus should not

⁶ Samdani, Tushar, *Xenotransplantation: Overview*, MedScape, URL: <http://emedicine.medscape.com/article/432418-overview>

⁷ Deschamps J.Y., Roux F.A., Sai P., Gouin E I., *History of Xenotransplantation*, Xenotransplantation, Blackwell Munksgaard, 2005, p.90-95

⁸ University of Michigan Cardiac Surgery website, *Heart Transplant - Overview*, University of Michigan Health System, URL: http://med.umich.edu/cardiac-surgery/patient/adult/adultcandt/heart_transplant.shtml

⁹ MedlinePlus Medical Encyclopaedia, *Heart transplant*, National Library of Medicine - National Institutes of Health. URL: <http://www.nlm.nih.gov/medlineplus/ency/article/003003.htm>

¹⁰ Deschamps J.Y., Roux F.A., Sai P., Gouin E I., *History of Xenotransplantation*, Xenotransplantation, Blackwell Munksgaard, 2005, p.90-95

provide a significant risk to xenografts recipients in light of screenings and appropriate treatment; though, endogenous retroviruses (ERVs) remain a concern.¹¹

Endogenous retroviruses are gene sequences embedded in the genetic materials that are passed on to progeny via germ cells. There are tens of thousands of ERVs entrenched in mammalian DNA with estimates that human ERVs (HERVs) comprised between 5-8% of the total human genome.¹² These are mostly traces of ancient viruses that do not function because they are missing large section of their own gene sequences; however, these traces have been found in connection with schizophrenia,¹³ multiple sclerosis, and a number of cancers.¹⁴ The leading candidate for xenografts, pigs, will also likely contain thousands of ERVs buried in their DNA, effectively making porcine endogenous retroviruses (PERVs) invisible until they activate and express symptoms. In addition, the ways in which ERVs are activated are not fully understood and may not activate for years or decades.

This provides another set of issues in regards to the novelty of the infection and its symptoms. The worst case scenario is similar to the HIV/AIDS pandemic. Retroviruses are persistent infections which remain clinically quiescent for long periods before showing the symptoms of disease.¹⁵ A lack of information and understanding about the virus could allow it

¹¹ Bernhard J. Hering, David K. C. Cooper, Emanuele Cozzi, Henk-Jan Schuurman, Gregory S. Korbitt, Joachim Denner, Philip J. O'Connell, Harold Y. Vanderpool and Richard N. Pierson III, *The International Xenotransplantation Association consensus statement on conditions for undertaking clinical trials of porcine islet products in type 1 diabetes – Executive summary*, *Xenotransplantation*, 2009: 16 196-202

¹² Ryan F.P., *Human endogenous retroviruses in health and disease: a symbiotic perspective*, *Journal of the Royal Society of Medicine* 2004;97(12), URL: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1079666/>

¹³ Yolken, Robert, *Viruses and Schizophrenia; a focus on herpes simplex virus*, *Herpes* 11:2(Suppl):83A-88A, 2004, Stanley Division of Developmental Neurovirology, Department of Pediatrics, Johns Hopkins School of Medicine, Baltimore, Maryland, URL: <http://www.ncbi.nlm.nih.gov/pubmed/15319094>

¹⁴ Ryan F.P., *Human endogenous retroviruses in health and disease: a symbiotic perspective*, *Journal of the Royal Society of Medicine* 2004;97(12), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1079666/>

¹⁵ Bernhard J. Hering, David K. C. Cooper, Emmanuelle Cozzi, Henk-Jan Schuurman, Gregory S. Korbitt, Joachim Denner, Philip J. O'Connell, Harold Y. Vanderpool and Richard N. Pierson III, *The International Xenotransplantation*

to spread and infect large portions of the general population. In addition to this, there are no clues to how an intact or partial PERV would interact with the human body outside a direct expression; as noted above, the associations between HERVs and illnesses such as schizophrenia, MS and cancer have only recently been observed.¹⁶

Within the last two decades there have been a small, though significant number of xenotransplant patients of various types. Studies of these patients have found no evidence of ERV infection. Some however, did demonstrate evidence of micro-chimerism showing that they continued to have a number of replicating porcine cells in their bodies that would provide ongoing exposure to gene sequences that would include PERVs.^{17,18}

In August 1998, The Lancet published three research articles on the subject of PERVs and the susceptibility of humans to infection. Two of the articles showed no indication of infection to people who had received living pig tissue. The third showed that invitro, PERV shed by pig kidney cells could infect human cells.¹⁹ As mentioned previously, subsequent testing has failed to find or produce PERV infection; yet biomedical science has shown issues in replicating published medical studies. Pharmaceutical companies Amgen and industry rival Bayer both revealed that they were unable to reproduce findings to replicate more the two-thirds of published studies identifying possible drug targets.²⁰ Bayer HealthCare in Berlin in particular,

Association consensus statement on conditions for undertaking clinical trials of porcine islet products in type 1 diabetes – Executive summary, Xenotransplantation, 2009: 16 196-202

¹⁶ Jern, Patric, and Coffin, John M., Effects of Retroviruses on Host Genome Function Annual Review of Genetics Vol. 42: 709-732 (Volume publication date December 2008) DOI: 10.1146/annurev.genet.42.110807.091501

¹⁷ Ibid.

¹⁸ Microchimerism is the presence of genetically different cells in the subject as a result of exposure to another subject. The most common form in humans is feto-maternal micro-chimerism, where foetal cells pass through the placenta and have cell lineages within the mother decades after exposure.

¹⁹ Grierson, Simpson, FindLaw.com – For Legal Professionals, *The Low Down on Xenotransplantation*, URL: <http://www.findlaw.com/12international/countries/nz/articles/1526.html>

²⁰ Prinz, Forian, Schlange, Thomas and Asadallah, Khusru, *Believe it or not: how much can we rely on published data on potential drug targets?*, Nature reviews, Drug discovery, 10; 712, September 2011, DOI: 10.1038/nrd3439-c1

published that they were unable to in 47 of 53 or 89% of apparently ‘landmark’ studies; in a call to raise standards of preclinical cancer research.²¹

According to Prinz et al., this *indicates the limitations of the predictivity of disease models and also that the validity of the targets being investigated is frequently questionable.*²² Meaning, that while the study was focused on repeating drug trials, this has consequences for all biomedical science and in particular relevance to this study, the predictive credibility of disease models and risk assessments based on those models that were used to inform public concerns regarding xenosis. So while there is no recent evidence to suggest a likely risk of infection through xenotransplantation, the ability of researchers to replicate the original Lancet studies appears to be substantially less than the expectations many might assume or claim, and as such, might not be considered to be evidence of low risk in of itself being that *in the absence of hard data, attempts to assess risks and develop a rational policy are excises in reasoned speculation.*²³

Indeed, recent data suggests PERV expression and interaction with human cells i.e. xenosis infection, while unlikely, is possible. Proponents of XTP have cited the use of breeding pathogen free pigs that in reality contain PERV variants. PERV-C while unable to infect human cells, PERV-A/C recombinant viruses are able to infect human cells and exhibit high viral loads, precluding assertions for PERV-C pig populations being free of infectious competence.²⁴ However, rather than risk a more virulent PERV-A/C recombinant the International Xenotransplantation Association recommends using pig populations with low viral loads of

²¹ Begley, C., Glenn and Ellis, Lee M., Drug Development: *Raise standards for preclinical cancer research*, Nature 483, 531–533, 29 March 2012, DOI:10.1038/483531a

²² Prinz, Forian, Schlange, Thomas and Asadallah, Khusru, *Believe it or not: how much can we rely on published data on potential drug targets?*, Nature reviews, Drug discovery, 10; 712, September 2011, DOI: 10.1038/nrd3439-c1

²³ Chapman, L., *Speculation, Stringent Reasoning and Science*, 1999, 77, 68-69, Bulletin of the World Health Organisation, URL: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2557575/>

²⁴ Fei Guo, Xiaowei Xing, Wayne J Hawthorne, Qiong Dong, Bin Ye, Juan Zhang, Qi Liang, Wei Nie1 and Wei Wang, *Characterization of PERV in a new conserved pig herd as potential donor animals for xenotransplantation in China*, *Virology Journal* 2014, 11:212, DOI:10.1186/s12985-014-0212-1, URL:<http://www.virologyj.com/content/11/1/212>

PERV-A and PERV-B with lower probabilities of xenosis transmission. So while transmission of PERV variants is generally accepted to be low, it remains a permanent risk of XTP research.²⁵²⁶²⁷

XTP and Ethics in New Zealand – Governmental Response

The concern about xenosis as a consequence of xenotransplantation peaked in August 1998 when The Lancet published three research articles on the subject of PERVs and the susceptibility of humans to infection. Two of the articles showed no indication of infection to people who had received living pig tissue. The third showed that in a lab, PERV shed from a pig kidney could infect human cells.²⁸

At the time these papers were published there was no distinction between xenotransplantation and any other type of clinical trials in New Zealand. XTP was therefore subject to the requirements of safety under the Medicines Act 1981.²⁹ The Ministry of Health's concern about ERV xenosis meant that the Minister declined all applications for clinical trials – amounting to a de facto moratorium.³⁰

²⁵ Burlak C, Wilhelm JJ. *Xenotransplantation literature update*, September—October 2014. *Xenotransplantation* 2014; 21: 584–587, 2014 John Wiley & Sons A/S. Published by John Wiley & Sons Ltd.

²⁶ Fei Guo, Xiaowei Xing, Wayne J Hawthorne, Qiong Dong, Bin Ye, Juan Zhang, Qi Liang, Wei Nie1 and Wei Wang, Characterization of PERV in a new conserved pig herd as potential donor animals for xenotransplantation in China *Virology Journal* 2014, 11:212DOI:10.1186/s12985-014-0212-1, URL:<http://www.virologyj.com/content/11/1/212>

²⁷ Hering, Bernhard J., Cooper, David K. C., Cozzi, Emmanuelle, Schuurman, Henk-Jan, Korbitt, Joachim, Gregory S., Philip J., Denner, O'Connell, Vanderpool, Harold Y., and Pierson III, Richard N., *The International Xenotransplantation Association consensus statement on conditions for undertaking clinical trials of porcine islet products in type 1 diabetes – Executive summary*, *Xenotransplantation*, 2009: 16 196-202

²⁸ Kiessig, Martin U, V, Blusch JH, Haverich A, von der Helm K, Herden T, Steinhoff G., *Expression of pig endogenous retrovirus by primary porcine endothelial cells and infection of human cells*, *Lancet*, 1998, Aug 29;352(9129):692-4.

²⁹ Grierson, Simpson, The Low Down on Xenotransplantation, FindLaw.com – For Legal Professionals, April, 2002, <http://www.findlaw.com/12international/countries/nz/articles/1526.html>

³⁰ The Evening Post, 17 NOV 2001, Edition 3, Page 10. *Diabetes treatment ban angers patients*, NAPP

In 2001 the Royal Commission on Genetic Modification recommended a moratorium on trials and deferred the issue to the Bioethics Council; a governmental advisory group run under the Ministry for the Environment. In December 2001, Under Urgency, the Supplementary Order Paper (SOP) 231 was attached to the Hazardous Substances and New Organisms (Genetically Modified Organisms) Amendment Bill. The intention of the Bill was to amend the Hazardous Substances and New Organisms Act 1996; *to allow time to establish a Bioethics Council, conduct research on environmental and socio-economic impacts.*³¹

SOP 231 amended the Medicine Act 1981, imposing restrictions on XTP because the procedure *may pose threats to individuals and to the public, and may raise ethical, cultural, and spiritual concerns.*³² In May 2005 The Medicines (Specified Biotechnical Procedures) Amendment Bill extended the moratorium controls on xenotransplantation to 31 December 2006, with the ability for this to be extended by Order in Council if considered necessary.

After this time, the restrictions on XTP meant that that an application to MedSafe for an exemption under Section 30 of the Medicines Act (1981) could be requested. As the legislation currently stands, xenotransplantation is listed as a *restricted procedure* in Part 7A of the Medicines Act, and can only be authorised by the Minister of Health.³³ For any application looking to be approved, clinical trials of xenotransplantation must be deemed to *not pose an unacceptable risk to the health and safety of the public, and any ethical, cultural, and spiritual issues associated with the procedure must have been adequately addressed.*³⁴

³¹ Peterson, Dana Rachelle, Background Paper No 26, Genetic modification: *A resource document for New Zealand MPs*, February 2002, Parliamentary Library, http://www.parliament.nz/NR/rdonlyres/4CA0C507-3047-486B-8E6C-DFE9AB761E/416/BP26_GeneticModification3.pdf p. 21

³² Ibid.

³³ Gene Technology Advisory Committee, *GTAC Guidelines for Preparation of Applications Involving Clinical Trials of Xenotransplantation in New Zealand*, September 2007, Ministry of Health, New Zealand, p 1

³⁴ Ibid.

International Response to XTP risk

Concerns regarding xenosis were not isolated to New Zealand. The Governments of Canada, Spain, The United Kingdom and The United States were also quick to put measures in place to not only help define the associated issues but also regulate, and in many cases, impose a moratorium-type hold on clinical trials.³⁵

The World Health Organization (WHO) also expressed concern about the risk of xenosis and in 2004 the member states of the WHO adopted a resolution addressing the risks associated with xenotransplantation; urging member States *to allow xenotransplantation only when effective national regulatory control and surveillance mechanisms overseen by National Health Authorities are in place*.³⁶ Additionally, the WHO advisory group and other experts concluded that more effective measures needed to be put in place to stop the illegal performance of xenotransplantation; and, that greater effort was needed to address the needs of harmonised quality of xenograft sources and safety controls.³⁷³⁸

Governments throughout Europe, North America and Oceania have had public dialogue regarding xenotransplantation. This has helped to produce significant literature on the public engagement of science (PES) and public understanding of science (PUS) which seeks to understand the methods, goals and intentions of the scientific community and their

³⁵ Biologics and Genetic Therapies Directorate Health Canada, *Revised Fact Sheet on Xenotransplantation*, URL: http://www.hc-sc.gc.ca/dhp-mps/brgtherap/activit/fs-fi/xeno_fact-fait-eng.php

³⁶ Bagozzi, Daniela, *Animal to human transplantation — future potential, present risk*, World Health Organization, Media Centre, 2 May 2005, URL: <http://www.who.int/mediacentre/news/notes/2005/np08/en/index.html>

³⁷ Ibid.

³⁸ WHO Global Consultation on Regulatory Requirements for Xenotransplantation Clinical Trials *The Changsha Communiqué*, Changsha, China, 19-21 November 2008, URL: www.who.int/transplantation/xeno/ChangshaCommunique.pdf

relationship with the public. This will be explored further in Chapter 2, but together, these efforts, alongside the IXA position regarding communal consent, express a rationale that because the public will be directly affected by developments in biomedical science and technology, some measure of public sanction is needed.

The measure of this admission appears to be in the form of governmental advisory bodies. In the cases of the New Zealand, the United Kingdom and Canada, advisory bodies set up extensive networks of workshops, published discussion documents and provided publically accessible conclusions and recommendations to their governments. This was communicated through the media and interacted with reactions within the public arena to form public debate and opinion. How this interaction shaped what was being discussed and how this influenced public policy is the topic of this thesis.

Research Aims and Methodological Approach: Frame Theory

Frame theory is the central lens this study views its primary data. This paper utilises the definition of framing put forward by Entman: *Framing is an omnipresent process in politics [...] It involves selecting a few aspects of a perceived reality and connecting them together in a narrative that promotes a particular interpretation.*³⁹ This is done as to shape audiences' perceptions by introducing or promoting the significance of ideas when evaluating a political object.⁴⁰

To achieve success, frames are generally required to resonate with the audience by melding congruent ideas that may include cultural knowledge, fairy tale references or character

³⁹ Entman Robert M., *Media framing biases and political power: Explaining slant in news of Campaign 2008*, *Journalism*, 2010, 11: 389, p. 391, DOI: 10.1177/1464884910367587, URL: <http://jou.sagepub.com/content/11/4/389>

⁴⁰ Ibid.

archetypes. Doing so enables the frame sponsor to convey information by providing a concise emotive direction and narrative. This is done by using conceptual hooks such as public safety or child welfare, in an attempt to galvanise support that crosses community schisms such as socio-economic status, cultural identity or religious conviction.

Since the 1998 halt on xenotransplantation in New Zealand and its subsequent resumption at the end of 2006, it is relevant to investigate how the debate changed and shifted over time and if this change could be seen as contributing to its current legality. Seeing what frames were used to discuss XTP over time, this thesis will analyse events and investigate frame sponsors to see how they sought to shape frame usage to mould public opinion.

The aim of this thesis is to determine how controversial policy is debated in the public arena, and how public discussion is influenced. Xenotransplantation provides an interesting case study, not only because of the potential risks, but also how these risks were received by broadcasting and print media and then related to the public. One reason for this is how XTP easily lends itself to creative interpretation. The idea of melding human and animal has provided countless folk tales and myths - all of which feed a collective mental association with modern XTP.

Framing XTP a certain way brings with it preconceived ideas, emotions and narratives that draw on these associations and can influence how an audience will respond. How the argument is framed, might provide answers to why certain sectors of the population respond in the manner they do, not only to the issue, but to other community groups. Framing enables stakeholders such as scientists to not only explain the technical aspects but direct what material brought to public attention, predicting public response. This research is designed to identify the frames used, what was being conveyed through the available material and what

narratives were being presented to the New Zealand public. In doing so, this thesis will identify how the discussion took shape, what frames - if any - achieved dominance, and if so, which issues were addressed by dominant frames and which were overlooked.

It is important to note at this point that identified frames in this paper are not assumed to dictate moral judgement. Identified frames, do not neatly fall into positive or negative categories. One example of this is how perceptions of medical risk came to be used over the course of the analysed time period; medical risk, whether high or low, was all tabled as a *Risk-Medical* frame because the connection of risk to XTP shaped how XTP was to be perceived and discussed.

Because of this, analysis of the particular frames in context is essential to providing insight to stakeholder framing; deploying frames in ways such as public health, risk, economic investment, potentially lifesaving technology or sensationalist, articulates clues as to what the stakeholder wants, and the ways in which they want the public to see the issue, and in some cases, the debate itself. Through analysing the debate using frame analysis, conclusions are able to be drawn on who is being addressed and what sectors of the population stakeholders are trying to mobilise.

How the different parties used competing language, allows for greater transparency of the process of political and financial mobilisation. The research is designed to illustrate how stakeholders attempt to do this through the use of key words, arguments and metaphors over the specified time period. In doing this, it is intended to provoke a greater understanding of public debate in media and its influence on policy, while contributing to the literature on frame analysis and public policy.

The findings in this thesis will reveal that public policy debate was effectively managed by frame sponsors; the relative obscurity and complexity of the xenotransplantation debate facilitated the mobilisation of varied interests and the acquiescence of the population in the deployment of public resources.⁴¹ The findings should be of interest to those in the areas of public policy, public engagement of science and frame analysis.

⁴¹These public resources include government grants to Living Cell Technologies and the Invercargill Mayoral Fund.

Chapter Two – Literature Review

This chapter covers the relevant literature for the public engagement of science, the concept of brand states and the public experience and attitude towards xenotransplantation. The potential medical and economic gains biotechnology presents has provoked many nations into funding various biotechnologies. Especially in smaller countries such as New Zealand, Singapore and Iceland with limited resources there have been efforts to brand countries with the ‘Biotechnology’ label in order to entice both domestic and international investment.⁴²⁴³

As part of this effort, there has been an increase in the public engagement with science (PES) in many countries. The literature regarding this development has been observed to be hopeful yet critical of methods and claims of success. It is these case studies of PES and their literature, which inform the theoretical framework of this research project.

Brand States / Public Engagement / Scientific Citizenship

The growth of biotechnology in smaller countries can be seen as an effort to deal with competitive advantage of nations in a global economy. Porter has argued that in contrast to traditional knowledge about national economies, industry-specific circumstances, choices and outcomes can overshadow national factors when influencing winners and losers in the global

⁴² Friedman, Yali, *A global Biotechnological Survey—Worldview Scorecard*, Scientific American Worldview, URL: saviw.com/article/a-global-biotechnology-survey-worldview-scorecard

⁴³ Chan, Robin, *Ministry of Trade and Industry; Making Singapore a city of opportunities*, Straits Times, 12 October 2011, Singapore Press Holdings Limited

economy.⁴⁴ This can be seen in how resource-poor nations become successful despite deficits, inflation and high interest rates.⁴⁵

For Porter, national competitiveness arises from how a nation's resources are deployed in order to export highly productive items.⁴⁶ Biotechnology is one such area and state branding is one way of bolstering small economies in the global context. This is an important tool for driving foreign investment as Van Ham argues that a state brandings comprises the international audience's perception of that nation and that having a poor brand, or a lack of brand affects their international competitiveness.⁴⁷ A notable example of the biotechnology brand is that of Singapore's Biopolis, where key biomedical research institutes were brought together with local and international biotechnology and pharmaceutical companies. This was an effort designed to create and develop a regenerative bio-economy for the Singaporean state, which included the [*recalibration of*] *the relationships between the biological and political life of the Singaporean population.*^{48,49}

This interaction of biological and political life in small nations is in many ways dependent on cultural factors and histories. This can be seen in the experiences of Iceland, Estonia and

⁴⁴ Friedman, Yali, *A global Biotechnological Survey—Worldview Scorecard*, Scientific American Worldview, URL: saviw.com/article/a-global-biotechnology-survey-worldview-scorecard

⁴⁵ Ibid.

⁴⁶ Ibid.

⁴⁷ van Ham, Peter, *The Rise of the Brand State: Postmodern Politics of Image and Reputation*, Foreign Affairs, Vol. 80, No. 5 (2001) p. 2-6, URL: jstor.org/stable/20050245

⁴⁸ Waldby, Catherine, *Singapore Biopolis: Bare Life in the City State*, East Asian Science and Technology Society: An International Journal, Vol. 3, No. 2-3, 2009, p. 367-383, URL: http://www.biocultures.org/index2.php?page=member_details&ID=113

⁴⁹ Normile, Dennis, *Can Money Turn Singapore into a Biotech Juggernaut?*, Science, New Series, Vol 297, No 5586 (2002), p.1470-1473, URL: jstor.org/stable/3832461

Tonga, and their relationship with biotechnology and the issues that arose.⁵⁰ Informed consent became an issue for Iceland as outcry grew in response to an imposed standard of presumed consent to acquire their health records and sample data.⁵¹

The Estonian public, despite a history of living under state oppression during their time in the Soviet Union, and an apparent general disregard for the notion of public trust, it was felt that legislative promises of legal protection regarding employment or insurance discrimination addressed their main concerns regarding growth in their biotechnology sector.⁵²

And in Tonga, the lack of public consultation, and that the extended family as the cornerstone of identity and daily life in the Pacific Islands, shifted focus from personal informed consent, to notions of collective consent.⁵³ This position in particular has significant implications for the New Zealand context where both Maori and Pacific identities view extended family and community as integral to an individual's daily experience; this is compared to a more individualistic approach typical of Western notions regarding informed consent. Later in this thesis, this disparity is shown to be a significant factor of New Zealand's XTP debate by how such concerns were received and reframed by stakeholders.

⁵⁰ Barker, Jeffrey H., *Common-pool resources and population genomics in Iceland, Estonia, and Tonga*, 2003, Kluwer Academic Publishers. Scientific Contribution, Department of Religion and Philosophy, Converse College, URL: <http://link.springer.com/article/10.1023/A%3A1024137832504>

⁵¹ Ibid.

⁵² Ibid, 140

⁵³ Within and Beyond: The Limits of Human Nature: A Working Conference on the Challenges of the New Human Genetic Technologies, 12-15 October 2003, Panel presentation transcript: *Biopolicy and Biopolitics in the Pacific Islands*, Heinrich Böll Foundation, Berlin, Germany, URL: http://www.biopolitics-berlin2003.org/program_rt.asp?id=59&summ=1

These cultural factors play heavily into what Tupasela refers to as an *economy of hope*.⁵⁴ This economy of hope is the drive for personal or financial investment, not for a particular drug or medical apparatus, but a *prospect of hope* - where the production and consumption of such a product is set in the near future when supporters, especially actual or potential investors, can take advantage of these promised technological advances.⁵⁵ In light of this Tupasela points out that money, political will or taxpayer support is being exchanged for promises; so much so, that the *economy is virtual and, in fact imaginative, based essentially on expectations*.⁵⁶

In relation to xenotransplantation and this research, an economy of hope has been deployed by referencing issues such as organ waiting lists or type 1 diabetes, suggesting XTP might be an effective treatment or cure in the near future. What tempers this economy of hope is the reputation of science and scientists in the country the economy of hope is being deployed.⁵⁷ So that if particular scientists or scientific communities too often deploy the economy of hope without results, or if the authority of the scientific community is undermined by perceived failures or scandals, deployment of an economy of hope narrative is unlikely to resonant with an audience and fail to generate the manner of support the narrative is designed for.

What has spurred the development of economy of hope narratives is the speed at which technological progress is progressing. Due in part to the lack of connectivity pre 20th Century technological advancement was significantly slower than the present. By the early 20th Century change in the public's daily lives by way of technological progress was occurring regularly and

⁵⁴ Tupasela, Aaro, *Re-examining medical modernization: framing the public in Finnish biomedical research policy*, *Public Understanding of Science* 16: 63, DOI: 10.1177/0963662506070182 2007, URL: <http://pus.sagepub.com/content/16/1/63>, p.67

⁵⁵ Ibid.

⁵⁶ Ibid.

⁵⁷ Ibid.

within living memory. Due to shift, Tupasela argues that expert framing shapes the context of biotechnology to that of commercial and medical promise, making policy formation easier to negotiate. More specifically, that medical modernisation and expert framing has formed an economy of hope essential to medical modernisation industry wide.⁵⁸

This enables the enlistment of public resources and vision regarding development in biotechnology where the construction of dual roles for citizens are deployed; they are to both accept the discourse applied by experts and then support these research agendas receiving public resources - a process Tupasela describes as the construction of passive/active citizens and considers necessary to the medical modernisation of developed economies.⁵⁹

The concept of passive/active citizens is of direct relevance to this research as it is suspected that a similar process occurred in New Zealand for issue of xenotransplantation. What follows is how this might have also occurred for the issue of genetic modification in New Zealand, another significant biomedical issue for the New Zealand Public.

The creation of passive/active citizens can be seen in the deproblematization of consensus politics. Goven describes how concerns brought forward by public consultation were rationalised into dominant scientific and economic narratives designed to produce 'resignation to the inevitable'⁶⁰ Due to the concerns and resistance new biological technologies tend to invoke, there has been an increase of the use of consensus conferences based on the model developed by the Danish Board of Technology.⁶¹

⁵⁸ Ibid, 64

⁵⁹ Ibid.

⁶⁰ Goven, Joanna, *Deploying the consensus conference in New Zealand: Democracy and de-problematization*, Public Understanding of Science, 12 (2003) p. 423

⁶¹ Ibid, 424

Goven evaluates the Danish model's potential in managing the known and continuing issues of competency and legitimacy in policy making, by utilising the participatory approach to remedy the shortcomings of expert discourse; primarily by providing a counterweight to the previously ignored or undervalued impact biotechnology may have on individuals and communities. Goven outlines the Danish method of consensus models and gives an account of its usage in New Zealand in 1996 and 1999, the manner in which it differed in practice, how it came to be framed by organisers and panellists, and the implications of this for future attempts.⁶²

The origins of the consensus conferences are a notable point of difference. In Denmark the program was part of a wider assessment program, while in New Zealand it spawned from public sector scientists focused on public understanding and support of science.⁶³ Because of this, New Zealand's initial 1996 and 1999 conferences can be considered to have suffered from a lack of perspective and support.⁶⁴

Primary factors were twofold: firstly, organisers centred on a deficit model, seeking to change debate by rationalising and educating - assuming that tensions regarding genetic modification came from a lack of understanding or rational thought.⁶⁵ Secondly, that the

⁶² The Danish Template: Panels of 12-16 lay people are drawn from random samples of 2000, recruited by letter or publication that requires they write a letter describing themselves, the reasons they should be in the panel and outlining their specifics of age, race, gender, education, occupation, etc. as to allow a diverse panel to be assembled of 'lay people' (i.e. people without professional expertise or vested interest). The selected panel is then give preparatory weekends (usually two, a month apart) to familiarise themselves with the issues, formulate an opinion and questions they would like to ask and the type of expert they would like to hear from. The conference itself is varied forms of question/answer between the panel and the experts in an open forum allowing the juxtaposition of expert opinions. The panel then formulates conclusions and recommendations and presents this to an audience that includes the previously mentioned experts who are given the opportunity to correct any factual errors, but not otherwise influence the panel's report, which is then released to Parliament and the public.

⁶³ While this may have been the case for the origins of the consensus conference in New Zealand, the Bioethics Council changed this, forming a wider technology assessment program.

⁶⁴ Goven, Joanna, *Deploying the consensus conference in New Zealand: Democracy and de-problematization*, Public Understanding of Science, 12 (2003), p. 426

⁶⁵ Ibid.

nature of these conferences, its origin and well based concerns about bias prevented the recruitment of non-governmental scientists, experts and organisations. It followed then, that in practice these conferences were criticised for having more time allowed for expert panels than citizen deliberation, for lack of independent oversight and investigation, and for producing reports focused on technical or regulatory critiques over providing a voice for the public.⁶⁶

This is not to say however that the organisers of the 1996 and 1999 conferences were unaware or not cautious of source bias. In both examples there were dissenting voices, in order to give the panel, *balance, even handedness or two sides*.⁶⁷ This does however, presents its own issues as there are naturally more than ‘two sides’ to complex biotechnology issues and such a position can be a frame in itself, undermining more nuanced positions.

Such *balance* characterised by for-or-against mentalities often ignores personal, cultural or spiritual concerns which don’t necessarily fit into such binary issue framing. Such problem framing, for the most part, fails to address these concerns or attempts to place them within an oppositional or advocacy role in contrast to science, further reinforcing a deficit model mentality. Further, this duality in ideas regarding public opinion is an interesting feature of the XTP debate in New Zealand, especially as it is often drawn down racial/ cultural lines. A more in-depth analysis of this aspect of the XTP debate will take place in the Discussion Chapter alongside other facets of the XTP debate.

Goven’s argument regarding the deficit model and its role in the construction of the scientific citizen is also seen in Irwin’s analysis of British reaction in the wake of the Foot and

⁶⁶Ibid.

⁶⁷Ibid.

Mouth (BSE) Crisis, as well as looking at how this crisis affected policy and consultation processes for the introduction of genetically modified foods.⁶⁸

After the BSE crisis, British public confidence in the effectiveness of government regulation and response to biological crises were visibly shaken.⁶⁹ Therefore reaction to the development of such technologies was tempered but not wholly negative; genetically modified organisms (GMOs) were met with apathy - provoked by general moods of inevitability and fatalism about biotechnology development with reports noting, *mixed feelings about the integrity and adequacy of government regulation, and in particular about the scientific assurances of safety.*⁷⁰ Numerous public consultations about GMOs in food took place in an effort to *explore public hopes and concerns and feed these in the policy process*⁷¹

Irwin asks how this factors into the construction of the scientific citizen as part of such processes. Noting in addition, this question's importance now that the literature and much public policy among developed nations has moved on from questions of *if* such public involvement is valid, to *what* forms public involvement will take. While public consultations were focused on the increase of knowledge and transparency, it is seen as done primarily to increase public confidence in the government and their ability to manage and utilise scientific knowledge.⁷²

Irwin shows that despite the calls for citizen-led public consultation in Britain: *it is through the agenda of Minister for Science, Lord Sainsbury, that by setting questions from the outset undoubtedly*

⁶⁸ Irwin, A., *Constructing the scientific citizen: Science and democracy in the biosciences*, Public Understanding of Science, 2001; 10; 1, DOI: 10.1088/0963-6625/10/1/301, p.1-18

⁶⁹ Ibid.

⁷⁰ Ibid, 5

⁷¹ Ibid.

⁷² Ibid.

*limited discussion by determining the legitimate areas of discussion.*⁷³ Irwin describes this as *pre-framing*.⁷⁴ So despite the opportunities for impromptu discussion, the public consultations were clearly shaped and guided by format, government, researchers from market research group Ipsos-MORI and the advisory group experts.⁷⁵

Public discussion was so prescribed that the House of Lords Select Committee, despite acknowledging it developed a rich understanding within the participants, noted that the *exercise [was] closer to market research than to public consultation.*⁷⁶ Because of this, the claims of that series of consultations and others which draw from a deficit model of public engagement as being citizen-led are undermined and undeserving of the legitimisation citizen participation offers.

While being aware of the deficit model, government organisers repeated its assumptions by imagining that science and fact could be detached from opinion and judgement, and that being able to do so would enhance public debate. This has implications for the value of the Bioethics Council-led consultations for XTP as its mandate was also based on the idea that scientific fact could be separated from opinion by focusing on the ethical, cultural and spiritual concerns of the public. It is reasonable to argue that the discussion document presented by the Bioethics Council - which outlined the issues of spirituality, nature, identity, animal rights and Maori views, were similar in effect as Lord Sainsbury's agenda-setting questions, limiting a potentially more diverse, representative ground-up approach to discussion in these areas.

⁷³ Ibid.

⁷⁴ Ibid, 9

⁷⁵ Ibid, 13

⁷⁶ Ibid.

These case studies have shown that the assumptions associated with the deficit model fails to account for the real abilities of the public to understand and react to complex scientific issues. Presumptions on how the public should respond to information ignore the knowledge and valid judgment public engagement can bring. Disregarding this input weakens the policies the public engagement of science is designed to inform. The changing role of the public understanding of science from lecturing from a position of authority to assisting in building informed opinions and critiques of new technology, reinforce this position.⁷⁷

How the production of 'better informed' citizens and debate will progress is as yet, unclear. While further education may indeed be the foundation of effective deliberative democracy, it also runs the risk of the deficit model assumptions regarding what is, and is not, legitimate debate on these issues and the correction of opinions not directly related to factual inaccuracies.

Ultimately, the literature reviewed suggest that public engagement with biotechnology is a process characterized by: cultural difference informing public concerns, interaction of biological and political life is observed most acutely in consensus politics, the 'economy of hope', and passive/active citizens. The next section illustrates how the presentation of scientific information is affected by the human element in these processes, by looking at factors such as source and audience bias.

⁷⁷ Elam, Mark and Bertilsson, Margareta, *Consuming, Engaging and Confronting Science: The Emerging Dimensions of Scientific Citizenship*, European Journal of Social Theory, 2003, 6:233, URL: <http://est.sagepub.com/content/6/2/233>, p239

The Human Element in Engagement Politics

Science, much like other specialised subjects, is prone to expert framing because much of the public lacks the prior knowledge or existing frames that can mitigate frame resonance in individuals. In light of this, science traditionally enjoyed a reputation of being factually unbiased by the reputation of relying on empirical evidence and the general inability of the public to refute or critique scientific claims. Together these factors cemented the place of the scientific community as position of authority on many diverse topics. In recent decades however controversies such as the Foot and Mouth (BSE) crisis in the United Kingdom, Bio Banking protests in Iceland and the meltdown at the Fukushima Daiichi nuclear reactor in Japan have shown the realities and fallibilities of scientific evaluations, crisis response, and risk assessment.

While initially the public understanding of science field (PUS) highlighted the disconnect between public ignorance of rudimentary science in developed societies, the more recent field of public engagement of science (PES) is dedicated to bringing scientific and public communities together after recognizing a lack of public confidence in science as the overriding concern.⁷⁸

As will be shown later in this section, the efforts in PES have generally received a positive reception from the public, yet those in industry and academia have more cautious in their response. While being mostly supportive of the idea of PES, the literature debates the methodology and legitimacy of the majority of large scale PES cases. Despite this, there has

⁷⁸ Elam, Mark, *When Scientists Meet Film-Makers: Inventing a Swedish Approach to Public Engagement with Biotechnology*, Gothenburg University, Sweden *Acta Sociologica* September 2005, Vol 48(3): 237–251, DOI: 10.1177/0001699305056565 (2005) p. 48

been substantial progress showing that uncertainty is more widely accepted than previously thought, and that the uninitiated public is capable of engaging and providing justifiable positions on a wide range of scientific issues -including bio-banks, nanotechnology and xenotransplantation.

Public distrust in science may well be appropriate as while the scientific method for observation and analysis has been generally held in high esteem, its weakness, the human element, can cause biased hypotheses, source material or interpretation of data. All of which can skew research and findings.

Murphy looks at this human element by exploring the personal bias of expert testimonies in regards to nicotine addictiveness, by three different types of organisation.⁷⁹ Pro-tobacco, anti-tobacco, and independent experts would consistently favour their own institutions through framing evidence to support the strategy of their sponsors.⁸⁰ Such obvious biases undermine the objectivity statistical extrapolation assumes and corrupts the foundation of how the public traditionally sees and understands science.

The growing realisation that numbers are not inert, can, and have, been manipulated in their presentation to the public, may ultimately lead to a hostile environment for science. As much of science community's interaction with the public are the statistical or lab-based approaches to risk management. The scientific community runs the risk of losing their credibility and weaken the efforts of those in PES. In addition to this, the culture of peer review and publically-feuding experts may well be normal within academia and industry, but

⁷⁹ Murphy, Priscilla, *Affiliation Bias and Expert Disagreement in Framing the Nicotine Addiction Debate*, *Science Technology Human Values*, 2001 26; 278 p. 301

⁸⁰ *Ibid.*

the public reaction is often of disillusionment and anxiety of presented risks due to lack of consensus.⁸¹

Further obstacles to effective science communication are how scientists and experts react during engagements between the public and the scientific community. Cuppen et al. found that attitude correspondence, phrasing and source bias were primary factors in how scientists responded to material, arguments and frames, and analysed how this corresponded to initial expectations of both expert and lay opinions.⁸²

It was found there was indeed a correspondence between negative initial expectations and credit given to presented opinions and materials - confirming one of their hypotheses about attitude correspondence and phrasing. The hypothesis failed though to predict the positive bias related to source and stereotypes.⁸³ For scientists, the lower the expectation of the public, the more negatively scientists viewed 'effective negative claims' i.e. scientists who already had low opinions of the public had a greater negative response to arguments centred on personal experience or stories.⁸⁴

Cuppen et al. proposes that this could be the response to effective-negative claims activating a stereotype of an emotional irrational public.⁸⁵ Despite this, those who held the most negative opinions about the public evaluated public claims in a more positive light than negative, and perhaps surprisingly and humorously, Cuppen et al. showed that scientists

⁸¹ Ibid, 279

⁸² Cuppen, E., Hisschemöller M., and Midden, C., *Bias in the exchange of arguments: the case of scientists' evaluation of lay viewpoints on GM food*, Public Understanding of Science. 2009 Sep; 18(5):591-606, p.601-602

⁸³ Ibid.

⁸⁴ Ibid.

⁸⁵ Ibid.

evaluated the claims from the public more favourably than those from competing experts in their field.⁸⁶

It is theorised this may be the result of the public exceeding the expectations of scientists while other expert claims or opinions fall short of professional standards, or alternatively this may be illustrating a discord between disciplines' definitions, phrasing and argument formulation.⁸⁷ The implications for the concept of open discussion, particularly on how to overcome the limitations of bias, remain an issue with the public engagement of science.

How sources are esteemed or ignored play heavily into public understanding of complex issues and also how experts and scientists relate to each other, interpret competing narratives and communicate with the public. These findings may undermine notions of 'free' speech and open deliberation - the cornerstones of public communication and engagement of science. While this might be the case, it does not negate these efforts but may offer partial explanation to specific successes and failures in the PES field.

Placing the Public in Public Engagement

Because of the efforts and desires of scientists and public officials to include the public, public consultation events such as town hall deliberations have become a regular feature in the process of scientific endeavour, and it acknowledges the place the public in research that directly affects them.

⁸⁶ Ibid.

⁸⁷ Ibid.

Pellizzoni used the case of genetically modified organisms (GMOs) when reviewing participatory policy making, and argues that the strengthening of the public sphere in virtue of itself was going to generate greater legitimacy, quality and public trust in the policy products.⁸⁸ The significance of Pellizzoni's work was the focus placed on the relations between institutions, experts and the public and how the GMO debate across five European countries navigated the countering interest and uncertain public risk - utilising interviews with informants, workshops with stakeholders and public workshops.⁸⁹

It was found that the directive of the European Union and the European Council was toward regulatory policies, depoliticising debate and reducing transparency as a result of the experts and interest groups dominating policy formation.⁹⁰ This is especially the case in areas of high uncertainty where knowledge may be scarce, costly or controversial; *where relevant debate is entrusted to expert advisory bodies.*⁹¹

Public awareness of the issue can bring into challenge *the single problem definition and the one best solution for the common good.*⁹² Public legitimacy then would depend on the acknowledgement of other viewpoints, as Pellizzoni would go on to show a general scepticism and distrust of institutions, the view of policy makers as self-interested and too reliant on expert advice, and widespread sentiment that the regulatory process had been overtaken by scientific advance and economic interests.⁹³

⁸⁸ Pellizzoni, Luigi, *Democracy and the Governance of Uncertainty: The case of agricultural gene technologies*, *Journal of Hazardous Materials*, 2001 Sep 14;86(1-3):205-22. p. 205

⁸⁹ *Ibid.*

⁹⁰ *Ibid.*, 206

⁹¹ *Ibid.*, 207

⁹² *Ibid.*, 209

⁹³ *Ibid.*, 211

The public participants in Pellizzoni's research had shown advanced analytical perspectives and understanding, had pragmatic and reasonable expectations of solutions and an acceptance of scientific uncertainty - essentially dispelling assumptions that the public require zero-risk assessments and that scientific authority is infallible compared to their own lay opinions.⁹⁴

This also undermines the deficit understanding of the public understanding of science i.e. that inadequate scientific knowledge leads to public opposition of scientific developments. What does seem apparent however, is that the lack of access to the relevant information determined the legitimacy of public deliberation and provides a more extensive understanding of risk, than a purely technical definition. What comprises relevant information is argued to be the transparency of source materials and argument formulation.

As Pellizzoni identified, one of the key complaints about the media debates was that the differing positions, arguments or explanations were presented as *given* or as *the* set of legitimate concerns, with no indication on how they were formulated and how conclusions were reached.⁹⁵ This critique has relevance for how this study views the Bioethics Council public engagement sessions considering their presentation of major points to those involved included pre-packaged information.

Exercises in public deliberation can provide support conducive to a strong scientific sector through identifying and addressing public concerns and opinions, though as Walmsley points out, that public deliberation can risk becoming a 'one size fits all' approach to public participation and the legitimacy it can bring.⁹⁶ In looking at PES in British Columbia, it was

⁹⁴ Ibid.

⁹⁵ Ibid, 215

⁹⁶ Walmsley, H., *Biobanking, public consultation, and the discursive logics of deliberation: Five lessons from British Columbia*, Public Understanding of Science 2010 19: 452 DOI: 10.1177/0963662509335523, p. 452

argued that while there remain elusive measures of success for public deliberation, enabling facilitators with known pitfalls can produce indications of greater success; such as the use of small groups to encourage less confident speakers to express their opinions; avoiding the frustration that can appear; fostering dissenting opinions, asking for reasons behind voiced arguments and cultivating a more 'deliberative' mind-set more aligned with the goals of public participation.⁹⁷⁹⁸⁹⁹

Walmsley concludes that deliberative discussion is not a monolithic process and can include many discursive processes, providing a context in which to judge public engagement programs, and an awareness that event aims, tasks and questions play heavily on how these processes take place and mature.¹⁰⁰ This has the potential to shift more attention to how the questions are formulated and presented to the discussion attendees. Without such attention, accusations of manufacturing consent through illegitimate deliberative processes may well be valid.

Additionally there was the realisation that the focus of public deliberation amongst uninformed publics - a reaction to the perceived over-involvement of interest groups, actively excludes those with investment in, or passion for these new developments. The prospect of choosing publics because of their lack of involvement or political engagement may seem a valid path for disinterested reasoning, but points to the failings of a system to incorporate the various publics. Because of this, Walmsley contends that the recorded outcomes of public deliberation should not just be successes or failures regarding consensus, but also the

⁹⁷ Ibid, 465

⁹⁸ Ibid, 455

⁹⁹ Ibid, 456

¹⁰⁰ Ibid.

controversies or frustrations.¹⁰¹ Identifying and recording issues of continued contention will undoubtedly complicate policy formation; however, such reporting would be more representative of the public outlook, present a greater level of transparency and would inform a more robust government policy.

Public engagement in science policy formation will also invariably contend with being tailored to national or regional cultural norms. How the Canadian model of public deliberation for xenotransplantation was viewed and responded to by American researchers and regulators was approached by Allspaw. When asked about the Canadian public consultation process, members of the American xenotransplantation community agreed that gathering public opinion was *usually desirable* but held serious concerns as to methods that are or might be used to obtain and qualify opinion.¹⁰² Also challenged was the definition of the *informed public*; requiring a *stringent adherence to representative sampling and more rigorous public education strategies*.¹⁰³

While the American XTP community held grave concerns as to the validity of the public deliberation, it also allowed for some interesting and significant questions, including: Which publics should be recruited? Should an informed public be deferred to over the ‘masses’ despite being less informed? How best are democratic ideals served? *Allowing the voices of the concerned and/or informed to rise above those of the indifferent and/or uninformed?* By what measure do you judge a group to be an informed citizenry? Can a public be sufficiently informed to

¹⁰¹ Ibid.

¹⁰² Allspaw, Kathleen M., *Engaging the public in the regulation of xenotransplantation: would the Canadian model of public consultation be effective in the US?*, Public Understanding of Science 2004; 13, DOI: 10.1177/0963662504044559, p. 417

¹⁰³ Ibid.

make decisions on highly complicated scientific issues? What weight is public judgement given when compared to that of industry experts?¹⁰⁴

Much of the sentiment from these experts was characterised through Dr. David Cooper of the Transplantation Biology Centre of Massachusetts General Hospital: *[He] would estimate that 90% of people have no interest in [xenotransplantation] and, furthermore, the vast majority of the public is not informed enough to be capable of making a reasoned decision. Most of the public is likely to say, "This is beyond me; we need the experts to decide."*¹⁰⁵

Allspaw repeats this belief; that opening up the discussion to the public will mostly indicate how disinterested the public are about specialised bioethical debates, unless they have a direct interest. Thus leaving discussion subject to extremist polarisation e.g. animal rights verses victim advocates.¹⁰⁶ Other considerations included that people elect representatives at state and national levels and it is these people who bear the burden of these decisions and responsibilities.¹⁰⁷

Most revealing, were the concerns researchers had about an informed public becoming objectionist and therefore becoming obstacles to progress, or that bad science policy came from ignorance. Such distain for bioethical processes may or may not be representative, but does provide a basis for more permanent regulatory or even legislative provisions for the public's place in biotechnology research. For this reason, when writing on xenotransplantation Bach and Finberg insisted:

¹⁰⁴ Ibid, 418

¹⁰⁵ Ibid, 421

¹⁰⁶ Ibid.

¹⁰⁷ Ibid.

*xenotransplantation should not be left to the traditional technical-based approaches [. . . that] before introducing a regulatory framework driven by technical considerations, an informed public debate is needed so that the public can decide whether it wishes to consent to clinical xenotransplantation at all, and, if so, under what conditions.*¹⁰⁸

This sentiment runs counter to the idea of the passive/active citizen and continues to inform the idea that public engagement has been motivated by consensus building and delivering compliance from citizens.¹⁰⁹ Yet efforts by the IXA to endorse and promote public engagement with XTP, and that population acceptance of XTP can reach as high as 82%, it would appear there is little cause or evidence for the organised manipulation of compliance, and instead point to efforts of genuine public debate performed in good faith if only hindered by a natural self-interest and inherent bias of stakeholders.¹¹⁰¹¹¹

It is important to note that the idea of public acceptance of xenotransplantation has not limited to the populations of countries looking to employ this procedure in the near future. States lacking the capacity for their own biotechnology industry capable of XTP procedures may expect access to the technology as the *'fair quid pro quo for their acceptance of the risk of a xenogeneic pandemic, their agreement to prohibit rogue xenotransplantation operations and their*

¹⁰⁸ Ibid.

¹⁰⁹ National Health and Medical Research Council, *Xenotransplantation Working Party, Animal-to-human transplantation research: A guide for the community*, Public consultation on XT 2003/04, Commonwealth of Australia, 2003, URL: nhmrc.gov.au/publications/_files/e54.pdf

¹¹⁰ Verte, D., Lambrecht, P., Ponjaert-Kristofferson, *Acceptance of future xenotransplantation of porcine insulin producing cells: differences amongst population groups*, Flanders Interuniversity Institute for Biotechnology, Ghent, Belgium, Vrije Universiteit Brussels, Belgium, *Xenotransplantation* Vol. 8, Issue Supplement 2003, p. 125

¹¹¹ Idvall M., Tibell A., *Xenotransplantation as a scientific problem in the context of a university hospital*, Department of European Ethnology, Lund University, Lund, Sweden, Department of Transplantation Surgery, Huddinge University Hospital, Karolinska Institute, Stockholm, Sweden, *Xenotransplantation* Volume 8, Issue Supplement 2003, p. 126

*obligation to monitor their populations for emerging [xenosis].*¹¹² If this does become the case, it will be interesting to observe how these concerns of economic disparity and public health play-out on a global stage.

As shown above, the process of discussion and deliberation is inherently fraught with complications. Not addressing these concerns would risk alienating the public and foster a hostile environment for scientific work, investment and eventual consumption of biomedical products. If public deliberation is considered appropriate for new biotechnology development and distribution to the public, open citizen deliberation will be the key to informing and achieving meaningful consent or dissension.

This chapter focused primarily on the public engagement of science. Chapter 4 expands on how framing influences public discussion in this area and shapes public policy as a result. It also explains the Methodology for this research and provides an overview on the research method of frame analysis. Together, Chapter 2 and Chapter 4 inform the research and analysis of the dataset and place the conclusions in context while Chapter 3 will provide further context for xenotransplantation by looking at the history, progress and reaction to the procedure.

¹¹² Rothblatt, M., Fisher, *Geoethical considerations relevant to the introduction of xenotransplantation*, Chartered, Washington DC/USA, Xenotransplantation Volume 8, Issue Supplement 2003 p. 127

Chapter Three – XTP Context: History and Regulation

This chapter will provide context for xenotransplantation by briefly describing a history of success and failure in the xenotransplantation field, presented in chronological order. This will bring the reader up to date with the subject of xenotransplantation (XTP) and its place in the modern medical and societal context. As this history moves forward, the challenges of XTP will be described; highlighting the difficulties faced and how these difficulties have been responded to by Government institutions and non-Governmental organisations. This is followed by a review of how publics around the world have responded to the potential risks and benefits of xenotransplantation.

The history of practicing xenotransplantation starts as far back as 1501 in modern day Iran, when a piece of dog skull was used to stem a head wound.¹¹³ However it wasn't until 19th Century that XTP was used with any sort of regularity. The majority of early cases were xenotransfusions that took place in Western Europe, most commonly in France.¹¹⁴ Because of the ignorance of the species barrier, these generally resulted in poor outcomes for the patients, notably death. Those patients that were considered a success in their time are more recently considered to have improved in spite of these transfusions.¹¹⁵¹¹⁶

Progress in xenotransplantation, as in many areas of medicine, was stunted because of the lack of communication and the false perceptions of growing success. Early pioneers such as

¹¹³ Deschamps, JY, Roux FA, Sai P, Gouin E, *History of Xenotransplantation*, Xenotransplantation, 2005: 12, p. 91-109

¹¹⁴ *Ibid.*

¹¹⁵ *Ibid.*

¹¹⁶ David, K. C. C., *A brief history of cross-species organ transplantation*, Baylor University Medical Center Proceedings, 25(1), 49, URL: <http://search.proquest.com.ezproxy.canterbury.ac.nz/docview/1032803837?accountid=14499>

Scottish physician John Henry Leacock failed to gain the notoriety that would've decreased patient suffering and even lives lost. During 1812-1816, John H. Leacock showing in eight xeno-transfusion trials, in which the donor and recipient must be from the same species, it was the perceived success of other cases and the need of replacement blood and tissue drove further experimentation that ignored the species barrier for almost 150 years.¹¹⁷

It was not until two Frenchmen, Mathieu Jaboulay and Alexis Carrel preformed what may be considered the first true organ xenotransplantation in 1906 that it was hypothesised of the difference hetero (different species) and homotransplantations (same species) could make. During 1909-1913 Surgeons Unger and Schonstadt used Japanese macaques as source animal and from 1920 Russian-born Voronoff also attempted solutions to the issue of rejection by using a *sister species* i.e. apes, as a donor source. This research period also identified the difficulties of acquiring an adequate supply of source animals, in this case, apes; an issue that was revisited in later discussions about potential xenograft sources.¹¹⁸

While there was promising results during this time, including the production of urine and the decline of glycosuria attributed to xenotransplantation surgeries, there was a decline in research for forty years until immunosuppressant techniques were considered sufficiently improved to continue.¹¹⁹

After a partially successful attempt where the patient survived 63 days after transplant, in 1964 a 23 year old school teacher received a chimpanzee kidney and survived nine months

¹¹⁷ Deschamps, JY, Roux FA, Sai P, Gouin E, *History of Xenotransplantation*, Xenotransplantation, 2005: 12, p. 91-109

¹¹⁸ Ibid, 90-95

¹¹⁹ Ibid, 97

before succumbing to an acute electrolyte imbalance coupled with infection – providing proof-of-concept regarding the feasibility of long term xenotransplantation of an organ.¹²⁰¹²¹

Attempts to replicate the success of whole organ transplants have been met with constant failure, including the now infamous ‘Baby Fae’ who did not survive long after receiving a baboon’s heart in 1984 despite the new immunosuppressive agent FK506.¹²² Further attempts failed in 1992, 1993 and 1996.¹²³¹²⁴ In 2000 however, there was success with extracorporeal (outside of the body) xenogeneic liver perfusion as a bridging technique for allotransplantation. However, bridging procedures are inherently short term and with advancements of liver and kidney dialysis, using extracorporeal xenogeneic techniques is unlikely to be in the best interests of the patient considering the risk of rejection and established alternatives.¹²⁵

Finding a replacement for allotransplantation of organs and tissue has also spurred alternatives other than XTP. Biomedical 3D printing, where the technology is being developed to grow organs for patients from their own cells is a burgeoning competitor to XTP. In the coming years advocates may have to prove that XTP is a robust technology when presented with alternatives.

¹²⁰ Tramper and Zhu, *Modern Biotechnology: Panacea or new Pandora’s Box?*, Wageningen University, Netherlands, ISBN 978-90-8686-725-7, p. 211

¹²¹ Soin, B., Vial, C. M and Friend, P. J., *Xenotransplantation*, British Journal of Surgery, Vol. 87, Issue 2, (2000) DOI: 10.1046/j. 1365-2168. 2000.01351.x, p. 138

¹²² Deschamps, JY, Roux FA, Sai P, Gouin E, *History of Xenotransplantation*, Xenotransplantation, 2005: 12, p. 91-109

¹²³ Ibid.

¹²⁴ David, K. C. C., *A brief history of cross-species organ transplantation*, Baylor University Medical Center Proceedings, 25(1), 49, URL:

<http://search.proquest.com.ezproxy.canterbury.ac.nz/docview/1032803837?accountid=14499>, p. 50

¹²⁵ Deschamps, JY, Roux FA, Sai P, Gouin E, *History of Xenotransplantation*, Xenotransplantation, 2005: 12, p. 91-109

This being said, modern XTP procedures are likely to remain competitive as the source tissue is easily scaled up to mass production while 3D printing in medicine, as with other personalised approaches, is restricted by its tailored design as well as the cost and complexity of specialised equipment and biomaterials. Additionally progress in immunosuppression and cell encapsulation technology has led to numerous successful islet xenotransplantation procedures to date. This suggests that while xenotransplantation is currently restricted to cellular transplants, it appears the technology will be able to compete effectively against the rising alternatives as well as providing a greater range of products.¹²⁶

Xenotransfusions may provide an adequate testing ground for public perceptions of XTP as red blood cells do not carry DNA, xenotransfusions can offer an opportunity as a testing ground for the feasibility of the practical and ethical concerns of large scale xenotransplantation. Such efforts however, may be little more than an exercise in the attitudes to foreign bodies within patients, rather than a necessity; there is little need for xenotransfusions in many countries where allotransfusions provide sufficient sources of blood. Attempts to increase xenotransfusions in these areas will not benefit patients, but subject them to a socio-attitudinal experiment acting as harbinger for organ xenotransplantation.

The outright rejection of xenotransfusions may be premature and hurt less developed countries where there is a need for safe blood substitutes. Nigeria for example, where blood transfusions are the second biggest cause of HIV/AIDS transmission, or South Africa where in

¹²⁶ Rengier, F., Mehndiratta, A., von Tengg-Kobligk, H., Zechmann, Unterhinninghofen, C. M., R., Kauczor, H.-U., Giesel, F. L., *3D printing based on imaging data: review of medical applications*, International Journal of Computer Assisted Radiology and Surgery, Vol. 5, Issue 4, Springer-Verlag, p. 335-341

certain regions HIV/AIDS infection stands at 40%.¹²⁷ Despite the urgent need for an alternative in said areas, the scientific community should be wary of turning the developing world into a proving ground for medical technologies such as xenotransplantation, something it has already been accused of doing in the recent past.¹²⁸¹²⁹

Concerns such as these prompted a position statement from the International Xenotransplantation Association (IXA), originally published in 2003, which presented a number of recommendations in an effort to standardise clinical precautions and ethical considerations.¹³⁰ These included recommendations related to the selection of adequately informed, appropriate recipients; animal welfare, safety issues and a favourable risk/ benefit assessment based data.

In 2009 the IXA, feeling the recommendations had been well received, produced a consensus statement extolling the regulatory models in The United States of America, Europe and New Zealand. It was seen that these nations in particular had converged around key concepts outlined in the IXA's earlier position statement: being that for any individual nation's XTP policy to be successful it would require a standardised approach amongst nations.

¹²⁷ Gupta, Aditi & Samson, Luke & Man, Alan & Cangemi, David F., & Burke, Brendan, *History of Blood Substitutes*, Brown University, Lecture material, Biology and Medicine, URL: <http://biomed.brown.edu/Courses/BI108/2006-108websites/group09artificialblood/index.htm>

¹²⁸ Coyle, Fiona J., Maslin, Crystal, Fairweather, John R., and Hunt, Lesley M., *Studies in Innovation and Change Public Understandings of Biotechnology in New Zealand: Nature, Clean Green Image and Spirituality*, November 2003, Research Report No. 265, Agribusiness and Economics Research Unit, Lincoln University, Canterbury, New Zealand, p.6-7

¹²⁹ Bhutta, Z.A, *Beyond informed consent*, Bull World Health Organ [serial on the internet] 2004 October [cited 9 November, 2012]; 82(10) 771-777, URL: scielosp.org/scielo.php?script=sci_arttext&pid=S0042-96862004001000013&Ing=en. <http://dx.doi.org/10.1590/S0042-96862004001000013>.

¹³⁰ Sykes, Megan, Apice, Anthony D., Sandrin, Mauro, *Position Paper of the Ethics Committee of the International Xenotransplantation Association*, Xenotransplantation, May, 2003 DOI: 10.1034/j.1399-3089.2003.00067.x. p.195

This reinforced the existing 2004 World Health Assembly Resolution WHA57.18, 2, 1 which urges member states:

- (1) To allow xenogeneic transplantation only when effective national regulatory control and surveillance mechanisms overseen by national health authorities are in place.
- (2) To co-operate in the formulation of recommendations and guidelines to harmonize global practices, including protective measures in accordance with internationally accepted scientific standards to prevent the risk of potential secondary transmission of any xenogeneic infectious agent that could have infected recipients of xenogeneic transplants or contacts of recipients, especially across national borders.
- (3) To support international collaboration and coordination for the prevention and surveillance of infections resulting from xenogeneic transplantation.¹³¹

This precautionary approach was seen to be required due to the nature of third-party risk XTP presents.¹³² Due to an increasingly connected world, the realities of xenotourism remain. National safeguards such as specific legislation or continued surveillance of patients are undermined by regimes that would allow XTP despite limited or non-existent regulatory frameworks designed to manage the risk of xenosis; analogous to an unimmunised individual risking the herd immunity of a community.¹³³

Standardised regulatory frameworks are desirable because of how it can protect consenting and non-consenting populations from xenotourism and its associated risks. As such, much of

¹³¹ World Health Organization, *Xenotransplantation: Hopes and Concerns*, Statement from the Xenotransplantation Advisory Consultation, Geneva, 18-20 April 2005, World Health Organisation, URL: <http://www.who.int/transplantation/XenoEnglish.pdf>

¹³² Megan Sykes, Anthony D'Apice, Mauro Sandrin, Position Paper of the Ethics Committee of the International Xenotransplantation Association, *Xenotransplantation*, May, 2003. 10.1034/j.1399-3089.2003.00067.x. p.195

¹³³ Ibid.

the literature is directed in gauging attitudes towards xenotransplantation and the factors influencing these attitudes. While a clear acceptance of XTP is preferable for those hoping to further the technology, the nuances and concerns that factor into the acceptance or rejection of XTP, can identify conflict and inform a more robust policy internationally.

Perhaps unsurprisingly, public concerns regarding XTP are seen to be nation specific. The tone in Europe, it appears, is that of unless XTP provides a cure, it is 'better the devil you know' when it comes to medical technology. Persson et al. (2003) showed that in Sweden there was a positive reaction to cell or tissue transplants, more so than organ transplants.¹³⁴ Deschamps et al. (2005) showed that in France attitudes to porcine islet transplants were favourable, but 68% would refuse if it did not exempt them from insulin injections. After further information was presented, 71% would rather not take the risk associated with an XTP procedure.¹³⁵ And in the Netherlands, Kranenburg et al. (2005) showed that 67% of patients waiting for a kidney transplant would rather wait four years for a human transplant than undergo XTP.¹³⁶

How populations respond to XTP is multifaceted and can be altered in ways not immediately observed. Rios et al. (2007) demonstrates that British and Irish residents overseas conform to the attitudes of their new homes; however, this opinion was also informed by more obvious cultural divides. This includes correlation with previous attitudes to allotransplantation; gender, where males were more favourable to XTP; and religion, atheist

¹³⁴ Persson MO, Persson NH, Ranstam J, Hermere'n G. *Xenotransplantation public perceptions: rather cells than organs*, *Xenotransplantation* 2003; 10: 72–79.

¹³⁵ Deschamps JY, Roux FA, Gouin E, Sai'P. *Reluctance of French patients with type 1 diabetes to undergo pig pancreatic islet xenotransplantation*. *Xenotransplantation* 2005; 12: 175–180.

¹³⁶ Kranenburg L.W., Kerssens C., Ijzermans JN., *Reluctant acceptance of xenotransplantation in kidney patients on the waiting list for transplantation*, *Soc Sci Med* 2005; 61: 1828–1834.

and agnostic were more positive towards XTP.¹³⁷ Other factors have also included education and attitudes held by spouses.¹³⁸¹³⁹

The choice to focus on British and Irish migrant communities in Spain is interesting as it observes how attitudes about XTP may conform according to new surroundings. It does however present a dataset of British and Irish migrants who chose to travel to Spain and as such, are more likely to be financially secure, meaning they could potentially afford the procedure. This may suggest wealth also factors into positive opinions of XTP, as it is a viable option for the extension of life and quality of life for those who could afford the procedure or adequate insurance.¹⁴⁰

Martinez-Alarcon et al. surveyed those on liver and kidney waiting lists and showed that attitudes shifted depending on a risk, compared to allotransplantation; a comparable risk to allotransplantation results in a strong majority finding XTP favourable, but if XTP involved more risks, then favourability dropped to 8%, with 21% unsure.¹⁴¹¹⁴² Interestingly, if XTP was offered as a bridge to allotransplantation while on the transplant list, 44% viewed this

¹³⁷ Rios A, Ramiraz P, Martinez L, Jarvis N, Sanchez J, Rodriguez MM, Alcaraz J, Montoya MJ, Parrilla P, *British citizens in a regional community of South Eastern Spain with a pre-clinical organ xenotransplantation program. A study of attitude towards xenotransplantation*. Xenotransplantation, 2007; 14: 255-26, Blackwell Munksgaard, 2007 p. 255

¹³⁸ Martinez-Alarcon L, Rios A, Pons JA, Gonzalez MJ, Ramis G, Ramiraz P, Parrilla P, *Attitudinal study of organ xenotransplantation in patients on the kidney and liver transplant waiting list in a country with a high rate of deceased donation*, Xenotransplantation, 2011: 18:168-175

¹³⁹ Rios A, Martinez-Alarcon L., Lopez-Navas A., Ayala-Garcia M., Sebastian, M.J., Abdo-Cuza A, Ramirez E.J., Munoz G, Palacios G, Suarez-Lopez J, Castellanos, R., Gonzalez B, Martinez M. A., Diaz E, Nieto A, Ramis G, Ramirez P, Parrilla P., *Level of acceptance of solid organ xenotransplantation among personnel in Spanish, Mexican, and Cuban hospitals*, Xenotransplantation 2014: 21: 84-90. © 2013 John Wiley & Sons A/S.

¹⁴⁰ This observation is based on that no countries, the author is aware of, have openly considered XTP as a procedure that would be covered by public health systems.

¹⁴¹ Martinez-Alarcon L, Rios A, Pons JA, Gonzalez MJ, Ramis G, Ramiraz P, Parrilla P, *Attitudinal study of organ xenotransplantation in patients on the kidney and liver transplant waiting list in a country with a high rate of deceased donation*, Xenotransplantation, 2011: 18:168-175p.169

¹⁴² Ibid, 170

favourably and 29% unsure. But of those that would accept XTP as a bridge, 90% would not have further intervention to insert a human organ if the xenotransplant functioned well - perhaps suggesting many of those who answered “unsure”, or were simply waiting for the technology to be proven, similarly to the 'better the devil you know' attitude mentioned in the European studies mentioned above.

One might expect those on waiting lists hold a high percentage of favourability toward xenotransplantation, likely because they hope to receive the benefits of this technology. Yet as seen in other studies, the correlation between attitudes about allotransplantation and xenotransplantation appears to be the foremost factor. Additionally, there was little difference in attitudes between the patients on liver and kidney waiting lists, which is significant, because liver dialysis is a burgeoning technology whose viability is not proven, compared to kidney dialysis which is a routine procedure.¹⁴³

This suggests that for many, self-interest may *not* override other factors when considering XTP as a viable alternative. Perhaps for this reason, a definite but not overwhelming majority of healthcare workers approved of XTP, as shown by Rios et al. (2006).¹⁴⁴ Of health workers surveyed, 67% were in favour of XTP, with 26% undecided, this is compared to the general public control group's response of 74%.

Hospital personnel varied in accordance to their position within the healthcare system.¹⁴⁵ Front line personnel such as physicians and nurses, who are exposed to third risk associated

¹⁴³ Ibid, 171

¹⁴⁴ Rios A, Martinez-Alarcon L., Lopez-Navas A., Ayala-Garcia M., Sebastian, M.J., Abdo-Cuza A, Ramirez E.J., Munoz G, Palacios G, Suarez-Lopez J, Castellanos, R., Gonzalez B, Martinez M. A., Diaz E, Nieto A, Ramis G, Ramirez P, Parrilla P., *Level of acceptance of solid organ xenotransplantation among personnel in Spanish, Mexican, and Cuban hospitals*, *Xenotransplantation* 2014; 21: 84-90. © 2013 John Wiley & Sons A/S.

¹⁴⁵ Ibid.

with XTP, were surveyed as being the most in favour of XTP. In comparison, healthcare assistants and ancillary were not so much *against* XTP donation of organs, but categorised their opinion as *undecided*.¹⁴⁶

Whether being front line medical personnel or patients on waiting lists, what is striking is the expression of goodwill being shown in relation to this technology, from both those it might help or endanger. Self-interest appears to be mitigated by a vast assortment of factors - informed by empathy, morality, rationality and education. The majority of regulators have rewarded that goodwill with efforts to standardise safety and ethical concerns across nations.

This chapter has sought to introduce the subject of xenotransplantation to the reader and place it in a historical and modern context. The following chapter will do the same for the public engagement of science - discussing how the public is introduced to and interacts with science and technology through issue framing; and, then how this has been applied to this research.

¹⁴⁶ Ibid.

Chapter Four – Methodology

This chapter explains frame theory and its use in this research. The first section builds upon the framing theory introduction in Chapter 1 by presenting how framing is used to shape discourse and what this means for both those taking part and those observing.

The news media is essential in how the public interacts with local and international issues. The following section will show how the media was shaped by their relationship with government, how those in industry and advertisers became the pre-eminent framers and how this is being challenged by public relations experts and internet discourse. These developments, in particular the internet, will inevitably change the nature of public discourse and can serve as an effective tool in the communication of science. The final section outlines more of the specifics of this particular research approach used in data evaluation for this project - including the definitions that are being used, a template of use for the prominent frames and the dataset sources being employed to analyse the discussion of xenotransplantation in New Zealand.

Frame Analysis

Frame analysis is the theory that when the public is informed of an issue there is the opportunity to influence the audience according to how an issue is framed. A common example is a news report about a protest; a might be used frame to emphasise free speech, thus directing what is said, heard and understood about the protest according to that organisation of thought. The same protest could also be framed in a way that provokes thought on public

safety, public pressure on the government or economic cost. In either case, the frame implies a logical format in which to organise debate and positions arguments outside the presented frame as awkward or illogical.

Issue framing can exert significant influence on the uninitiated, as individuals are sensitive to accessible information whilst in the process of formulating arguments, decisions and expressing opinion. The effect of this however, can be mitigated through prior knowledge, even more so if the prior knowledge was recently used.¹⁴⁷ Because framing-on-introduction can be so pervasive it can paradigmatically dominate news stories, which in turn can dominate the audience i.e. when an issue is introduced and subsequently referenced, a particular frame can become the dominant lens it is viewed through.

This has significant implications for public discussions, particularly when dominant frames are linked to hegemonic processes such as public submissions on public policy; which, according to Entman, may erode the potential for a democratic public sphere by limiting the range of debate.¹⁴⁸

Frame analysis was initially tied, in large part, to framing by television media as practical considerations, such as relatively short broadcast times and the drive for viewership, made issue framing integral in the modern news scape.¹⁴⁹ Framing enables the development of problem identification, problem description and structure formulation, and as such has proven itself in the quick, effective conveyance of knowledge.¹⁵⁰ Due to this its usage is not restricted

¹⁴⁷ D'Angelo, Paul, *News Framing as a Multiparadigmatic Research Program: A Response to Entman*, Journal of Communication, International Communication Association, 200, p. 870-888

¹⁴⁸ Ibid.

¹⁴⁹ Davies, J.; Mabin, V. J., *Knowledge Management and the Framing of Information: A Contribution to OR/MS Practice and Pedagogy*, The Journal of the Operational Research Society, Vol. 52, No. 8, Part Special Issue: OR42 Papers, Palgrave Macmillan Journals, 2001, URL: <http://www.jstor.org/stable/822947>, p. 856.

¹⁵⁰ Ibid, 859

to news media. Education for example, provides an effective model of how the same issue can be framed according to its audience. Teachers are presented with scholastic concerns by administrators - such as low grade medians within a government funding frame, rather than effective teaching or student management frames. The teacher in turn frames low grades as a personal issue for students, perhaps selling them a potential job or future based on extra effort, in the hope of mobilising their support.¹⁵¹

Mobilisation may be the most significant reason for problem framing through frame alignment; frame sponsors produce and invoke frames with the intent of matching these frames with the interests, values, and beliefs of the audience they are attempting to mobilise.

In practical terms, the use of conceptual hooks such as child safety, freedom or justice hold broad appeal, cutting across societal cleavages by achieving frame resonance (identification) with a large audience.¹⁵² This is when the audience links the invoked frame to their own personal experiences, philosophies and faith.¹⁵³ In this manner, individual motivation can be socially organised by accessing existing belief structures and culture.

These structures act as categories of thought and action that are drawn upon to shape interpretation of the problem and the frame.¹⁵⁴ The broadest conceptual hook is often desired, as specificity might alienate certain individuals or communities, generate or isolate issue stakeholders and imply variant solutions.¹⁵⁵

¹⁵¹ Coburn, Cynthia E., *Microprocesses of Policy Implementation: Framing the Problem of Reading Instruction: Using Frame Analysis to Uncover the Microprocesses of Policy Implementation*, American Educational Research Journal, 2006, Vol. 43, No. 3, URL: <http://aer.sagepub.com/cgi/content/abstract/43/3/343>, p. 343–379.

¹⁵² Ibid, 347

¹⁵³ Ibid.

¹⁵⁴ Ibid, 379

¹⁵⁵ Fletcher, Amy L., *Clearing the Air: The Contribution of Frame Analysis to Understanding Climate Change Policy in the United States*, Environmental Politics, Vol. 18, No 5, Sep 2009, p. 816.

Different frames can substantially transform how an issue is viewed and thus frame divergence is able to shift the focus of the issue, mobilising rival sectors of society over different interpretations over one policy issue.¹⁵⁶ Gamson and Modigliani (1987) envision contesting frames in an arena:

*Every public issue is contested in a symbolic arena. Advocates of one or another persuasion attempt to give their own meaning to the issue and to events that may affect its outcome. Their weapons are metaphors, catch phrases, and other condensing symbols that frame the issue in a particular fashion.*¹⁵⁷

How this affects debate is predicated on how frame sponsors and their audiences react to frame divergence. Those who continue to debate under contradictory frames will toil under a context suited for polarisation, escalation and protracted disagreement.¹⁵⁸ Counter to this, frame convergence, which is characterized by compromise, is attuned to negotiation and substantive agreement.¹⁵⁹ This in part is how framing affects its audience, but also the discussion itself.

Frames, it is argued, are able to provide a shift in focus which reprioritises current beliefs rather than the inception of new beliefs.¹⁶⁰ I.e. framing doesn't change beliefs, it allows for

¹⁵⁶ Ibid.

¹⁵⁷ Scheufele, Diatram A, *Framing as a Theory of Media Effects*, Journal of Communication, winter, 1999, International Communication Association p. 106

¹⁵⁸ Murphy, Priscilla, *Affiliation Bias and Expert Disagreement in Framing the Nicotine Addiction Debate*, Science Technology Human Values, 2001 26; 278 p. 301

¹⁵⁹ Ibid.

¹⁶⁰ Druckman, James N.; Nelson, Kjersten R., *Framing and Deliberation: How Citizens' Conversations Limit Elite Influence*, American Journal of Political Science, Vol. 47, No. 4, Midwest Political Science Association, 2003, URL: <http://www.jstor.org/stable/3186130>, p. 739

prompt accessibility of existing beliefs into conscious thought.¹⁶¹ As frames are drawn from existing philosophies, the modern context, dominated by instant and diverse forms of information renders elite framing more fragile than previously thought.¹⁶² Over the course of a conversation the original frame can be moderated, if not outright discarded, for another frame.¹⁶³

Framing and the Media

This section presents how modern media is both a framer and yet is vulnerable to news framing for stake holders; and how the internet may or may not be challenging the authority of traditional media by enabling various forms of counter framing structure that are not hinged upon the consent of government or industry.

Print, radio, and television media previously enjoyed unparalleled access and audience to political actors and events. More recently, anyone with access to an internet enabled computer or phone can view events, hear testimony, produce frames and reframe and publish for literally millions of people to view; possibly changing how the audience view and later frame the issue. How this emerges in practice however, is dependent on various factors - including visibility, audience bias, frame recidivism and counter framing.

¹⁶¹ Nelson, Thomas E., Oxley, Zoe M., *Issue Framing Effects on Belief Importance and Opinion*, The Journal of Politics, Vol. 61, No. 4, Cambridge University Press, 1999, URL: <http://www.jstor.org.ezproxy.canterbury.ac.nz/stable/pdfplus/2647553.pdf>, p. 1059

¹⁶² Druckman, James N.; Nelson, Kjersten R., *Framing and Deliberation: How Citizens' Conversations Limit Elite Influence*, American Journal of Political Science, Vol. 47, No. 4, Midwest Political Science Association, 2003, URL: <http://www.jstor.org/stable/3186130>. 739, p.1048

¹⁶³Ibid.

This second section discusses how framing can be an effective mechanism to deliver complex scientific information in a more accessible form and how framing has been used this way in the past.

The purpose of media framing is widely considered to be the protection of the various interests of privileged groups that dominate domestic society and the state, by placing them in a biased context.¹⁶⁴ When looking at the American public's response to tax cuts implemented by President Bush in 2001 and 2003, Bell and Entman (2011) contend this policy was not only tolerated but supported, due to the crucial role of elite influence over political communication.¹⁶⁵ This was achieved, according to Herman and Chomsky, as through the *selection of topics, distribution of concerns, framing of issues, filtering information, emphasis and tone, and by keeping debate within the bounds of accepted premises*¹⁶⁶

Kinder and Sanders reinforce this point by saying that the media frame will allow for points of controversy, but only what is deemed to be legitimate controversy - which is clearly defined as it will still utilise the frame as the central point around which the debate focus.¹⁶⁷

How media framing began to be seen as protecting interests is explained by the dynamics of survivability in the media industry that shifted influence from the audience to interests. Before advertising became as prominent as it is currently, newspapers had to cover the cost of printing and sale of the paper through its price. Advertising shifted the burden of revenue gathering, meaning newspapers could offer a price below production costs, making it

¹⁶⁴ Bell, Carole V., Entman, Robert M., *The Media's Role in America's Exceptional Politics of Inequality: Framing the Bush Tax Cuts of 2001 and 2003*, *The International Journal of Press/Politics*, Vol 16, no 4, 2011 p.548-572

¹⁶⁵ Ibid.

¹⁶⁶ Chomsky, Noam, Edward, Herman S., *Manufacturing Consent: The Political Economy of the Mass Media*, Random House, 2010, ISBN: 1407054058, 9781407054056

¹⁶⁷ Kinder, Donald R., Sanders, Lynn M., *Mimicking Political Debate with Survey Questions: The Case of the White Opinion on Affirmative Action for Blacks*, *Social Cognition*, Vol. 8, No 1, 1990, p 73-103

considerably more competitive. Those who did not rely on advertising went out of business or were marginalised.¹⁶⁸

In this context, Herman and Chomsky state: *[With] advertising, the free market does not yield a neutral system [...] the advertisers' choices influence media prosperity and survival; thus leading to a narrowing of interests that need to be served to maintain viability.*¹⁶⁹ The media's ability to frame so effectively comes from the reality that politicians, CEOs and activists no longer stand before the public in the manner they would have in the past, but instead through the media to get their messages to the public.¹⁷⁰

The owners, managers and staff of mass media make decisions about what to report on and how to present it, how significant any piece of news is and how they should feel about it. McCombs and Shaw illustrated what this can mean for current events and politics, by analysing the 1972 presidential campaign coverage. They showed that the emphasis was not on the political issues but on analysis of the campaign itself. To them, it suggested a shift from journalism of telling the news, to commentary on the issues; firmly asserting the influence of the agenda setting and framing effects of news agencies to this day.

This conclusion however, rests on restricted informational diets - a reality of the 1970s news scape. Yet McCombs and Shaw's study remains significant as to the extent to which highly specialised information is palatable to the general public; reinforcing traditional news sources as intermediaries - condensing and summarising the issue and associated concerns.

¹⁶⁸ Chomsky, Noam, Edward, Herman S., *Manufacturing Consent: The Political Economy of the Mass Media*, Random House, 2010, ISBN: 1407054058, 9781407054056

¹⁶⁹ Ibid.

¹⁷⁰ McCombs, Maxwell E., & Shaw, Donald L., *The Agenda-Setting Function of Mass Media*, *The Public Opinion Quarterly*, Vol. 36, No. 2., Summer, 1972, p.176-187

Despite the access to alternative informational sources via the internet, news corporations continue to hold authority for much of the public. Even with shifts towards the internet as the primary information medium for many individuals, traditional information sources have remained as the dominant authority for news and opinion in many countries. I.e. despite a large shift to the internet for news consumption, it has been shown that that the traditional networks' online presence remains the dominant choice.¹⁷¹ As this change is mostly taking place in the younger demographics (<30) this trend can be expected to continue as these populations age.¹⁷²

In addition to this, complex or specialised issues such as xenotransplantation or foreign policy will have ideas, opinions, emotions connected to them that don't necessarily translate well into forty-second television news slots - which by nature, require substantial simplification or outright elimination of alternative angles outside of the expected binary (for/against) dynamic.

So despite the substantial increase of information, alternate sources of information are not as readily available as could be assumed. Traditional news media maintains a distinct level of authority due reputation, political access, and resources both human and financial. Whereas non-traditional reporters of news such as blog authors or twitter users could be expected to be the white noise of political commentary unless validated by traditional frame sponsors. Graber (1996) argues, that despite the increase of access, *the demand for political information has already*

¹⁷¹ *Trends in News Consumption: 1991-2012: In Changing News Landscape, Even Television is Vulnerable*, 27 September, 2012, The Pew Research - U.S. politics and policy, Center for the People and the Press, URL: <http://www.people-press.org/2012/09/27/in-changing-news-landscape-even-television-is-vulnerable/>, p. 1-5

¹⁷² Ibid.

been reached for most people.¹⁷³ And when there have been spikes in political interest and news consumption, Graber shows it's not indicative of a permanent shift, but rather the result of other competing formats entering the fray e.g. talk shows, and more recently, social media.¹⁷⁴¹⁷⁵

Kinder and Sanders also discussed the effect political awareness has on framing effects. While there are many people who enjoy politics, are aware of the issues through independent investigation that enables them to hold well thought-out and defensible positions on public policy – the majority of the public do not.¹⁷⁶ Because of this, the former will be more likely to have their own frames and as a result will be less affected by imposed frames, than the latter more passive political audience. The implication being that those who have not encountered these issues before are much more likely to use and therefore think through the frames that introduce them to said issue. Essentially, that *frames [...] matter more to the less-informed - as they expressed their opinion[s]*.¹⁷⁷

Further restrictions to accessing alternate information sources are education, finances, time restraints or general apathy. This opens the door for public relations (PR) experts or public-tuned scientists to organise their ideas and present them in a way appropriate for those not actively seeking out alternative information sources.

Indeed the evolution of political journalism has become increasingly dominated by public relations staff that restricts access to political figures whilst bombarding journalists and news

¹⁷³ Graber, D. (1996). *The 'New' Media and Politics: What Does the Future Hold?*, PS: Political Science and Politics. 29:1, p. 33-36

¹⁷⁴ Ibid.

¹⁷⁵ *Trends in News Consumption: 1991-2012: In Changing News Landscape, Even Television is Vulnerable*, 27 September, 2012, The Pew Research - U.S. politics and policy, Center for the People and the Press, URL: <http://www.people-press.org/2012/09/27/in-changing-news-landscape-even-television-is-vulnerable/>, p. 1-5

¹⁷⁶ Kinder, Donald R., Sanders, Lynn M., *Mimicking Political Debate with Survey Questions: The Case of the White Opinion on Affirmative Action for Blacks*, Social Cognition, Vol. 8, No 1, 1990, p. 73-103

¹⁷⁷ Ibid.

staff with pre-packaged content of video, pictures and press releases designed to show the political figures and their messages, in positive lights.¹⁷⁸ In some cases, these attempts to pre-package political events by PR staff have caused conflict with those in the media.

Canadian Prime Minister, Stephen Harper, became notorious for shunning the media gallery in favour of choosing the journalists who could ask questions and by only giving Government or military photographers permission or the opportunity to document certain events.¹⁷⁹ This then became the basis for its own media frame of *the bubble*.¹⁸⁰ Even editors who consciously refused the use of those releases and hand-outs have admitted to its effect: E.g. *It's always in the back of your mind*, and *There's some small psychological impact*.¹⁸¹

As scientific issues gained greater levels of coverage in the media and became directly relevant to public policy in the latter half of the 20th Century, the application of frames in this area gained larger attention. Analysts began to focus on the communication of science, the public understanding of science and how this affected science policy discussion and outcomes.

Framing in Science Communication

Shaping issues for public consumption though, is not an inherently negative proposition and remains an effective tool for communication. For scientists, who now more than ever are being called to justify and defend their work in the public arena, framing is an effective tool for the reduction of complex topics for public consumption. Even for those scientists or experts

¹⁷⁸ Ibid.

¹⁷⁹ Marland, Alex, *Political Photography, Journalism, and Framing in the Digital Age: The Management of Visual Media by the Prime Minister of Canada*, the International Journal of Press/ Politics 2012 17(2), p.214-233

¹⁸⁰ Ibid.

¹⁸¹ Ibid.

experienced or trained in public interaction, doing so is fraught with the dangers of misunderstanding, fear or impatience.

Framing a particular issue then can enable the effective communication of science that guides both the scientist in the presentation of issues and the audience in understanding them. Despite being an effective tool, Nisbet argues that particularly when the subject of debate is science, the public use their social values to pick and choose ideologically-friendly interpretations - not necessarily those provided.¹⁸²

Making judgment and forming opinions based on ideology, in the absence of readily understood information, is offered as the cause for the public's mostly modest understanding of science; this is propagated and reinforced by homogenous networks and selection of media sources that reinforce existing ideological or religious views and behaviour.¹⁸³

Because of this, framing presents to scientists an effective method in the communication of science to the public; by helping them to generate interest or concern, influence personal or political behaviour, unite the public, or rally other scientists around shared goals. Reoccurring frames familiar to the public have been shown to cross different scientific issues, include nuclear power, stem cell research, and Evolution/Creationism in schools. This attests to their effectiveness in reducing and presenting complex information.

Members of different scientific communities showed they were able to provide a solution in light of some of the concerns raised. E.g. scientists involved in the nuclear power debate in America found that *social progression* and the *middle way* frames worked successfully. In this context, nuclear power was seen as the solution between concerns about CO² emissions

¹⁸² Nisbet, Matthew C., *Framing Science: a new paradigm in public engagement*, Chapter 2, *Communicating Science: New Agendas in Communication*, Ed Leeann Kahlor and Patricia A. Stout, Routledge Press

¹⁸³ Ibid.

balanced against the continued rise in energy needs and energy independence; both of which are considered an issue of national pride and security.¹⁸⁴

For those debating the teaching of evolution in American schools the frame use was identical, with *social progression* featuring prominently; this was on the basis that an understanding of evolution is essential to the way vaccines and cures are derived. The *middle way* frame also featured predominantly - outlining that there was no reason why religious ideas could not exist alongside scientific ones.¹⁸⁵

This was followed by many religious leaders who came out in support of evolutionary teaching in schools, agreeing that they need not be incompatible. Though, success in framing does not always produce such harmonious results. As seen when Richard Dawkins published his book, *The God Delusion*, once again placing the issue of evolutionary education in conflict by instigating and driving Science vs. God/Religious vs. Science frames as well as sound bites for an enthusiastic media.¹⁸⁶

Similar cross-issue framing can be seen in the British media's use of metaphor when discussing biotechnology. Between 1973-1996, the biotechnology debate was covered by seven 'super categories': *Promise* (economic and progress), *Scare*, *Other Science* (analogous technology), *Religion*, *Natural Order*, *Gene Person*, and *(the mad) Scientist or Designer*.¹⁸⁷

While some of these metaphors were defined as clearly positive or negative, a third category of *Popularisation* (including examples of the *Gene Person*', *Engineering* and *Archaeology*,

¹⁸⁴ Ibid.

¹⁸⁵ Ibid.

¹⁸⁶ Ibid.

¹⁸⁷ Liakopoulos, Miltos, *Pandora's Box or panacea? Using metaphors to create the public representations of biotechnology*, *Public Understanding of Science*, 11; 5 2002, 5-3

was considered to be aimed at informing the public of the issue and had the ability to be used by both affirmative and negative camps on the particular issue.¹⁸⁸

One such example of a popularisation frame was the concept of the *Gay Gene*. It was initially used by some to derogatively describe homosexuality as a genetic mistake; though using the same *Gay Gene* frame, this argument was countered by the idea that homosexual behaviour is a result of natural biological occurrences and not a matter of choice.¹⁸⁹

Metaphors used in framing vary in response to their pertinence to the current issues, yet some metaphors remain in use. Suggesting, such imagery will continue to be valid as they provide clear partition between countering sides and because archetypes such as Frankenstein's monster remain in the public psyche.¹⁹⁰

Cultural relevance is key for this effect to work as using Frankenstein's monster whilst framing will have little resonance with a community, culture or generation that is unfamiliar with that archetype. As such, Zemanova examines cultural relevance during framing as an important factor in audience resonance and subsequent mobilisation in social movements. Zemanova (2009) argues it is because framing taps into cultural representations - when looking to *create a resonant frame language, images and emotions matter*.¹⁹¹ Zemanova observes that cultural representations in framing are changed according to *cultural schisms*, offering that as long as a

¹⁸⁸ Ibid.

¹⁸⁹ Ibid.

¹⁹⁰ Ibid.

¹⁹¹ Zemanova, Stepanka, *Cultural Context of Multilevel Collective Social Actions: Framing, Reflection, Resonance and the Impact of Global and Local Anti-Poverty Movements*, Human Affairs, 19; 4, 2009, DOI: 10.2478/v10023-009-0048-2 p.341-349

frame is able to communicate and provoke an emotional response, it will continue to resonate with its target audience.¹⁹²

This can lead to its own dilemmas, as the media's propensity to focus disproportionately on the negative, produces fear-inducing news frames because of their emotional resonance.¹⁹³ The impact of this can scare a crisis into existence, causing public servants to act on an emergency of hyperbole to stem public panic.¹⁹⁴ As such, framing runs the risk of being a tool of fear-mongering and producing poor public policy as a result.

Reducing complex issues to the most basic emotions for the sake of resonance, takes away from the informative potential of issue framing and lends credibility to those who have a wholly-negative view on framing as merely 'spin'.

Framing can be a useful tool for producing effective communication with an uninitiated audience. As middlemen, the media can allow scientists and experts to present their work or ideas in such a manner as to counter pre-existing cultural or religious ideological biases. For many in the media however, there is cause for concern due to the growing perception of conflict between news generators and reporters.

For news generators like Government and industry officials, using the tools of PR staff, media packets and embedded framing enable the production of positive images. For others, media-experienced scientists or public relations staff and their media packages replace real access, and embody a denial of a free press and the check and balance it ideally provides for democratic systems.

¹⁹² Ibid.

¹⁹³ Waymer, Damion, *Walking in Fear: An Autoethnographic Account of Media Framing of Inner-City Crime*, *Journal of Communication Inquiry* 33: 169, 2009, URL: jci.sagepub.com/content/early/2009/01/05/0196859908329628.full.pdf

¹⁹⁴ Ibid.

How the media industry will react to this shift of framing power remains unclear but the prevalence of digital distribution as an alternate information source; from blogs to WikiLeaks, and the demand of digital disguises such as proxies (VPNs) and the TOR network may provide clues to future resistance to the framing by traditional authorities.

In order to analyse these interactions between the public, government and the science industry as this research does, the latter half of this chapter will outline certain specifics of the research - including definitions, how the coding was performed and how the dataset was compiled.

Definitions

For much of the early history of framing theory there was an issue of how to define the phenomena that was being observed. Entman (1993), called for a cohesive frame analysis paradigm – as he lamented the inconsistency of even the most core terms, conceived a single location where framing concepts could be brought together, exposed and explored.¹⁹⁵ This general mission statement on framing theory did not go unchallenged.¹⁹⁶ D’Angelo (2002) claimed there was no need for a meta-framing paradigm, and that strength came in diversity.¹⁹⁷ That a diverse approach would form a comprehensive view of the framing process, far more so it is argued, than ‘fragmented findings in isolated research agendas.’¹⁹⁸ D’ Angelo utilised

¹⁹⁵ Entman, Robert M., *Framing: Toward Clarification of a Fractured Paradigm*, Northwestern University, Journal of Communication, Vol 43, No 4, Autumn, 1993, p.52

¹⁹⁶ D’Angelo, Paul, *News Framing as a Multiparadigmatic Research Program: A Response to Entman*, Journal of Communication, International Communication Association, 200, p. 870-888

¹⁹⁷ Ibid.

¹⁹⁸ Ibid.

Lakatos's (1974) disagreement with Kuhn (1962) and Popper (1963), who like Entman (1993), argued for standardised definitions and agreement on theoretical statements and methods. Lakatos asserted that *researchers should study phenomena using many different theories [as] researchers are still 'connected by a remarkable continuity which welds [...] into a research program.* From this, it was expected that the gradual refutations of academic peer review would fuel scientific progress.¹⁹⁹ Perhaps confirming Lakatos, academics such as Bedford, Entman, Gamson and Snow have, despite lacking a cohesive paradigm, made significant progress towards a generalised theory of frame analysis.²⁰⁰

Entman's definitions do provide concise definitions of key terms this paper chooses to utilise. Entman defines framing as *selection and salience* - the act of choosing a perspective to present, based on what information is made salient.²⁰¹ Salience meaning, making chosen information noticeable and memorable to the chosen audience. By connecting to the context of the frame to information, they are processed and remembered together furthering the frame's objective as they *diagnose, evaluate and prescribe.*²⁰²

Making information more salient may include *placement, repetition or association with cultural symbols.*²⁰³ Yet the focus framing places on certain information is naturally to the detriment of other relevant information. Entman notes that *most frames are defined by what they omit as well as include.*²⁰⁴ This being the case it is important to note that while all framing might not be

¹⁹⁹ Ibid.

²⁰⁰ Sanfilippo, Antonio, Franklin, Lyndsey, Tratz, Stephen, Danielson, Gary, Mileson, Nicholas, Riensche, Roderick, McGrath, Liam, *Automating Frame Analysis*, Social Computing, Behavioral Modeling, and Prediction 2008, ISBN : 978-0-387-77671-2 pp 239-24, p. 240

²⁰¹ Entman, Robert M., *Framing: Toward Clarification of a Fractured Paradigm*, Northwestern University, Journal of Communication, Vol 43, No 4, Autumn, 1993, p.52

²⁰² Ibid.

²⁰³ Ibid.

²⁰⁴ Ibid, 54

deliberate or with defined purpose, information is rarely politically inert and nor is its selection and presentation.

Coding

Coding of the dataset focused on keywords, tone and intent in order to characterise a frame to a unit approximately one sentence long, which may include multiple sub-categorical frames. The xenotransplantation debate placed significant importance on the role of the public as both potential benefactor and potential victim of contesting XTP policy ideologies. In light of this, this paper uses a description of the collective action framework originally described as the call-to-action for social movements by Bedford and Snow et al.²⁰⁵ In the case of the XTP debate, it is both a call-to-action and to the buy-in of the economy of hope and active passivity.

The structure for coding is Bedford and Snow's Collective Action Framework:

- Diagnostic Frame: Tell new recruits what is wrong and why
- Prognostic Frame: Present a solution to the problem suggested in the diagnosis
- Motivational Frame: Give people a reason to join collective action²⁰⁶

²⁰⁵ Sanfilippo, Antonio, Franklin, Lyndsey, Tratz, Stephen, Danielson, Gary, Mileson, Nicholas, Riensche, Roderick, McGrath, Liam, *Automating Frame Analysis*, Social Computing, Behavioral Modeling, and Prediction 2008, ISBN : 978-0-387-77671-2, p. 241

²⁰⁶ Benford, Robert D., Snow, David A., Rochford, E. Burke, Jr., Worden, Steven K., Reviewed work(s): *Frame Alignment Processes, Micromobilization, and Movement Participation*, Source: American Sociological Review, Vol. 51, No. 4 (Aug., 1986), American Sociological Association, URL: <http://www.jstor.org/stable/2095581> p. 464

The following section will specify specific sub themes which outline certain frames and place them within Bedford and Snow's Collective Action Framework. This is done to make the frame purpose clear, and was used in the analytical process.

Diagnostic Frames

- **Conflict/Controversy:** Reference to strong points of contention or countering views. Extremists, opposed/opposition, warning, critic/ism; all suggesting a tension of the issues and notes controversy.
- **Government Interference:** Mention or tone of perceived governmental hindrance, filibustering and the expression of annoyance on the behalf of scientists, business leaders and potential benefactors of xenotransplantation.
- **Government Alienation:** Expression of a perceived or real disconnect between the New Zealand Government and political process being described. E.g. 'Rubber Stamp'.
- **Mad Science:** The notion that science in New Zealand or others, is out of control. E.g. Runaway science, maverick science.
- **Person vs. Public:** The direct comparison of personal gain against public risk.
- **Problem Frame:** Outlines the problem that is being faced, with the solution - in this case xenotransplantation. E.g. transplants, waiting list, diabetes epidemic.
- **Risk - Medical:** Mentions of risk, likelihood of possible outcomes, includes fears or threats about ERV's but also missing out on possible medical gains. E.g. HIV/AIDS, retrovirus vs. people dying on organ waiting lists or poorly controlled diabetes.

- **Risk - Economic:** Explicit notions or inference of economic risk. E.g. offshore, global biotech industry.
- **Scandal:** Accusatory statements or inference about misdealing, not being to safety or ethical standards, potential or real illegality

Prognostic Frames

- **Public Safety:** Reference to measures in place or taken to ensure public safety. E.g. mentions of regulation, precaution, banned, guidelines, safeguard/s, independent or third party (in relation to oversight) and further research.
- **Public Understanding of Science (PUS):** Reference to public engagement of science, possible understanding, debates with or about science, misconceptions, surveys, awareness, consultation, wider views, informed, public meeting.
- **Sociological Frames:** Reference to ethical cultural, community, spiritual concerns or issues.

Motivational Frames

- **Hope - Medical:** Expectations, hope or promise regarding the medical benefits of xenotransplantation, including other medical gains as a result of an expansion of biotechnology in New Zealand.

- **Hope - Economic:** Expectations, hope or promise regarding the economic gains to be had of xenotransplantation, including other economic gains as a result of an expansion of the biotechnology industry in New Zealand.
- **Victim:** Focus on individual with diabetes or those on waiting lists, the main candidates for xenotransplantation technology. E.g. Diabetes suffering, viewpoints and hopes.

Chapter Five – Data Analysis

Key Features of Public Discussion 1998-2013

This chapter provides an outline of the key issues and features of the xenotransplantation (XTP) debate, as highlighted in the research. It describes the ebb and flow of certain frames but also focuses on short-lived but significant frame usage. It demonstrates that frame usage was shaped over time by a number of factors, such as stakeholder interests, political context and journalistic integrity. This discussion, in turn, provides a foundation for Chapter 6, which explores what this case study means both for the public engagement of science and public policy in New Zealand.

As expected, the data confirms that public discussion of xenotransplantation was dominated by those with direct interests and the ability to make those interests heard. News coverage was almost entirely reactive with stories often being the very press releases sent out from stakeholders and seldom providing considered analysis or relevant context for their audience. This in part contributed to frame usage being dominated by the logical reduction of counter framing attempts facilitated by media *balance* engaging with stakeholder positions. This in effect became a meta-framing effort which constituted an overall cost/benefit analysis. This is seen in the use of *Hope-Medical*, *Hope-Economic* and *Risk-Benefit* frames being juxtaposed against *Risk-Medical*.

Risk-Medical framing underwent a substantive shift in usage over the time period analysed (see Figure 1). Initially its dominant use was to illustrate the dangers of endogenous retroviruses and other potential risks xenotransplantation presents. Later it was primarily

used to show how these risks were extremely low based on the safety of the *special* pigs and New Zealand's strict biosecurity laws, but little mention of the current risk assessment of porcine ERVs. Living Cell Technologies went so far as commenting on risks not associated with its technology; regarding the 2009 Swine Flu epidemic LCT sent press releases and commented on swine flu despite it being unconnected to XTP, Swine Flu being easily tested for and extremely unlikely in highly regulated medical grade piggery:

*LCT has special herds in Kumeu and Invercargill which have been bred from pigs isolated on the Auckland Islands for about 200 years, resulting in pigs which are comparatively free of viruses. They are also housed in bird-proof facilities. Dr Tan said regular testing of the herds showed no swine influenza and an outbreak of flu was more likely to occur in nature than in a regulated pig facility.*²⁰⁷

While this could be seen as precautionary public relations, this contingency was so unlikely that such engagement is in effect misdirection while other stakeholders such as the Sustainability Council of New Zealand were still seeking public consultation on XTP, PERV and public risk.²⁰⁸

Over time this meant there was a clear shift in frame usage - where *Hope-Medical* is seen to be growing in contrast to a consistently declining use of the *Risk-Medical* (see Figure 1). As the concerns of medical risk declined there was swift expansion in the use of the *Hope-Benefit* frame, which is characterised by the potential of economic gains.

²⁰⁷ McLean, Elspeth, Extra tests for special pigs in diabetes treatment trial, 30 April 2009, Otago Daily Times, Allied Press Limited.

²⁰⁸ Dye, Stuart, NZ 'ill-prepared' for pig cell trials, 4 October 2007, New Zealand Herald (c) 2007 The New Zealand Herald

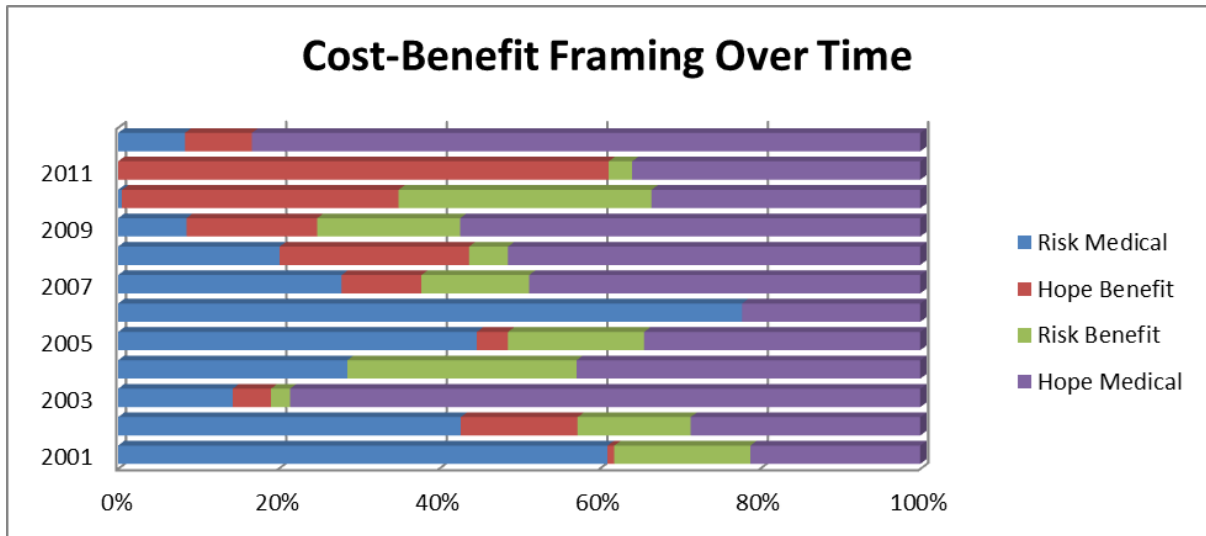


Figure 1

The 2008 and 2011 period in particular, illustrates how dramatic a shift is occurring as the *Risk-Medical* frame is all but absent and the *Hope-Benefit* framing exceeds an otherwise dominate *Hope-Medical* frame. Interestingly the amount of people for whom an XTP operation is needed was often placed in positive terms alongside how many jobs the development is hoped to create.

*Venture Southland strategic projects manager Steve Canny said having LCT set up a facility in the province was "fantastic". "This has enormous potential and could not only provide a diverse range of jobs in the future but also help an enormous number of people. "It is expected more than 11,000 New Zealanders have type 1 diabetes."*²⁰⁹

Framing efforts that achieved dominance by continued use during the observed time period were *Hope-Medical* and *Pharma-Pig* frames. The *Hope-Medical* frame was a constant feature of the public debate, by presenting that this technology had the potential to tackle the modern epidemics of organ shortage and Diabetes.

²⁰⁹ McNeilly, Hamish, *Pigs may fly for mayor* 19 July 2008, Otago Daily Times, Allied Press Limited.

How *Hope-Medical* was marketed changed significantly. The Royal Commission on Genetic Modification's (RCGM) report specifically mentions xenotransplantation in the context of organ donation – spring boarding a relatively obscure development of biotechnology into the public sphere, particularly in relation to the public backlash by Living Cell Technologies, then named Diatranz. This was due to their belief that the RCGM went outside its mandate in approaching the topic of xenotransplantation and that this put a hold on a promising medical development.

Frame usage on the medical benefits of xenotransplantation was split between organ donations as a promising solution to the growing issue of organ waiting lists and type one diabetes. This enabled the *Hope-Medical* frame to be used in relation to prospective gains in organ replacement but was able to show promising results of islet XTP and patient testimonials, enabling the effective use of the *Victim* frame in conjunction with *Hope-Medical*. Such as the report focusing on eleven year old Sophie Foster:

“Diabetes is quite a pain for me, because at my age a lot of people have sugary drinks and unhealthy food and I'm stuck with fruit and vegetables. I would like to eat other things, probably stuff like lollipops.”

She has an insulin pump, which gives regular doses of insulin through a 'port' into her abdomen. That gives better blood- glucose control than insulin injections, but the hope is that the transplants will stabilise blood glucose levels even more and reduce or end the need for synthetic insulin.

*This would simplify diabetics' lives and reduce the risk of complications such as blindness and kidney failure.*²¹⁰

In the period 2003-2006, *Hope-Medical* became less about organ XTP prospects and more directly related to the issue of LCT's Diabecell trial, and the transplantation of foreign tissue and cells. Once the trials were able to progress with the expiration of the moratorium, the *Hope-Medical* frame was shifted to forms of tissue other than islets that included the potential of transplanting brain cells in order to treat Parkinson's disease.

"We are the ultimate place in the world to build an industry out of turning pigs and other animals into medical grade use," he said.

"We have an opportunity to build a multibillion-dollar industry and it's sitting there, it's not like it's a dream, it's a real reality now."

*The company was also working on a treatment for Parkinson's disease and Collinson said there were about 2500 disorders that could be treated with animal cell therapy.*²¹¹

The *Pharma-Pig* frame was a consistent feature of the xenotransplantation discussion in New Zealand. The effect of this frame usage was two-fold; firstly it cemented pigs as being the dominate source for tissue, organs and cells for xenotransplantation. Secondly it was used in conjunction with numerous positive framing attempts including *Safeguard* and *Hope-Medical*.

The geographical isolation of the Auckland Island pigs became of distinct importance, combined with acclaimed measures to ensure a standard of cleanliness of medical grade xenographs to serve as a viable cell and tissue source. Because of this, there was a strong correlation between *Safeguard*, *Pharma-Pig* and *Hope-Medical* (see Figure 2).

²¹⁰ *Transplants, today, lollipops tomorrow* 22 October 2008, Hawke's Bay Today, APN New Zealand Ltd - Regionals

²¹¹ Hembry, Owen, *Transplant approval is dream come true*, 22 October 2008, New Zealand Herald

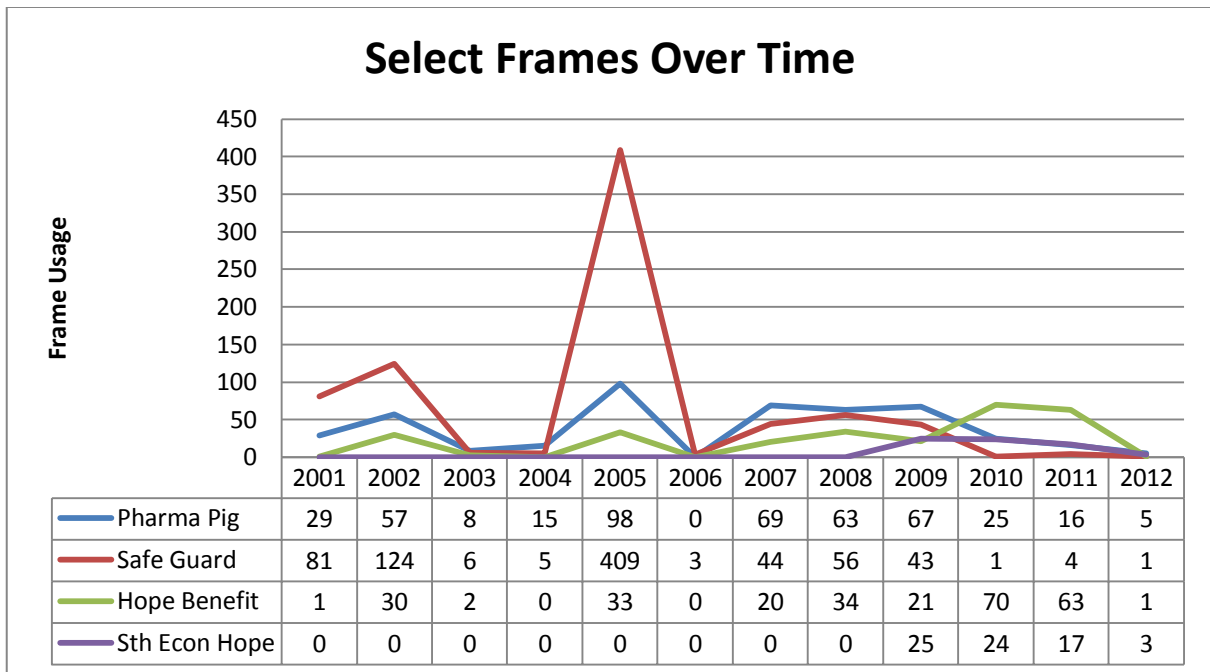


Figure 2

Hope-Benefit and *Southland-Hope* were frames used in conjunction with the *Pharma-Pig* frame to exhibit the potential (mostly) economic benefits New Zealand and in particular Southland would receive, as a result of a successful xenotransplantation industry - including large scale piggeries and an increase in reputation in the areas of biomedical practice and investment in New Zealand.

The *Southland-Hope* frame was an interesting feature of the xenotransplantation discussion, as this frame was in many ways tied to Invercargill personality and Mayor, Tim Shadbolt. The *Southland-Hope* frame emerged from the more general *Hope-Economic* frame which was used to describe the positive effects of xenotransplantation in New Zealand, not specifically medical in nature.

This focused on the many economic and non-economic features that were expected to emerge from a successful xenotransplantation program in New Zealand. Much of this focus

looked at the New Zealand Pharma-Pig, touted as a main feature of New Zealand's competitive advantage. The fact that LCT had a small piggery in Southland, and would possibly expand there, meant that xenotransplantation could introduce millions of dollars into the Southland economy.

This became linked to Invercargill's Mayor Tim Shadbolt, as he enthusiastically supported the piggery and its potential expansion. This included financial support he drew from his Mayoral Contingency Fund; eventually amounting to \$12,000, resulting in the fund being revoked and renamed the Council Contingency Fund. This mirrored the financial difficulties LCT was reportedly undergoing due to the moratorium stalling the Diabecell trials. Therefore the expiration of the moratorium vindicated both LCT and Tim Shadbolt's efforts and commitment. E.g.:

*The trademark smile of Invercargill Mayor Tim Shadbolt grew even wider yesterday after Health Minister David Cunliffe approved clinical trials of a controversial diabetic treatment involving pig cells. Mr Shadbolt faced derision when he insisted on rescuing pigs being culled from the sub-Antarctic Auckland Islands, paying for the pig-feed to keep them in Southland. However, yesterday's announcement has given the mayor the last laugh. The genetically pure, disease-free pigs are to provide the cells for the treatment trials. Mr Shadbolt said the decision was great for the city and for diabetics. "I am hoping the story one day will be 'Invercargill saves the world'."*²¹²

In the articles which included the *Southland-Hope* frame, this became an 'underdog' story which linked and benefited both parties while it was being used. This enabled LCT to be framed through the *Grassroots* framing efforts which coincided with those of *Southland-Hope*.

²¹² Milne, Amy, *Pig Cell Treatment Trials Approved*, 22 October 2008 The Southland Times

There were numerous short lived framing attempts. These frames generally belonged to two distinct groups. The first being counter-framing attempts which focused on cultural interpretations such as *Animal Rights* and the *Cultural* frame which focused on public interpretations of xenotransplantation through different lenses such as religion or cultural heritage. The second group of frames were attached to, or provoked by, certain events or context - such as those seen during a controversy or Parliamentary debate. These were frames tailored to specific events and generally had short term goals, never gaining salience outside these contexts. Details of these short lived frames can be found in the following section.

2005: The High Water Mark

2005 represented the peak of overall framing for the period studied. With the Bioethics Council documents and parliamentary debates regarding xenotransplantation legislation occurring, this provided the greatest volume of framing efforts but also the greatest range of framing attempts.

The Bioethics Council produced both their discussion document and final report on xenotransplantation in 2005. This feature, coupled with the encroaching end of the XTP moratorium date, prompted Hansard debate on the parliamentary floor; specifically, the three readings of the Medicines (Specified Biotechnical Procedures) Amendment Bill debated in May 2005. The most significant frames usage by volume is found in Figure 3 and Table 1.

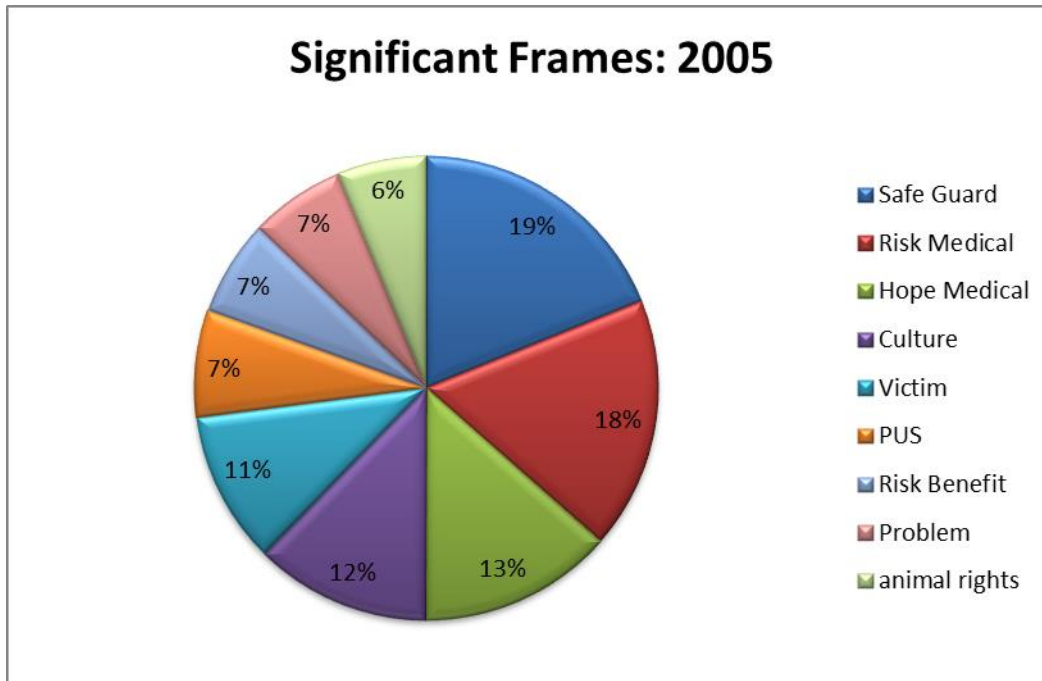


Figure 3

Outside of the described major framing efforts, outstanding concerns were seldom engaged after the 2005 presentation of Bio Ethics Council documents and parliamentary debate regarding an extension of the existing moratorium. There are different factors with possible correlative relationships, which could help explain this including: the lack of evidence related to risk is matched with the perception of adequate safeguards which undermined outstanding ethical concerns - such as public consent, third party risk or animal rights; the shift of issue context due to successful framing or current events; the change in government lead to the disestablishment of The Bio Ethics Council - the primary source of counter framing; the lack of media interest or investigation i.e. the reliance on pre-packaged press releases that featured human interest stories; and the lack of public awareness and understanding of public policy development in general but also biotechnological development outside of their immediate concerns e.g. diabetic support groups and those on organ waiting lists.

Frame	Number of Instances
Safe Guard	409
Risk Medical	382
Hope Medical	294
Culture	266
Victim	231
PUS	162
Risk Benefit	145
Problem	144
Animal rights	135

Table 1

What is notable from the table of dominant frames is the surprising lack of expected archetypal frames. An issue such as XTP lends itself readily to such interpretations as: Mad Scientist, Pandora's box, and Frankenstein's monster. The *Pandora's Box* and *Mad Scientist* frames were only used three times respectively during Hansard debates. For the latter, its use

was to specifically point out that New Zealand scientists are nothing like this analogous construct e.g. *I do not think there are any mad scientists in New Zealand.*²¹³

Interestingly, the *Good-Guy-Scientist* frame arose in 2005 to exemplify that New Zealand had well trained and respected scientists. This was often coupled with the *Risk-Benefit* frame, which suggested or argued that these scientists would leave New Zealand in favour of other countries less burdened by intervening bureaucracy.

*Labour [political party then in government] can pontificate about the cultural issues and sensitivities, yet people are waiting for life-changing treatments. We need to trust the scientists, who are very careful, sensible, and ethical in the work that they have done and are doing. We know that the moratorium will not stop the work being done. It will just send our scientists offshore so that the work can be done there. Is it any wonder that we are seeing a brain drain of scientists right now? There are simply too many hurdles and barriers in their way when it comes to New Zealand science to do leading-edge work.*²¹⁴

Then there was the inaccurate use of framing in 2005; whether intentionally or by ignorance, two framing attempts were prominent in their misrepresentation of the issue. The Green Party sponsored the *Prevention* frame during Hansard debates, saying that we should be taking action to prevent individuals from needing the sorts of treatments xenotransplantation can provide, e.g. by promoting healthy eating and exercise.

[I]nstead of looking at doing something as radical and with such political risks as xenotransplantation, why do we not look in the first instance at the causes of diabetes and at

²¹³ Katherine Rich, National Party, Hansard, Medicines (Specified Biotechnical Procedures) Amendment Bill, First Reading, 2005

²¹⁴ Ibid.

*some simple steps that we as a population could take, which are right under our noses, to try to prevent diabetes or reduce the epidemic of diabetes?*²¹⁵

This frame ignored vital pieces of information. Firstly that Diabecell was being offered as a solution to type one diabetes, not the obesity-related type two diabetes. Secondly, this frame ignored that an increase in organ donation (the other preventative approach furthered by the Green Party) would not meet demand for organ and tissue sources now or in the future as seen by Spain's highly successful but still inadequate organ donation policies.²¹⁶ In both cases, prevention is not a solution for those suffering from these conditions.

Representatives of the political right also sought to direct framing in ways that did not accurately describe how their position would resolve the debated concerns.

*We have volunteers who have sought information themselves, and who have consented, voluntarily, to the treatments, and to the research that they have undertaken, and they are well aware of the consequences of their actions. They know that there are risks associated with the treatment, risks associated with research, and, in fact, there are risks associated with life. They take this on board and they make a voluntary, conscious decision to participate or to not participate.*²¹⁷

This focus on xenotransplantation being a personal choice between Doctors and patients actively side-stepped the issue of third party risk as well as concerns regarding adequate public consultation that had dominated concerns up to this point; and, included in the

²¹⁵ Sue Kedgley, Green Party, Hansard, Medicines (Specified Biotechnical Procedures) Amendment Bill, First Reading, 2005

²¹⁶ Fabre John, Murphy Paul, Matesanz Rafael. Presumed consent: a distraction in the quest for increasing rates of organ donation *British Medical Journal*, 2010; 341:c4973

²¹⁷ Heather Roy, ACT Party, Hansard, Medicines (Specified Biotechnical Procedures) Amendment Bill, Third Reading, 2005

positions of all the major political parties. Their use of the *Government Intervention* frame in this context undermined the potential risks to third parties - such as family, sexual partners and medical personnel not engaged within this context.

What is significant about these short lived framing attempts is that they did not gain salience outside of their immediate sponsors or context, which itself became a dominant feature of this discussion. As mentioned in Chapter 2, those who use conflicting frames will labour extensively to find and build upon common ground, while frame cohesion lends itself to productive discussion. Frame usage was consistently used or attributed directly to frame sponsors, producing many short lived and conflicting framing efforts. Despite a change in government in 2008 there is no evidence to suggest a shift in government sponsored framing efforts. Dominant framers in government and industry were able to continuously frame xenotransplantation as their role, as key stake holders and their close relationship with the media meant they were able to direct the line of framing through event-driven press releases which other frame sponsors appeared unable to replicate.

Initially this meant while the risk of xenosis was considered unknown, *Risk-Medical* was coupled with *Safeguard* framing - dominating this initial stage of the xenotransplantation discussion. Once the issue of endogenous retroviruses were seen to be of minimal or manageable risk and it was deemed by the major stakeholders that appropriate safeguards were in place, these frames declined in use giving way to the increased use of the *Hope-Medical* and *Hope-Benefit* frames.

After the moratorium expired and Diabecell trials were able to resume, central government no longer featured predominantly in the xenotransplantation discussion. LCT, as the main

sponsors of *Hope*-based framing efforts, was able to dominate post-2006 xenotransplantation discussion through numerous press releases.

While counter framing attempts remained, these were very seldom engaged; instead, they were often presented alongside but not directly referenced by the more dominate frames. This however, is a logical step in framing. Once framing dominance had been achieved, any engagement with counter framing would only serve to legitimise opposing concerns.

A notable exemption from this is the presence of the *Public Consent* frame which featured sporadically from 2005-2008. While this was never a dominant frame, LCT did feel the need to respond. This issue arose in response to third party risk and the perceived need for a measure of public consent. LCT argued this matter had been resolved by The Bioethics Council. This is despite that was not the mandate of the Bioethics Council, nor discussed in their published documents. Instead, by using the *Safeguard* frame to argue that The Bioethics Council had been a part of rigorous safeguards, this minimised public consent - an ethical concern - by refocusing on safety measures, placing the discussion back into a risk -based cost/benefit discussion.

The defining events of the xenotransplantation discussion were the Hansard debates regarding the one year extension of the moratorium, and the presentation of the Bioethics Council's findings. This is the key time where overall framing efforts peaked, were some frames were discontinued in some cases, or began to rise.

One notable case of how this changed affected issues was the initial concern regarding xenotourism. Xenotourism is when people travel outside of their country to have xenotransplantation. Prior to 2005 xenotourism was viewed in regards to *Risk Medical* and was

used in this regard by those who thought New Zealanders would go to other countries - where it was argued or implied there would be less stringent safeguards regarding XTP - and pose a risk to the New Zealand public upon their return. This was used by those who were concerned about the risk of xenotransplantation and those who argued in favour of XTP in New Zealand; so it could be done to New Zealand medical and ethical standards.

After 2005 however, xenotourism was no longer framed as a risk, after the expiration of the moratorium. Instead introducing XTP was viewed as a potential economic gain; xenotransplantation would now bring xeno-tourists to New Zealand to undergo the operations here - coming under *Hope-Benefit* framing.

In summary, the major stakeholders dominated public debate. Through their press releases and close relationships with news media they were able to consistently create news and frame it to their choosing. Prior to 2005 there were a greater variety of frames, yet the processes of government debate and the Bioethics Council's final report substantially reduced the number of frames after this time. The Chapter 6 will explore this in greater detail - putting this analysis within the context of the public engagement of science, as well as other ideas explored within the Literature Review, Chapter 2.

Chapter Six Discussion

Main Findings

This chapter analyses what implications the discussion of xenotransplantation has for the public engagement of science in New Zealand. This places the discussion and the previously mentioned trends in context, as to present a better picture of the successes and failures of those framing efforts.

The first section illustrates how the main framing efforts achieved salience; in essence, that the major frames formed a basic cost/benefit argument - shaping which frames did or did not gain salience from their lack of inclusion into the binary focus. Then it is contended this cost/benefit discussion framed not just the issue but the debate; that while xenotransplantation was being discussed, the larger issue of biotechnology in New Zealand society and in particular Maori culture and biotechnology, was explored and presented to the public.

In addition to this, an examination of how uncertainty and risk became some of the most interesting factors of the public deliberation, and how this conversation has shaped the social contract between the biotechnology industry and the New Zealand public.

The main findings of this research are that there was a logical reduction of narrative based upon a meta-framed cost/benefit analysis, and that this was achieved through persistent framing efforts by key stakeholders - combined with an emergent perception of low risk and New Zealand's safeguard standards. The extensive use of the *Risk-Medical* frame ensured xenotransplantation had a risk assessment attached to it. Yet this risk was overwhelmingly

presented as low and manageable, especially as it often coincided with the use of the *Safeguard* frame.

2005 represented the peak of framing efforts with the Hansard debates regarding the extension of the moratorium and the presentation of the Bioethics Council's discussion and findings documents. Afterwards, the expiration of the moratorium meant trials were able to proceed and Living Cell Technologies (LCT) was able to frame extensively. This was furthered by content sharing through the New Zealand Press Association, which produced near-identical articles in regional and national newspapers - bolstering nationwide issue framing.²¹⁸ Post-2005, *Safeguard* framing exceeded *Risk-Medical* which had begun to decline, whereas *Hope-Medical* remained steady and the use of *Hope-Benefit* framing grew.

As mentioned in Chapter 3, episodic framing is often used by news media - as it can produce personal and emotive storytelling. Episodic framing was effectively used by LCT, as the company was able to frame itself as positive and relatable. More than presenting itself within an economy of hope by focusing on the potential medical and financial benefits of xenotransplantation, the recurring frame of *Govt-Interference* from 2009-2010, and the introduction of the *Grass-roots* frame, conferred a relatable persona. This was personified by Director, and Chief Science and Medical Officer, Professor 'Bob' Elliot. Professor Elliot's cultural rapport with the New Zealand audience was achieved through emulating language and cultural archetypes of New Zealand; such as the pioneering spirit, hard work and 'the underdog'. This can be seen in the exchange below:

²¹⁸ The NZPA ceased operations 2011 and has been replaced by three Australian-owned services: APNZ of APN News and Media, Fairfax New Zealand News (FNZN) and the Australian Associated Press which established NZ Newswire (NZN).

Q: *What has been the biggest obstacle in running your company?*

A: *(Professor Elliot): The regulatory procedures [...] You'd be amazed at the mountain of paper generated to get through this xenotransplantation thing and thousands and thousands of hours have gone into getting regulatory approval.*

Q: *Why did you keep going?*

A: *I was not going to let the bastards grind me down. Nothing was going to stop me, nothing, and if it requires thousands of hours, then I will find those hours.*²¹⁹

This approach positions and shapes the emotional reaction to one of the main stakeholders in the xenotransplantation debate in New Zealand. This reduces the context given to XTP in New Zealand and abbreviates medical and ethical concerns into an embattled underdog facing an intrusive and obstinate regulatory system. As mentioned previously, this framing, by and of, LCT took place when counter framing and the *Risk-Medical* frame in particular was in steep decline, meaning there were few dissenting voices to an otherwise sympathetic stakeholder.

This underdog status is also relevant to New Zealand's self-perception in contrast to Australia, whose geographical proximity and shared heritage has fostered a friendly but culturally significant rivalry. As described in Chapter 2, countries such as Iceland and Tonga were able to draw from ethno-nationalism in support of their biotechnology ventures. New Zealand did this in a certain manner by focusing on the potential of the Auckland Island pig population through the *Pharma-Pig* frame, but more prevalent was cultural insecurity.

The extensive use of the *Risk-Benefit* frame - a frame primarily used to highlight the risk of economic loss or missing out on the expected biotech boom, was used extensively prior to

²¹⁹ Rotherham, Fiona, *CELL SCIENTIST DETERMINED*, The Press (Christchurch, New Zealand), p. 21 – Data set, Factiva, subset 4, p. 9

2006. *Risk-Benefit* played a significant role in the case for xenotransplantation in New Zealand – through the often implied or inferred notion that LCT would move operations overseas, likely to Australia, in response to supposed regulatory hurdles in New Zealand. This was a salient point for the New Zealand audience, hence its popular usage.

The Logical Reduction of Narrative

The research showed the major frames produced a meta-framing effort that constituted a cost/benefit analysis, restricting what was considered acceptable approaches to the issue of xenotransplantation in New Zealand. Cost/benefit analysis is a persuasive method of thinking, as it is often presented as a fair and forthright mode of analysis and decision making, but its use in public policy has numerous drawbacks. The first of which is that cost/benefit analysis does not identify the population segments whom the proposed measure would benefit or harm.²²⁰

When discussing the benefits of a successful xenotransplantation research program, New Zealand was described as gaining from this development as if it were a monolithic entity, with few specifics being given by frame sponsors in government or industry as to who were to gain.

Initially, as Diabecell became the focus of the debate, diabetics became a specific group which was singled out as one that would benefit, but with no specific information or proposed ideas anywhere in the dataset about the pricing of Diabecell, or its place in the public health

²²⁰ Dorfman, Robert. Rothkopf, Micheal H., *Why cost benefit analysis is widely disregarded and what to do about it*, Interfaces, Vol 26, no 5 1996, p. 1-6, URL jsot.org/stable/25062162

program. In light of this there is no assurance that diabetics at an economic disadvantage will not receive a lesser standard of care despite their use in framing efforts.

Yet while benefits were framed in more general terms, risks were framed in a way that localised concerns and minimised third party risk and, by proxy, greater public engagement. Initially, when the evidence of retroviral infection was discovered and reported on in the *Lancet* documents, fears over the possibility of an epidemic was widely reported. This concern provoked numerous references to, and statements about, New Zealand's laboratory and regulatory safeguards - which continued until the decline of the *Safeguard* frame in late 2008, after observing a brief resurgence in response to the Swine-flu epidemic. This effort, and the lack of corresponding research showing retroviral infection by xenotransplantation, saw generalised *Risk* framing itself, decline steeply after 2005.

As tool for public policy, cost/benefit analysis's efficacy can also be challenged on the basis it attempts to reduce all comparisons to a single dimension.²²¹ The segregation of public discussion of biotechnology is most apparent with Maori, where Maori opinion was regarded as value and culture based, denying its input in intellectual or scientific conversation and placing it aside or in perceived opposition to scientific conversation. Activist Ken Mair said in relation to Maori input in the biotechnical discussion, that the issues raised were '*more than cultural*' and that *they are at an intellectual and scientific level. [...] We are tired of being relegated into some subservient little box called 'cultural understanding'*.²²²

This is also made apparent by the mandate given to the Bioethics Council, of seeking public views on the cultural, spiritual and ethical aspects of the technology while the Ministry of

²²¹ Ibid.

²²² *Public still in the fire zone as gene engineering battle rages on*, 28 December 2001, NZPA

Health reviewed its safety. It was, and remains, a clear demarcation of where public input is asked and where it is unwelcome. This enables a false equivalency - where the issue is framed in terms of the mutually reinforcing scientific and economic rationalities, juxtaposed by Maori value assessments. This juxtaposition presents different viewpoints as being equal in societal value assessments, when this is not the case. For example, human rights are by their virtue non-negotiable if compared to economic considerations, but placing them side-by-side would not present this difference.

Cost/benefit analysis, even on this meta-scale, is significantly reductive in its presentation of community ideas and positions. This can generate social tension by not presenting the diversity of Maori and European views. This can be especially damaging as the cultural concerns of Maori are routinely portrayed as a significant obstacle for scientific and economic progress.²²³ Not only does this undermine Maori voices in scientific contexts but also means that cultural and ethical concerns in general are undermined by the binary discourse, depriving the conversation of nuances that could make for better policy outcomes.

What is crucial is that an informal cost/benefit analysis represents a measure of what a society values by how it assigns value within this analytical method. It should be used to provide information relevant to the decision-making process - not make the decision itself as logical reductions of narratives do.²²⁴ Further, any decision a cost/benefit analysis facilitates still rests on all existing values of society; as a method, it doesn't ignore, generate or develop values but its application can create bias.²²⁵ So when cultural and personal values are discussed

²²³ Goven, Joanna, *Deploying the consensus conference in New Zealand: democracy and de-problematization*, *Public Understanding of Science*, 12, (2003) p. 436

²²⁴ O Zerbe, Jr., Richard, *Is Cost/benefit Analysis Legal? Three Rules*, *Journal of Policy Analysis and Management*, Vol. 17, no. 3 (1998) p. 419-456, p. 420-421

²²⁵ *Ibid.*

in this context, it means that the myriad of Maori and Pakeha cultural interpretations were reduced to the '*cultural and spiritual issues associated with the procedure*' against an economy of hope.²²⁶

This is a core weakness in how binary discourse weakens public policy development by reducing public input. It lends itself to an economic model where there are clear values that can be incorporated into the decision-making process. Despite this, cost/benefit models do not presume a decision, but to facilitate them. This is why in research where the public has been questioned by cost/benefit analysts on how much they would be willing to pay to save a particular wilderness environment or specific species, these questions commonly go unanswered.²²⁷ As value assessments are heavily subjective, they cannot be adequately measured against each other or economic factors. This increases the likelihood of controversy or stalemates that result in policy that doesn't fit the communities it was designed to serve.

As mentioned in Chapter 2 it was a common complaint, from those involved in public engagement of science events, that many of the starting points of discussion or supporting information were presented without background information on how a certain position, conclusion or risk assessment was achieved. It was simply presented as part of a public engagement of science effort that repeated the assumptions of a deficit model of public understanding. This focus on process from the public points to one of the key elements of the scientific method in that a position requires a defence of argument or evidence – serving as testament to the public's ability to engage actively with science, in areas not specific to value-based argument.

²²⁶ Gene Technology Advisory Committee, *GTAC Guidelines for Preparation of Applications Involving Clinical Trials of Xenotransplantation in New Zealand*, September 2007, Ministry of Health, New Zealand

²²⁷ Ibid.

Such an approach can be used to conceal degrees of inaccuracy or uncertainty in estimates - risking the possibility of audiences forming conclusions from misleading information and directly affecting their buy-in to the economy of hope. In the context of the XTP debate, the degree of accuracy in the presented risk assessments were not specified in the print media, nor the discussion documents produced by the Bioethics Council or the background documents supplied to Members of Parliament. Instead, the risks were consistently portrayed as extremely low, with uncertainty or variation of risk assessments undisclosed and in 2007 LCT's Professor Elliot went so far as to reassure the public that: *'the move [to stop trials] had been purely precautionary because of limited research suggesting that pig retroviruses could infect patients. Now we are confident that this isn't the case. After more animal studies and carefully following patients for more than a decade, the scare has gone.'*²²⁸

Uncertainty, Risk and Public Deliberation

The inability to recreate the original *Lancet* studies was at the centre of the initial low risk assessments that were an integral part of the xenotransplantation debate in New Zealand. This meant that early in the public debate risk assessments concerning xenosis were consistently low. However more recent information presented in *Nature* and reported in *New Scientist*, undermines this assumption and has far-reaching consequences for biomedical science as a whole.²²⁹ Two large pharmaceutical firms independently revealed they could not reproduce the

²²⁸ Kent Atkinson, *Diabetes researcher wants to re-start NZ xenotransplant trial*, 31 March 2007, NZPA

²²⁹ Elizabeth Irons, *Is medical science built on shaky foundations?* *New Scientist*, no 2882, 17 September 2012, Newscientist.com/article/mg21528826.000-is-medical-science-built-on-shaky-foundations.html

vast majority of published studies.²³⁰²³¹²³² Yet, such studies remain an important tool for alleviating the financial burden for proof-of-concept, that work towards providing new and better treatments.

In September 2011 Bayer Healthcare revealed they had performed an in-house survey of 67 projects and found that *only in ~20-25% of the projects were relevant published data completely in line with [their] in-house findings.*²³³ Further, that the reproducibility - or lack thereof - *did not significantly correlate to journal impact factors, the number of publications on the respective target or the number of independent groups that authored the publication.*²³⁴

Soon after, another company and rival of Bayer, Amgen, reported even higher levels of failed reproducibility trials. They showed that in their effort to reproduce 53 landmark cases, only six cases were a success - a failure rate of almost 90% - *despite knowing the limitations of preclinical trials, this was a shocking result.*²³⁵ They responded that *given the inherent difficulties of mimicking the human micro-environment in preclinical research, reviewers and editors should demand greater thoroughness.*²³⁶

²³⁰ Begley, C., Glenn and Ellis, Lee M., Drug Development: *Raise standards for preclinical cancer research*, Nature 483, 531–533, 29 March 2012, DOI:10.1038/483531a

²³¹ Prinz, Forian, Schlange, Thomas and Asadallah, Khusru, *Believe it or not: how much can we rely on published data on potential drug targets?*, Nature reviews, Drug discovery, 10; 712, September 2011, DOI: 10.1038/nrd3439-c1

²³² Arrowsmith, John, *Trail Watch: Phase II failures: 2008-2010*, Nature reviews Drug Discovery 10, 328-329, May 2011, DOI: 10.1038/nrd3439

²³³ Prinz, Forian, Schlange, Thomas and Asadallah, Khusru, *Believe it or not: how much can we rely on published data on potential drug targets?*, Nature reviews, Drug discovery, 10; 712, September 2011, DOI: 10.1038/nrd3439-c1

²³⁴ Ibid.

²³⁵ Begley, C., Glenn and Ellis, Lee M., Drug Development: *Raise standards for preclinical cancer research*, Nature 483, 531–533, 29 March 2012, DOI:10.1038/483531a

²³⁶ Ibid.

It is important to make clear that this does not mean, as was often inferred at the time, that 90% of science cannot be reproduced.²³⁷ It does mean however, that a greater level of uncertainty needs to be acknowledged, especially in the preclinical stages. For the xenotransplantation debate, the certainty in which the economy-of-hope was deployed, the low risk assessments should have been tempered considering the apparent long-time knowledge of unreliable preclinical trials and, as the researchers from Bayer argued, this non-reproducibility *indicates the limitations of the predictivity of disease models.*²³⁸²³⁹ This revelation should temper how biomedical technology is introduced and understood, how benefits are marketed, and how risks are presented to the public.

A large part of the reasons for preclinical trials is to prove the safety and efficacy of treatment before it reaches the public, yet for the XTP debate, it reinforced the authority of LCT's risk assessment, where the non-reproducibility of The Lancet studies became the basis for communicating low risk; a designation that was commonly used, seldom explained and not completely accurate.²⁴⁰

While uncertainty was not attributed to any risk assessment by the major stakeholders, in December 2010 there was the short-lived introduction of the *Not-a-Cure* frame – used to temper the expectations of Diabecell within the economy of hope. Though LCT and others in the scientific community were generally responsible in the description of what Diabecell could

²³⁷ Picha, Bad, Thompson, Matthew and Vondriska, Thomas M., *Preclinical Trials: Keep 'reproducibility' in context*, Nature 485 (3 May 2012) DOI: 10.1038/485041d

²³⁸ Begley, C., Glenn and Ellis, Lee M., *Drug Development: Raise standards for preclinical cancer research*, Nature 483, 531–533, 29 March 2012, DOI:10.1038/483531a

²³⁹ Prinz, Forian, Schlange, Thomas and Asadallah, Khusru, *Believe it or not: how much can we rely on published data on potential drug targets?*, Nature reviews, Drug discovery, 10; 712, September 2011, DOI: 10.1038/nrd3439-c1

²⁴⁰ Ibid.

mean as a diabetes treatment, those in the media, or victim advocates, often inferred greater and sometimes misleading conclusions. This led to statements such as

*Medical researchers have successfully treated diabetes in laboratory monkeys by transplanting pancreatic tissue from pigs – giving hope that pig transplants may one day be used to cure childhood diabetes in humans.*²⁴¹

And:

*Xenotransplantation has been advanced a potential cure for a number of serious health concerns, including diabetes and Huntington’s disease.*²⁴²

This was understandable misreporting of the immediate potential of xenotransplantation - media sensationalism can easily misinterpret statements regarding clinical trials, what is hoped to be achieved by them and what successful trials might mean for the future of xenotransplantation. However the misrepresentation of xenotransplantation as a cure for diabetes is not entirely the fault of a scientifically naive media. Professor Elliot, in arguing the benefit-risk threshold had been crossed, stated *[animal trials] had demonstrated the efficacy of pig cell transplants. Fifty percent of mice are cured with the treatment: ‘Crikey, any treatment that can cure at least half of any condition, you’d want that, wouldn’t you?’*²⁴³

This idea that xenotransplantation - specifically Diabecell - would provide a cure, became pervasive amongst the mainstream media. In May 2008 it forced Minister of Health David Cunliffe to respond:

²⁴¹Steve Connor, *Pig parts offer hope for diabetics*, New Zealand Herald, 9 June 2003

²⁴²Michael Herman Sunday roast straight from lab, 20 December 2005, The Press

²⁴³Rebecca Macfie, 4 November 2007, NZ Listener, APN Specialist Publications NZ Ltd

I want to make it clear to New Zealanders that while the application is for a clinical trial involving only 8 diabetics subjects, there are risks associated with this not only for the subjects but also for the wider public. Unfortunately [...] diabetes sufferers were led to believe that a cure for the disease was being withheld from them. Nothing could be further from the truth as this clinical trial is not offering a cure. Quite apart from misrepresenting my position, I am appalled that [the media] has misled the public on this very serious matter.²⁴⁴

This expectation within the economy of hope, fostered by inaccurate reporting from industry and the media, placed significant public pressure on the government to allow xenotransplantation. That it became the responsibility of government to address the inaccurate expectations is a damning representation of LCT and a scientifically illiterate media. It was not until clinical trials resumed, that LCT made a concerted effort in 2010 to temper the expectation that Diabecell was a treatment for diabetes rather than a cure.

The scientific community is often presented as offering definite predictive knowledge on the consequences of new technologies in the form of institutionalised risk assessments. Yet those involved in their production are frequently exonerated from responsibility if there are negative consequences, as scientific knowledge and its predictive qualities are also accepted as provisional.²⁴⁵ As the risk assessments associated with new biotechnologies factor strongly in the arguments and conclusions about disease models, safeguards and response, greater accountability is required to make future discussions more transparent and equitable. The

²⁴⁴ New Zealand Government Press release, *A proper process for xenotransplantation*, 21 May 2008, Scoop.co.nz

²⁴⁵ Waterton, C, Wynne B E, Grove-White, R.B., and Mansfield, T., *Scientists reflect on Science: scientists' perspectives on contemporary science and environmental policy*, A research report by the Centre for the Study of Environmental Change and the Institute for Environmental and Natural Sciences, Lancaster University, Lancaster 2001, URL: www.csec.lancs.ac.uk/docs/Waterton_SROS_report.doc

current format has in effect silenced the public side of the debate not directly related to value based arguments as the provided information is given as fact as opposed to expert opinion.

This makes the same false assumptions as the deficit model discussed in Chapter 2. Scientists, experts and scientific discussion are often seen as unbiased and drawing direct conclusions from clear data - in this case a low risk assessment, while public input is presumed to be value-based, which holds less significance and credibility in intellectual discussion.

Important to this discussion is timing. As mentioned previously, in 2005, the Bioethics Council produced a discussion document on xenotransplantation and preformed a number of public deliberation meetings and Hui in major centres in New Zealand. Later that year the Bioethics Council presented their conclusions to the New Zealand government.

Its mission was broad: to consider the ethical, cultural and spiritual issues connected to XTP. Yet it was not until 2008 that the Minister of Health ordered an investigation by the National Health Committee into LCT's application for clinical trials.

This meant Bioethics Council researchers and the public who took part in the public deliberation, were not in a position to make their submissions with access to an independent scientific examination of LCTs information. One main reason being that clinical trial applications were not being accepted by the Ministry of Health in 2005, because the moratorium was still in place. Considering that scientific and value based arguments were segregated, it is intriguing that ethical considerations were so far removed from the independent risk assessment provided by the NHC, and that it was not deemed that ethical considerations would need to be publically re-examined in light of this new risk assessment.

As part of the clinical trial review process, the NHC did take public submissions which included written and oral submissions and public meetings in major centres.²⁴⁶ This was a commendable effort, but the submission process did not allow for the NHC's independent review as it was for the application for clinical trials and xenotransplantation in New Zealand – not as a response to the findings of the NHC review.

In essence, there was a lack of public space for the review of the new information brought forward by NHCs risk assessment and their procedural recommendations. This included issues the public would have strong interest in, such as non-patient involvement; such as life-long monitoring of the patient's intimate partners not involved in the original consent process, and the issue of long term liability in the case of PERV infection - which the NHC acknowledged as unresolved.^{247,248}

Despite this, the NHC used the Bioethics Council consultation as the basis for their conclusion that the ethical considerations had been adequately considered - a key factor in their overall recommendations to the Minister of Health.²⁴⁹ The NHC had to consider as part of the application review process, that ethical issues '*raised by the conduct of the procedure or class of procedure to which the application relates and by any technology involved in that conduct have been adequately addressed.*'²⁵⁰ Yet upon examination of LCT's submission towards that specific criterion that put forward these definitions:

That 'adequately' is a low threshold, which only requires that these issues be addressed in a way that is 'barely sufficient'.

²⁴⁶ National Health Committee, *National Health Committee's Advice on Living Cell Technologies Application for Xenotransplantation Clinical Trials in New Zealand*, Ministry of Health, New Zealand, p. 10

²⁴⁷ Ibid, 20

²⁴⁸ Ibid, 48-49

²⁴⁹ Ibid, 10

²⁵⁰ Ibid, 21

And,

That 'addressed' does not mean these issues need to be resolved or that people with concerns need to have consented to the trial, only that such issues have been 'considered and acknowledged'.²⁵¹

While the NHC took exception with the qualifier of 'barely' before the word 'sufficient' - arguing that this made the threshold standard 'too narrow', they were satisfied in this response to third party concern. Significantly, this third party concern was ascribed almost exclusively to Maori:

There is an ethical argument that, because the trial has the potential to impact a wider population beyond individual patients, that a form of collective consent is required. For some cultures, such as Maori and Pacific peoples, the requirement for collective rather than individual consent is valued. Such an approach may be applicable to any medical procedure a Maori or Pacific person might undergo.'²⁵²

During the Bioethics Council investigation, Health and Disabilities Commissioner Ron Paterson had warned individual consent to xenotransplantation research was insufficient and that a method of collective consent was necessary.²⁵³ This suggests that the issue of third party consent was a valid topic of discussion post-2005, yet it was represented only marginally through the *Public Consent* frame - sponsored by a lobbyist for the Sustainability Council.²⁵⁴

Further, as third party risk and fear of a PERV epidemic featured so heavily in the initial discussion and eventual moratorium on xenotransplantation, it is somewhat difficult to

²⁵¹ Ibid, 22

²⁵² Ibid.

²⁵³ Stewart Dye, *NZ 'ill prepared' for pig cell trial*, the New Zealand Herald, 4 Oct 2007

²⁵⁴ Ibid.

understand the motivation for describing this issue along racial lines. As mentioned before, this issue-segregation alienates Maori and non-Maori from open discussion. It presents Maori concerns as solely value based and obstructionist, and minimizes the ethical concerns of non-Maori New Zealanders.

The opportunity for these discussions is important, as it addresses significant and material concerns related to xenotransplantation. In 2008, when asked about further public consultation, LCT chief executive Paul Tan referred to the Bioethics Council public engagement, saying there was no need for more consultation on the aspect of community risk and liability. This is despite the Bioethics Council report showing the public wanted a reliable medical authority to declare XTP as not presenting a significant risk to public health and that the possible risks could be managed.²⁵⁵ One can only assume that risk assessments in 2008, from GTAC and the NHC, would have gone some way to providing this but were unavailable for another three years and thus unable to be incorporated into the Bioethics Council public engagements and subsequent recommendations.

The issue of liability is another area that the New Zealand public was unable to provide input. The Bioethics Council stated in its 2005 conclusions that liability in the event of xenosis would be an appropriate issue for the Law Commission - in the same manner they had investigated the concept in relation to genetic modification that led to their establishment. In 2008 the NHC continues that the issue of liability is unresolved - as LCT does not accept liability after five years from the beginning of the trial period. Considering ACC legislation would not cover participants in this clinical trial, the NHC recommended participants should

²⁵⁵*The Cultural, Ethical and Spiritual Aspects of Animal-to-Human Transplantation: A report on xenotransplantation by Toi te Taiao: the Bioethics Council* Ref. BC 13, The Bioethics Council, Ministry for the Environment, New Zealand, August 2005

have access to liability cover for the entirety of their lives.²⁵⁶ This would likely come at the expense of taxpayers.

So despite Paul Tan and others attesting that public consultation was unwarranted, it appears there would be a substantive case for further deliberation if Diabecell, or another xenotransplantation procedure, were to continue past Stage Three clinical trials and eventual commercial release.

Public Engagement

In addition to these outstanding issues, the public submission process did not work effectively. Public deliberation on XTP, as in general, have low turnout in submissions. This is generally attributed to lack of topic interest or general public apathy but this may not be the case. As mentioned in Chapter 2 arguments have been made that suggest that if that the public is supposedly uninterested, there is little cause to involve them.

This would seem compelling when public submission processes are dominated by interest groups. For the NHC public submission process, 95% of those came from people with diabetes. It is clear why: diabetes is a terrible affliction that can substantially affect a person's quality of life. As such, the prospect of normality - in so far as reducing the need for insulin and regular blood testing - is cause for hope and support.

This being said, xenotransplantation in New Zealand is an issue that extends past victim advocacy, and 95% of submissions being from sufferers or diabetes advocacy is not a fair

²⁵⁶ National Health Committee, *National Health Committee's Advice on Living Cell Technologies Application for Xenotransplantation Clinical Trials in New Zealand*, Ministry of Health, New Zealand, p. 20

representation of the New Zealand public that will also take part of the risk of clinical trials but also a future in which xenotransplantation may become a regular feature in diabetes.

Public apathy in the civil engagement has regularly been attributed to ineffective or untrustworthy media outlets.²⁵⁷²⁵⁸ This, in combination with how the public sector advertises for public submissions, has led to accusations that public input is being actively discouraged by how it is presented - in contrast to how the private sector advertises itself.²⁵⁹²⁶⁰²⁶¹

This is important, as public submission processes are often in contrast to well-funded framing efforts, as seen in the research. LCT, as a major stockholder in the issue of xenotransplantation, was able to give itself a regular platform to make its ideas heard and felt.

Public submission processes have funding provided by governmental organisations such as the Bioethics Council and do not have marketing experts working on increasing active political engagement to the same degree as private firms advertising for consumer goods. This partially explains the relatively poor attendance for the Bioethics Council public engagement sessions with the highest attendance of 33 attending the 2005 bi-cultural Hui in Christchurch.²⁶² How certain events like public submission processes are reported by the media, can heavily skew the information available in articles. In Chapter 2, Allspaw presented concerns of whether

²⁵⁷ Pinkleton, Bruce E., Weintraub, Erica, *Media Perceptions and Public Affairs Apathy in the Politically Inexperienced*, Mass Communication and Society, 2004: 7:3, p. 319-337

²⁵⁸ Pinkleton, Bruce E., Weintraub, Erica, Yushu Zhou, Austin, Willoughby, Jessica Fitts, Reiser, Megan, *Perceptions of News Media, External Efficacy, and Public Affairs Apathy in Political Decision Making and Disaffection*, Journalism & Mass Communication Quarterly March 2012 vol. 89 no. 1 23-39

²⁵⁹ Meslin, David, *The antidote to apathy*, recorded Oct 2010, TEDx, URL: ted.com/talks/dave_meslin_the_antidote_to_apathy

²⁶⁰ Cowan, James, *Sending a Message on Posters*, National Post, Toronto, 12 October 2002

²⁶¹ Levin Laura., Solga, Kim, *Building Utopia: Performance and the Fantasy of Urban Renewal in Contemporary Toronto*, TDR: The Drama Review, 53.3 (2009) 37-53

²⁶² *The Cultural, Ethical and Spiritual Aspects of Animal-to-Human Transplantation: A report on xenotransplantation by Toi te Taiao: the Bioethics Council* Ref. BC 13, August 2005, The Bioethics Council, Ministry for the Environment, New Zealand.

democratic ideals are better served by, ‘*allowing the voices of the concerned and/or informed to rise above those of the indifferent and/or uninformed?*’²⁶³

As a response to this thinking, urban activist Dave Meslin has become notorious for illustrating the differences between calls for public submissions on urban planning, and private sector advertisements.²⁶⁴ For example, news media stories related to theatre shows, new technology and restaurant reviews were shown to provide clear information on specifics such as topic or genre, location, date, time and contact information, as distinct from the story itself; presented either before or after the review article.

Yet in instances in which news articles discuss issues open for public submissions, there was little to no relevant information for getting involved in a similar manner to the private sector advertising.²⁶⁵ This distinction reinforces the idea that politics and science are distinct from everyday life - the strict purview of those in government, industry or special interest groups.

This idea is furthered by the focus on leaders and episodic framing in these news stories; describing leaders in their field and leaders in group advocacy - such as the focus on Professor Elliot and his story as an embattled entrepreneur. This undermines the position of the public because, when combined with a lack of information in news stories, there is no popularised method for community involvement or a local or central government service for the dissemination and translation of documents for public consumption and deliberation.

²⁶³ Allspaw, Kathleen M., *Engaging the public in the regulation of xenotransplantation: would the Canadian model of public consultation be effective in the US?*, Public Understanding of Science 2004; 13, DOI: 10.1177/0963662504044559, p. 418

²⁶⁴ Meslin, David, *The Antidote to Apathy, Presentation*, Recorded Oct 2010, TEDx, URL: ted.com/talks/dave_meslin_the_antidote_to_apathy

²⁶⁵ Ibid.

While currently only anecdotal, there was very little specific contact or event information within the dataset - this may suggest why the Bioethics Council public events received so few participants. And while the NHC did take public submissions, they also note that GTAC was under no obligation to do that same; there is no requirement that GTAC or the other various advisory committees invite public submissions when deliberating on clinical trials involving third party risk. There is also *no requirement that the information gathering, deliberative and other procedures used by these committees be available for public scrutiny.*²⁶⁶ Or that the committee has to publically approve, disapprove or provide their reasoning to a public audience.²⁶⁷

The Social Contract

That the authorities tasked with ethical considerations were under no regulatory obligation to invite public submission, is concerning. For more than a decade the social contract with science had been seen to be renegotiated in a manner which cemented public engagement with the scientific community. Prior to this, science was effectively left alone, expected to produce reliable knowledge and communicate this knowledge to society.²⁶⁸ This was a relationship between the scientific community and the public based, in part, on trust.

Yet in recent decades the relationship between university, government and industry labs has become more intertwined.^{269,270} As a result of this, pressures to produce objectives or real-

²⁶⁶ National Health Committee, *National Health Committee's Advice on Living Cell Technologies Application for Xenotransplantation Clinical Trials in New Zealand*, Ministry of Health, New Zealand, p. 48

²⁶⁷ Ibid.

²⁶⁸ Gibbons, Micheal, *Science's New Social Contract with Society*, Nature 402, C81, 1999, Macmillan Publishers, URL: sciencepolicy.colorado.edu/students/envs_5100/Gibbons_1999.pdf, p.11

²⁶⁹ Ibid.

²⁷⁰ Guston, David H., *The demise of the social contract for science: misconduct in science and the non-modern world*, working paper number 19, 1992, Massachusetts Institute of Technology, web.mit.edu/sts/pubs/pdfs/MIT_STS_WorkingPaper_19_Guston_2.pdf

world application of science rose.²⁷¹ For some in the public sphere this interconnectedness and focus on the scientific ‘product’ was cause for concern.

As observed in Chapter 2, Murphy showed that the assessments of nicotine addictiveness shifted dramatically depending on the associations of the science team.²⁷²²⁷³ In 2001 the Royal Commission on Genetic Modification specifically mentions the concern the New Zealand public held regarding the motives and trustworthiness of scientists. Quoting Dr Roger Wilkinson, the report says:

*People don't trust genetic engineering. [...] They also don't trust genetic engineers. Some groups described how scientists have let us down too many times [...] The Industry group observed the lack of trust in proponents. [...] Scientists were described in the Opponents group as arrogant [...] Biotechnology companies were being described as being interested only in profits: [...] Someone in the Provincial group even suspected a conspiracy. [...] Motives of the scientists were regarded as important, along with the source of their research funds and who their employers were.'*²⁷⁴

Considering the opinion of the New Zealand public at the time, it is perhaps unsurprising that their recommendation for the establishment of the Bioethics Council was taken as seriously as it was. In New Zealand this represented a sea-change in how biotechnology was presented and marketed to the public. The Bioethics Council sought public consultation on issues from genetic modification, xenotransplantation, human assisted reproduction and

²⁷¹ Gibbons, Micheal, *Science's New Social Contract with Society*, Nature 402, C81, 1999, Macmillan Publishers, URL: sciencepolicy.colorado.edu/students/envs_5100/Gibbons_1999.pdf, p.11

²⁷² Royal Commission on Genetic Modification, Chairperson: Thomas Eichelbaum, *Report of the Royal Commission on Genetic Modification: Report and Recommendations* ISBN 0-477-01944-7 p. 64

²⁷³ Murphy, Priscilla, *Affiliation Bias and Expert Disagreement in Framing the Nicotine Addiction Debate*, Science Technology Human Values, 2001 26; 278, p. 301

²⁷⁴ Royal Commission on Genetic Modification, Chairperson: Thomas Eichelbaum, *Report of the Royal Commission on Genetic Modification: Report and Recommendations* ISBN 0-477-01944-7 p. 64

Maori responses to biotechnologies. Interestingly, in quotes from the public the Bioethics Council chose to display, the suspicion of scientists, apparent in the RCGM report, is absent. Instead of questioning the scientist's motives, the quotes question their science or their ability to speak on values issues.

The reason for this is not entirely clear. The apparent openness of modern science is likely to have been a significant factor, or that biotechnological research is pointed to becoming a successful industry; or perhaps, because of the very palpable diseases and needs that xenotransplantation could provide solutions for. In its most basic form, xenotransplantation can be considered a simple solution for a simple problem i.e. replacing broken body parts with comparative body parts. As such, the benefits and motivations appear to be clear; in contrast, the rationale and application for genetic modification are diverse and therefore more open to interpretation or audience bias.

Issues with Balanced Discussion

The narrative formed by the overarching discussion formed a meta cost/benefit analysis. Ideas of an ethical nature, such as 'Should the New Zealand public have to give a form of collective consent?', do not fit neatly into either category and like Maori cultural concerns, were viewed as obstructionist, or that they should be left to ethicists to discuss amongst themselves.

The apparent risk of losing New Zealand's competitive advantage, or that time spent discussing these issues came at the cost of lives, helped reinforce this concept within the debate. For this reason, the debate is relatively streamlined - ethical or value concerns never gain salience. Despite the remaining unresolved issues, the prospect of medical advancement

and economic gain overshadowed other apparently less salient concerns and thus dominated the public discussion.

Additionally the separation of Maori and Pakeha voices came under inspection from the Bioethics Council. In their reflection on the dialogue process, the Bioethics Council identified the interactions between Maori and Pakeha at the bicultural Hui as a highlight.²⁷⁵ They mention a particular Pakeha woman who spoke about European New Zealanders perhaps lacking the language to express cultural or value based ideas - which for her, identified an area of potential community growth.²⁷⁶

The same sentiment was expressed in the Bioethics Council's reports suggesting that such a cultural exchange allows Maori and other New Zealand communities to explore the diversity of their perspectives.²⁷⁷

This chapter has illustrated that the public discussion of xenotransplantation was shaped by elite framing by government and industry. This effectively shaped the national discussion into a cost/benefit analysis which maligned Maori cultural and spiritual concerns as obstructionist, while denying these same concerns to non-Maori New Zealanders.

The result was a logical reduction in narrative - where medical and economic hope was largely contrasted against cultural concerns; after xenosis risks failed to materialise, and over a decade of public reassurance regarding the standards of New Zealand laboratory and clinical trial standards, the economy of hope won-out over concerned communities delegated solely to cultural consultations.

²⁷⁵ *The Cultural, Ethical and Spiritual Aspects of Animal-to-Human Transplantation: A report on xenotransplantation by Toi te Taiao: the Bioethics Council* Ref. BC 13, August 2005, The Bioethics Council, Ministry for the Environment, New Zealand, p. 38

²⁷⁶ Ibid

²⁷⁷ Ibid, 39

This meta cost/benefit frame overlooked some considerable concerns - such as third party risk, liability and equitable access to this technology. Additionally, the manner in which the New Zealand public was invited to partake in the submissions process actually inhibited public access through a lack of visibility and desirability. The continued inability to rectify this situation undermines the democratic ideals that are the foundation of a negotiated social contract - without which, the support of the public will inevitably erode, making science and technology sector in New Zealand an industry labouring under a context of fear and suspicion.

Chapter 7, the final chapter, will review the findings presented here and place them within the greater context of the public engagement of science. It will also review the research, describe its limits, discuss the situation as it stands, and how this can spur further research in this area.

Chapter Seven – Conclusions

This research was designed to assess the evolution of the xenotransplantation debate in New Zealand from 1998 after the first and only reports of xenosis infection of human cells, the moratorium on xenotransplantation and onwards to 2013. This was done in order to observe if the shifts in public discussion were a key feature that contributed to xenotransplantation's legal and ethical status within New Zealand. In order to analyse this debate, a frame analysis methodology was used to track the most significant themes and issue stakeholders. As expected there was a distinct framing effort from the political and industrial elite that dominated the description of xenotransplantation and the issues that surrounded it. Unexpected however was the clear manifestation of cost/benefit narrative that arose from the dominate frames.

This occurred as the framing elite were able to consistently sponsor favourable frames through press releases, episodic framing and event driven content. After the Therapeutics and Medicines Bill had been debated and the Bioethics Council had presented their final report in 2005, counter framing efforts declined dramatically. The previous varied ethical concerns, many of which remain outstanding, became collectively referred to as “ethical considerations”.

From 2005 these ethical considerations were deemed, according to its framing, as effectively resolved. This designation did not acknowledge that many legitimate issues had yet to be explored by the law. A key issue in this context is liability and extended risk; as it stands Living Cell Technologies only accepts liability of its patients for five year after the completion of

clinical trials.²⁷⁸ Of further issue is that current ACC legislation would not provide cover for those affected by xenosis.²⁷⁹ The NHC recommended that the Minister of Health refer this issue to the Law Commission, as of the time of this research is being submitted there has been no publically released information to state or suggest this issue has been resolved.

The ability to reasonably assert that the cultural, ethical and spiritual concerns had been observed through the Bioethics Council's public consultation sessions was a powerful factor in facilitating later reviews by the Gene Technology Advisory Committee (GTAC) and the National Health Committee (NHC). As part of these assessments these institutions had to ensure that ethical and cultural concerns were consistent with the current legislation. GTAC and NHC both invited public submissions that were dominated by victim's advocacy, and the Bioethical Council's public engagement sessions were poorly attended. This suggests that the public engagement of science (PES) in New Zealand requires a reassessment in the efficacy of its submissions processes and the recruitment of public interest.

As outlined in Chapters 2 and 6, the idea that the largest challenge to public involvement is apathy is misleading. Increasing the focus on public relations and media presence of issues and contact information would substantially bolster the public submissions process. The importance of the public submission process should not be underestimated. Firstly, the use of biotechnology in the day-to-day experience of the public has increased and as such the ethical concern that sufficient consultation is undertaken has been coded into law. And secondly, there is the renegotiation of the social contract between science and the public; this

²⁷⁸ National Health Committee, *National Health Committee's Advice on Living Cell Technologies Application for Xenotransplantation Clinical Trials in New Zealand*, Ministry of Health, New Zealand, p. 20

²⁷⁹ Ibid.

acknowledgement of the public's place in science allows for a more stable environment for the biotechnology industry and informs robust policy formation.

What exactly is the public place in scientific development was explored in chapter five. There was the distinct concern about the lack of space for public submission not directly related to cultural concerns. Maori activists expressed the feeling amongst Maori that their opinions were limited by labels of cultural and spiritual concerns and argued their contributions were also at an intellectual and scientific level. This segregation of values and intellectual debate often posited Maori as being obstructionist, holding back scientific progress due to cultural apprehensions.

This heavy focus on Maori culture and the assumptions of value bias did not adequately represent the diversity of Maori opinion. This sentiment though, should not be limited to Maori. The general public as a whole is consistently confined to value based arguments and as presented in Chapter 2 the negative bias by those in industry hold towards personal narratives and values arguments is high. Yet the same study shows promise for growth as Cuppen et al. describes that scientist evaluated public claims higher than industry experts when they were not forced to, in the words of Cuppen et al., activate *a stereotype of an emotional, irrational public*.

This stereotype meant that the lack of a definitive risk positioned cultural and ethical considerations against medical and economic hope. This formed the basis for the logical reduction of frames towards a more simplified cost/benefit analysis. This cultural reductionism produced rational conclusions about the future of xenotransplantation, being: that under the right supervision and appropriate safeguards there is little reason as to why those practicing xenotransplantation should be hindered in their efforts towards providing cures and treatments for a variety of sickness. This may represent a fair balance of risk and

benefit, yet the manner in which this conclusion was reached discounted the variety of ethical and cultural concerns and did not allow for the inclusion of the NHC's independent risk assessment. Despite this, the public discussion was used by those in government and industry to assume the mandate to further xenotransplantation development. In light of this there is little doubt the manner in which XTP was framed affected its current legal status by using the machinations of public engagement without the sincerity that a timely independent review was produced and presented to the public in a transparent manner and allowed for the desegregation of scientific and ethical discussions.

The Current Legal Status of XTP in New Zealand

Xenotransplantation is currently a restricted procedure and is regulated as a “specified biotechnical procedure” requiring the approval of the Minister of Health and is expected to be in accordance with “Good Clinical Practice” standards.²⁸⁰ This became the legal status of xenotransplantation after the expiration of the Medicines (Specified Biotechnical Procedures) Amendment Bill in 2006 that briefly extended the moratorium of this procedure. In the unlikely event of a xenosis emergency the Medical Officer of Health has the power to intervene. This responsibility incorporates intrusive response such as forceful quarantine and

²⁸⁰ *Ministry of Health Inquiry into Improving New Zealand's Environment to Support Innovation through Clinical Trials: Response to Health Committee request for information: System framework for considering applications for approval of clinical trials*, Ministry of Health, New Zealand, Report No 4, 2 August 2010

retrieval of biological samples as outlined in the Law Reform (Epidemic Preparedness) Bill 2006.²⁸¹

During the debate the Bill's implications for rights and freedoms affirmed in the Bill of Rights Act were defended by the Honourable Pete Hodgson, then Minister of Health, saying:

*The rights of people in our communities have to be weighed against individual rights. The bottom line is that people in our communities deserve a good degree of protection from being unnecessarily infected with a dangerous disease, so some of the measures in this bill will infringe on the personal liberties of some individuals in order to prevent them from unnecessarily infecting others.*²⁸²

This position is warranted by the provision within the Bill of Rights Act, Section 5, which absolves the Medical Officer in breaches of the act so long as they can be demonstrably justified in a free and democratic society.²⁸³ The NHC considers the current legislation as providing the appropriate capacity to respond to the infectious disease risk.²⁸⁴

²⁸¹ Law Reform (Epidemic Preparedness) Bill, 2006 No 39-2, Supplementary Order Paper 2006 No 82, Explanatory Note, p. 2

²⁸² Law Reform (Epidemic Preparedness) Bill, Second Reading, Hon PETE HODGSON (Minister of Health)

²⁸³ R v Hansen [2007] 3 NZLR 1 (SC) the Supreme Court considered this provision and concluded that if the objective is sufficiently important and the means chosen to address the objective is proportional, such breaches are justified under the law. Being that the objective in this case is ensuring the public health of New Zealand it is likely that the means used in pursuit of this goal is the likely cause of debate and would be decided by the courts after the fact.

²⁸⁴ National Health Committee, *National Health Committee's Advice on Living Cell Technologies Application for Xenotransplantation Clinical Trials in New Zealand*, Ministry of Health, New Zealand, p. 18

Limits on Research

This research was designed to track frame usage in the xenotransplantation debate, analyse the debate and discuss the process of the public engagement of science in the New Zealand context; it was not designed reveal the intentions of frame sponsors or to moralise frames. Nor, was this research designed to express an opinion on whether xenotransplantation is, or is not, an appropriate treatment for use within New Zealand.

A further limit on this research is bias. Framing as a research method will continues to have on-going issues with bias due to human fallibility. As this research was done manually there will undoubtedly an element of inherent bias. This was mitigated by having a post-graduate student review every 15 pages of the dataset after receiving a tutorial in frame identification and when difference was noted this was discussed and a framing was either included, deleted depending on consensus before being added to the final frame table.²⁸⁵

Contributions to the Biotechnology and Public Policy Debate

This debate fits within the larger context of the public engagement of science and the current state of bioethics in New Zealand as it looks to distinguish itself in this area of science. The frequency and legitimacy of the public engagement of science is going to become increasing important. The social contract between science and society is still being negotiated as ideas of what public engagement of science means in terms of policy and regulation.

²⁸⁵It would have been interesting to note the difference as a point of investigation yet time restraints did not allow for this to occur in this particular research.

The groundswell of resistance to genetic modification in New Zealand, and the resistance to bio-banking in Iceland and Tonga serves as examples of the difficulties of practicing science without the public mandate. Institutions such as the RCGM and the Bioethics Council have been great vectors of communication, yet since the former fulfilled its mandate and the latter has been disestablished, the future of PES in New Zealand is uncertain. Despite this, the social contract between science and society continues to be negotiated, public debate on these issues will continue under increasing observation by the media and academia.

Tracking the development of public debate in this area of biotechnology in New Zealand contributes to the understanding of how science as a field interacts with the public. Due to the reality that xenotransplantation presents a risk to third parties, the necessity of this interaction all the more apparent. For this reason, the public has a greater investment in the success or failure of this technology and therefore public's contributions should carry greater weight. This research presents a history and analysis of the public discussion that can serve as snapshot of New Zealand's interaction with biotechnology and public policy formation.

Prospects for Future Research

The biotechnology industry in New Zealand has a strong global reputation that continues to invite both domestic and international investment. A strong biotechnology sector will produce many opportunities for the public engagement of science field. Living Cell Technologies is at the forefront of this development with plans to investigate Parkinson's disease and Alzheimer's disease. This direction is itself controversial in some respects, as deals with the brain, undoubtedly raising new issues of chimerism and identity. Other areas of research could

include the treatment of public submissions and cultural and ethical concerns since the disestablishment of the Bioethics Council.

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Appendix B – Observed Frames and descriptions

CODES	DESCRIPTION
Diagnostic frames	This tells the frame audience what the issue and is and why it is significant.
Government Interference	Stated or suggested perceived governmental hindrance, filibustering and the expression of annoyance on the behalf of scientists, business leaders and potential benefactors of xenotransplantation.
Government Alienation	Expression of a perceived disconnect between the New Zealand Government and political process being described. E.g. Rubber stamp.
Person vs. Public	The direct comparison of personal benefit against public risk.

Problem Frame	Outlines the problem that is being faced to which the solution is xenotransplantation. E.g. transplants, waiting lists, rates of diabetes.
Risk-Medical	Mentions of risk, risk assessments likelihood possible outcomes such as xenosis.
Scandal	Accusatory statements or inference about misdealing, being related to safety or ethical standards and potential or real illegality.
Controversy	The label attached to events, people, items or procedures e.g. controversial medical practice.
Culture	The presentation of concerns directly related to cultural interpretations of an issue or event.
Runaway Science	The reference to scientific progress being considered 'out of control', which is allowed through corrupt of ineffective regulation.
Pioneer	The direct reference to someone or something being a "pioneer" or "pioneering".

Animal Rights	A reference to the rights of the animal that is used in the xenotransplantation procedure.
Bad Science	An accusatory frame designed to undermine the credibility of a person or argument by referring to their work or reasoning as “bad science”.
Pandora’s Box	A reference to XTP as the Pandora’s Box archetype, out of which evil came out and was unable to be put back.
Yuck	A reference to the opinion that xenotransplantation is messy or disgusting.
Uncertainty	The reference to scientific knowledge bearing an element of uncertainty, mostly used in regards to risk.
Extremist	The reference to another party as being extremist in their views towards XTP.
Guinea Pig	The reference to patients undergoing xenotransplantation or the nation being test subjects for the pitfalls of XTP.

Liability	A reference the issue of liability in the event of xenosis.
Luddite	An accusation of the other party being anti-progress.
Public Consent	The reference to the opinion that XTP is a collective risk that should result in collective consent from the New Zealand public.
Chimera	The reference to the chimera archetype or the description of xenotransplantation as being analogous.
International	A reference to xenotransplantation progress or regulation in a global context, usually applied in comparison to New Zealand.
Natural Order	The reference of a natural order that is being imbalanced by human interference.
Prognostic Frame	Presents a solution to the problem outlined by the diagnostic frame.
Safeguard	Reference to measures in place or taken to ensure public safety. E.g. mentions of regulation, precaution, banned, guidelines,

	safeguard/s, independent or third party (in relation to oversight) and further research.
Medical Ethics	The reference of an issue or aspect of a procedure or process being of concern, interest or investigation from a medical ethics point of view.
Not-A-Cure	Used in reference to the idea that xenotransplantation of porcine islet cells into diabetics does not provide a cure for diabetes, but is a treatment.
Rationality	A call to face an issue rationally or to be rational. Generally used to undermine the opposing party.
The Public Understanding of Science	A reference to the need for, or efforts, to increase a greater public understanding of science, not a reference to the academic field.
The Public Engagement of Science	A reference to the need for, or efforts, to increase a greater level of public engagement with science, not a reference to the academic field.
Alternative	A reference to the idea that there are

	alternatives to the medical concerns that xenotransplantation aims to treat.
Grassroots	A reference to the idea that xenotransplantation in New Zealand is a local operation that started from humble beginnings.
Prevention	A reference to the idea that xenotransplantation would not be needed if the public took greater care of their everyday health with healthy diet and exercise.
Designer	The reference to a scientist or scientists as being a designer in their manipulation of genetic material.
Pharma-Pig	The reference to the Auckland island pig population that had been geographically isolated for almost 200 years and later housed in medical standard piggeries in Invercargill.
Personal responsibility	The reference to the opinion that the risk of xenotransplantation as an issue to be discussed primarily between a doctor and patient.

Comparable	The reference to xenotransplantation being a comparable to known medical technology or practice.
International	A reference to xenotransplantation progress or regulation in a global context, usually applied in comparison to New Zealand.
Good-Guy-Scientist	The reference of scientists having positive human elements such as ethics used to counter negative assumptions or associations about scientists.
Motivational frame	Offering a reason for people a reason to invest in xenotransplantation.
Hope-Medical	The presentation of expectations, hope or promise that regard the medical benefits of xenotransplantation. This includes other medical gains as a result of an expansion of biotechnology in New Zealand.
Hope-Benefit	The presentation of expectations, hope or promise regarding the potential gains to be had of xenotransplantation in New Zealand, including economic gains as a result of an

	expansion of the biotechnology industry in New Zealand.
Brand-State	A reference to the idea that biotechnology could be incorporated into the national brand.
Stewardship	A cultural interpretation or reference to humans being stewards or bearing stewardship of nature, identity, genes.
Southland Economic Hope	A reference to the potential economic benefits to the Southland region of New Zealand as result of xenotransplantation, due to the specially made piggeries for housing the Auckland Island pig population used in Living Cell Technologies xenotransplantation procedures.
Victim	Focus on individual with diabetes or those on waiting lists, the main candidates for xenotransplantation technology in an effort to draw empathy. E.g. Diabetes suffering, viewpoints and hopes.

Future Generations	The reference to children and grandchildren being possibly affected by the issue being discussed.
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Appendix C: Factiva Dataset

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