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Going against the flow: a sociotechnical network analysis of endemic acute rheumatic fever and rheumatic heart disease in remote indigenous communities of Australia

Elizabeth Maree Carter

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Going against the flow: a sociotechnical network analysis of endemic acute rheumatic fever and rheumatic heart disease in remote indigenous communities of Australia

Abstract

Acute rheumatic fever (ARF) and rheumatic heart disease (RHD) are autoimmune conditions caused by Group A Streptococcus (Group A Strep) infections. ARF/RHD are mostly eradicated from the Global North yet are endemic in many remote Aboriginal and Torres Strait Islander communities of Australia. The risk factors for ARF/RHD are similar to the material conditions of poverty, including overcrowded housing and poor access to health services. Despite extensive interventions, surveillance, and evaluation of these conditions over many years, an entrenched experience of illness persists due to a complex array of social, material, political, cultural, and economic factors. Using actor network theory (ANT) as a primary analytical lens I will examine processes leading to the current socio-technical network conformation of ongoing ARF/RHD. I focus on three nodes, each centring on a different element of this network: firstly, benzylpenicillin G (BPG) antibiotics used for prevention, secondly, echocardiograms (ECGs) used for diagnosis and screening, and finally, Group A Strep vaccines that are yet to be developed into a useable product. For each node I analyse the scientific, policy, and sociological literature by mapping and tracing associated human and non-human elements and considering how their configurations have changed over time. Further, I explore the contingent ways in which these nodes have become important elements in temporarily stabilised network conformations. Despite the persistent and embedded presence of ARF/RHD in remote Indigenous communities for many decades, the dynamic nature of the network reveals that this is not an inevitable inequality. Rather, there is vast potential for socially just change through local Indigenous-led approaches to holistic healthcare.

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**GOING AGAINST THE FLOW: A SOCIOTECHNICAL NETWORK ANALYSIS OF
ENDEMIC ACUTE RHEUMATIC FEVER AND RHEUMATIC HEART DISEASE IN
REMOTE INDIGENOUS COMMUNITIES OF AUSTRALIA**

Honours thesis submitted in partial fulfilment of the
requirements for the award of the degree

BACHELOR OF ARTS (HONOURS)

from

UNIVERSITY OF WOLLONGONG

Elizabeth Maree Carter

2021

Abstract

Acute rheumatic fever (ARF) and rheumatic heart disease (RHD) are autoimmune conditions caused by Group A *Streptococcus* (Group A Strep) infections. ARF/RHD are mostly eradicated from the Global North yet are endemic in many remote Aboriginal and Torres Strait Islander communities of Australia. The risk factors for ARF/RHD are similar to the material conditions of poverty, including overcrowded housing and poor access to health services. Despite extensive interventions, surveillance, and evaluation of these conditions over many years, an entrenched experience of illness persists due to a complex array of social, material, political, cultural, and economic factors. Using actor network theory (ANT) as a primary analytical lens I will examine processes leading to the current socio-technical network conformation of ongoing ARF/RHD. I focus on three *nodes*, each centring on a different element of this network: firstly, benzylpenicillin G (BPG) antibiotics used for prevention, secondly, echocardiograms (ECGs) used for diagnosis and screening, and finally, Group A Strep vaccines that are yet to be developed into a useable product. For each *node* I analyse the scientific, policy, and sociological literature by mapping and tracing associated human and non-human elements and considering how their configurations have changed over time. Further, I explore the contingent ways in which these *nodes* have become important elements in temporarily stabilised network conformations. Despite the persistent and embedded presence of ARF/RHD in remote Indigenous communities for many decades, the dynamic nature of the network reveals that this is not an inevitable inequality. Rather, there is vast potential for socially just change through local Indigenous-led approaches to holistic healthcare.

Declaration

I certify that this thesis is entirely my own work except where I have given full documented references to the work of others, and that the material contained in this thesis has not been submitted for formal assessment in any formal course and the word length is 16500.

17 October 2021

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Acronyms and Abbreviations

ANT – actor network theory

ARF – acute rheumatic fever

BPG – benzylpenicillin G

ECG – echocardiogram

FDA – Food and Drug Administration

FoCUS – focused cardiac ultrasound

Group A Strep – Group A *Streptococcus*

NACCHO – National Aboriginal Community Controlled Organisation

NHFA – National Heart Foundation of Australia

NRC – National Research Centre

NT – Northern Territory

QLD - Queensland

RHD – Rheumatic Heart Disease

SA – South Australia

TGA – Therapeutic Goods Administration

WA – Western Australia

WHO – World Health Organisation

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Chapter 1: Introduction

Topic Overview

In this thesis I examine the ongoing presence of endemic acute rheumatic fever (ARF), and its sequela, rheumatic heart disease (RHD) in remote Indigenous communities of Australia. ARF/RHD are debilitating, yet preventable diseases, that are commonly associated with material conditions of impoverishment and disadvantage (Watkins et al. 2018, p. 1398). ARF/RHD primarily impact young people in developing nations, and Indigenous communities within developed nations. ARF/RHD are conditions caused by Group A *Streptococcus* (Group A Strep) bacterium infection (Welch et al. 2020, p. 121). Group A Strep is a member of the *Streptococcus pyogenes* bacterial species and is known for its pathogenicity, causing a wide range of diseases in humans (Reglinski and Sriskandan 2015, p. 675; May, Bowen and Carapetis 2016). ARF manifests in genetically susceptible individuals as an autoimmune response to Group A Strep infection (Dooley et al. 2021, p. 3). A common result of ARF is lasting damage to heart valve tissues, most likely caused via cross-reactivity in which immune cells inadvertently attack host tissues, as well as Group A Strep (Gray et al. 2017). Scientific understandings of the biological mechanisms of this autoimmune reaction remain under investigation (Dooley et al. 2021). After an initial ARF episode, the heart valves become vulnerable to subsequent Group A Strep infections (Watkins et al. 2018, p. 399). Following recurrent ARF episodes or a single extreme incident, RHD can develop due to irreversible damage to the mitral and/or aortic heart valves that can no longer maintain a unidirectional flow of blood through the heart (Jackson, Steer and Campbell 2011, p. 2). Without a combination of long-term antibiotic administration, early diagnosis, heart failure medication, heart surgeries, and lifelong usage of anticoagulants, RHD can lead to issues such as “heart failure, stroke and infective endocarditis” and ultimately preventable death in the sufferer (RHDAustralia 2020, p. 286).

Recently, there has been a push for global action towards Group A Strep vaccine development, led by the World Health Organisation (World Health Organisation 2018; Vekemans et al. 2019). To date, there has been limited success in this venture due to a variety of factors including inadequate understanding of the diverse mechanisms of Group A Strep pathogenesis, and the large diversity of genetic variants and strains in hyperendemic

areas (Dooley et al. 2021; Kumar and Tandon 2013; McDonald, Currie and Carapetis 2004). Despite growing global attention, ARF/RHD rates are increasing in Aboriginal and Torres Strait Islander communities. In this introductory chapter I provide a background of ARF/RHD, highlight the sociological significance of this health inequality, and convey some of the persisting issues with prevention programs. I close this chapter with my thesis outline.

Background

In the 1930s-40s ARF was a prominent illness in Australia. It was considered a common disease in children with low socio-economic status (150 per 100000) and moderately common in children from a wealthier background (47 per 100000) (Steer 2015). Due to a variety of factors, such as a general rise in standards of living and the development of penicillin antibiotics to treat Group A Strep infections (Jackson, Steer and Campbell 2011), case numbers have gradually declined (Wyber, Johnson and Patel 2015). Despite broad improvements across Australian society and in other industrialised nations, ARF/RHD remains a global health concern (Watkins et al. 2018, p. 1398). While reports vary widely and are likely an underestimation of prevalence (Paar et al. 2010), RHD affects approximately 33-40 million individuals around the world and causes over 350000 deaths per year (Katzenellenbogen et al. 2020; Macleod et al. 2019b).

In Australia, ARF/RHD is present endemically in remote Aboriginal and Torres Strait Islander communities, while in non-Indigenous populations, it is either unknown or largely considered eradicated (Parnaby and Carapetis 2010, p. 527). The group most commonly diagnosed with ARF are young Indigenous females aged 5-14 years old that live in remote communities (Katzenellenbogen et al. 2020). There are approximately 6000 people diagnosed with RHD in Australia, 71.2% of whom are Aboriginal and Torres Strait Islander peoples (Wyber et al. 2020; Katzenellenbogen et al. 2020). Each year 500 new RHD cases emerge with 90% of these affecting Indigenous peoples, two thirds of whom are female (Katzenellenbogen et al. 2020). These statistics reflect an ongoing state of endemic illness in remote Indigenous communities, indicative of systemic health inequality in the Australian context.

The Surface of the Issue?

Primary prevention of Group A Strep treats early signs of superficial infections with antibiotics to avoid disease progression to ARF/RHD. Numerous failed attempts at systematic primary prevention have resulted from under-resourcing, underfunding, and insensitivity to the complexities of the task (Wyber et al. 2020). In Australian Indigenous communities with endemic ARF, Group A Strep is commonly contracted via skin sores (Parnaby and Carapetis 2010), while in most other contexts it is contracted via an infection of the nose or throat resulting in pharyngitis (Steer 2015). These infected skin sores are known as impetigo and are highly contagious (Reglinski and Sriskandan 2015). This unique mode of infection in remote communities means that efforts for early detection, via skin swabs, and appropriate antibiotic treatments are ungeneralisable to most other international endemic settings where pharyngitis is the primary mode of infection (Wyber et al. 2021; Amgarth-Duff et al. 2019). While the causal link between impetigo and ARF remains poorly understood and underexamined in clinical settings (Yeoh et al. 2017), the strong concurrence is undeniable (O'Sullivan et al. 2017) indicating the need for further investigation of this unique mode of transmission in remote Australia.

A Material Health Injustice

The endemic occurrence of ARF/RHD in remote Indigenous communities of Australia is strongly associated with environmental factors linked with poverty and socio-economic disadvantage (Haynes et al. 2020). These factors, such as overcrowded housing, poor access to healthcare, and limited or unclean water supplies, are ideal conditions for contagious bacterial transmission (Barnett, Bowen and Carapetis 2018). As these are material concerns determined largely by poor access to resources, ARF/RHD are often considered “preventable diseases of socio-economic disadvantage” (Dooley et al. 2021, p. 8). Despite its preventability, ARF/RHD persists in remote regions of Australia (Carapetis and Brown 2020). The Northern Territory (NT) has the greatest ARF/RHD cases (3544.08 per 100000), followed by Western Australia (WA) (1012.3 per 100000) and Queensland (QLD) (862.1 per 100000) (Katzenellenbogen et al. 2020). The availability of these case numbers reflects improving detection methods, statistical analysis, disease registration, and surveillance techniques,

which assist greatly in refining the official understanding of disease epidemiology and population trends (May, Bowen and Carapetis 2016). At the same time, they highlight the extreme and disproportionate impact of ARF/RHD in regions with large and diverse Indigenous populations and where established infrastructure and access to resources is critically inadequate.

While case numbers continue to grow and data collection techniques are expanded and refined, there remains an absence of holistic primordial prevention programs – ones that seek to address the socio-material inequalities leading to ARF/RHD (Parnaby and Carapetis 2010; RHD Australia 2020, p. 36). The policy and funding focus over recent decades has not been directed towards sustainable projects for systemic improvements. Rather, they have consistently focused on collecting data for evaluation of existing prevention programs and increasing the reach of population health statistics (Health Policy Analysis 2017, p. 3). The material conditions of poverty enabling the endemic experience of ARF/RHD in remote Indigenous communities are malleable, and the persistence of these conditions in one of the most affluent nations in the world is entirely avoidable (May, Bowen and Carapetis 2016, p. 202). Prioritising efforts to inhibit initial Group A Strep infection, such as through provision of culturally appropriate housing to reduce overcrowding (RHD Australia 2020, p. 45), could lead to sustainable healthy environments, preventing key risks associated with this severe inequality.

Biomedical Models in Indigenous Healthcare

ARF/RHD prevention, treatment, education, and research has been historically produced through Western biomedical models of health and illness (Haynes et al. 2021, p. 2). Utilising a biomedical lens positions illness within the biological site of the body and evaluates its medical treatability (Saggers and Gray 2007, pp. 1-3). The focus on curing bodily disease in the biomedical model formulates healthcare in terms of case numbers, key performance indicators (KPIs), and quantitative goals, fundamentally reducing the role of systemic intergenerational inequality to an isolated numerical measure (Khoury 2015, p. 483). Haynes et al. (2020, p. 9) identify the tendency of biomedical texts to describe ARF/RHD as a “disease of poverty” while employing minimal effort towards understanding the

mechanisms that lead to associated conditions of impoverishment. Additionally, biomedical models have been criticised as a largely incongruent approach to Indigenous health concerns (Wyber et al. 2020, p. 46), simultaneously dismissing Indigenous knowledges while reinforcing colonial norms in institutional settings (Sabati 2019, pp. 1061-1062).

Alternatives to the systemic epistemological dominance (Rix et al. 2019) of biomedicine in the ARF/RHD project is now a tangible possibility with novel multi-stakeholder proposals emerging that privilege Indigenous voices and research (Wyber et al. 2020; RHD Australia 2020). However, it remains crucial to investigate and reconsider the many aspects of this preventable illness which have led to its entrenched normalisation in Indigenous Australia (Haynes et al. 2020, pp. 9-10). For example, consideration of the social determinants of health accounts for many broader issues that contribute to a person's state of wellness, such as socioeconomics and education (Heard et al. 2019). The continuing mainstream focus on data, biomedical care, and reactive treatment regimens have failed to reduce the health inequality of ARF/RHD. Greater attention to the broader system of processes leading to socio-material disadvantage could reveal opportunities for holistic prevention and realign the focus to the reduction of inequality beyond ARF/RHD. This is what I examine here through the lens of actor network theory (ANT).

Research Questions and Thesis Outline

Through an analysis of ARF/RHD literature, I will consider the following research questions: *(1) What are some of the socio-technical and material aspects of ARF/RHD in Australia that have led to its endemic and ongoing presence in remote Aboriginal and Torres Strait Islander communities? (2) How has the construction of ARF/RHD changed over time? (3) Are there any opportunities for alternative ways of approaching prevention of ARF/RHD?*

In the next chapter I describe my analytical and methodological approach. I draw on actor network theory (ANT) as a primary lens of analysis, with additional insights from ethics of care, governmentality theory, and post-colonial studies. I consider ARF/RHD as a socio-technical network comprised of a contingent assembly of disparate human and non-human actors, tools, and techniques. These actors each play unique roles through their situated

interactions that stabilise and shift the conformation of the network over time in response to network processes of power, knowledge, and communication. In the subsequent three chapters, I present my findings. Each chapter centres on a different focal non-human network actor called technological *nodes*. These *nodes* are important network components that shape and are shaped by activities, decisions, and expectations of surrounding actors. ANT is a useful approach to this investigation as it highlights the combined importance of social, technical, biological, and material dimensions of the ARF/RHD issue. This enables the examination of the ways the focus of research and the areas of most concern to key actors have shifted over time. These shifts were contingent and dynamic, signalling opportunities for more change into the future that is inclusive of alternate voices that sometimes go against the mainstream flow of knowledge.

I have organised the three findings chapters in order of the historical stability of each technological *node* in the network. The benzylpenicillin G (BPG) chapter highlights the elevated role of antibiotics as a mainstay of ARF/RHD prevention and treatment despite the ever-increasing burden of illness, showing the ways that the responsibility for care in addressing ARF/RHD has been placed largely on this biomedical actor and shifted away from community leadership. The echocardiogram (ECG) chapter explores the ways that standardisation can both obscure and visibilise marginal groups that do not conform with normalised disease presentations, and the ways that expertise draws boundaries in networks that can be overcome through de-professionalisation processes. The vaccine chapter outlines the ways that material aspects of Group A Strep and long term expectations of success contribute to an extended narrative that promises development of a safe and effective vaccine yet has not delivered, leading some advocates to suggest that primordial prevention is the key to holistic ARF/RHD prevention. I end with a brief conclusion outlining key findings and make suggestions for future research.

Chapter 2: Analytical and Methodological Approach

Introduction

Undertaking sociological research on ARF/RHD prevention and treatment in Australian remote Indigenous communities is crucial to understanding this condition beyond the mainstream biomedical framing of health, illness, and disease (Haynes et al. 2014). In this chapter I discuss the main theoretical approaches I will draw on and how they can be usefully brought together. Firstly, I will identify the key aspects of actor network theory (ANT) that will help me to show the role of both human and non-human actors and the ways they are stabilised in various conformations over time. Then I examine the ways that ANT can be bolstered with insights from ethics of care, governmentality, and post-colonial studies of technoscience. In the final section I describe my data collection and analysis.

Actor Network Theory Overview

ANT is a Science and Technology Studies (STS) approach to sociological analysis that highlights the researcher's role in mapping out associations and interactions between human and non-human actors in socio-technical networks (Latour 2005; Law 1992).

Networks are webs of relations between diverse actors that are arranged by the "uncertain consequences of ordering heterogenous materials" (Law 1992, p. 390). This way of thinking about socio-technical networks radically rejects the exclusive humanness of "society" which has been "traditionally seen as a separate domain of reality" (Latour 2005, p. 3). Instead, it attends to the many material elements (including people and technologies) that interact, repel, and stabilise to make up a dynamic socio-technical arrangement. The elements of a network could be small and mundane, such as a paper note written by the pen in the hand of a clinician, or much more advanced, such as complex high-throughput bioinformatics technologies. In each case, ANT facilitates the consideration of the ordering "*energies*" that flow between actors and that are often overlooked in other restrictive techniques of appraisal that only see what is there and not how it came to be (Latour 2005, p. 17).

Network *energies*, such as power, knowledge and communication, travel through network spaces, connecting and stabilising human and non-human elements around existing

objectives (McCarthy and Martin-McDonald 2007, p. 84) or harnessing their potential to move their position to achieve new goals (Latour 1990).

Guided by ANT concepts and vocabulary, I will interpret the diverse arrangements of elements in ARF/RHD as a network of actors that perform unique and consequential roles in reproducing and resisting the unjust assemblage of endemic ARF/RHD. The human and non-human actors in this assemblage are considered symmetrically as participants that each contribute to the maintenance of the ARF/RHD network composition (Callon and Latour 1981, p. 280). *Energies* work to stabilise the network in a mutually negotiated or coercive conformation. The results of these stabilising interactions can be harmonious, leading to a subdued collaboration between actors that reflects a common purpose. At other times, these goals are resisted, leading to movement and defiance against powerful *energy* flows. It is at these resistant junctures of the network that the possibility of gradual change and rearrangement exists (McCarthy and Martin-McDonald 2007, p. 95). A network cannot remain in a state of flux indefinitely, and this leads to compromise, innovation, and adjustment that is continuous with previous network forms. This does not necessarily exclude existing actors and their roles, rather it shifts them to a more favourable location in the network, making way for new processes and positioning, relative to others (McCarthy and Martin-McDonald 2007, p. 85).

ANT, Care, and Change

ANT is less a theory and more a way of attending to the surprising ways that many actors interact and are situated in relation to others in a network (Mol 2010, p. 261). While some may see the formlessness of this framework as a weakness due to its lack of reproducibility across contexts, it is rather a huge strength when analysing issues such as ARF/RHD that have been considered through the same biomedical lens for decades. By commencing this analysis with the intention to understand the ways that the ARF/RHD network has been constructed over time, I will be free from the explanatory frames that so often confine and direct research of “the social” (Latour 2004, pp. 16-17). In considering the ways the network has been assembled, my attention will be drawn to the localised issues of ARF/RHD prevention and treatment in remote Indigenous Australia. Subsequently, I will be sensitised

to this network's propensity for change as a constructed socio-material arrangement. What has been constructed can thus be critically unconstructed and reconstructed (Latour 2004) into a more socially just conformation.

This social justice concern aligns with the framing of critique via "matters of care" proposed by Puig de la Bellacasa (2011). Building on Latour (2004) and feminist ethics of care, Puig de la Bellacasa puts forward care as an "ethico-political" commitment to the heterogeneous things in an assembled network. By drawing on the traditionally feminist concern of care as an undervalued domestic labour, this concept can be effectively employed in technoscientific spaces with the intention of gathering network elements together in a mutualistic arrangement through the caring work of the sociologist. In doing so, it gives "significance to particular socio-material practices by generating care for undervalued and neglected issues" (Puig de la Bellacasa 2011, p. 94). This work towards a caring analysis involves attending to all connected actors that may share oppositional views, but that must be considered in a respectful manner, no matter who or what they are. This approach moderates the fundamentalism that can otherwise emerge through strong critiques and avoids the broad stroke diagnoses that often feature in reductionist arguments. This approach does not exclude power relations from the analysis but rather redirects them from being seen as a political motive by "evil" actors, towards a more dispersed political process that absolutely produces a network effect, whether intended or otherwise. Further, this approach reveals that the caring load could be shared across network spaces more evenly to avoid reliance on discrete actors from hegemonic knowledge systems and by doing so, "share the burden of stratified worlds" (p. 94).

Latour (2004, p. 232) and Puig de la Bellacasa (2011) argue that the heavily critical focus of STS requires a reorientation towards an ethos of protection and care, and away from debunking and deconstruction. Additionally, Law and Singleton (2013, p. 485) suggest that ANT is not geared towards the formulation of immediate solutions, but is rather a sensitising craft that appreciates the "slow processes of knowing". I believe that it is this sensitive, empirical teasing out and intensive deliberation of how the ARF/RHD network has come to be in its current state that will unlock a door to new possibilities for remote Indigenous

peoples. It is this articulation of contextual and political issues and the belief that a better world could exist that could lead to a socially just ARF/RHD network reassemblage.

A Powerful Addition to ANT

In some of the early canonical works of ANT, scholars examined a variety of topics, such as scallop domestication (Callon 1986) and pasteurisation (Latour 1988), exemplifying the radical significance of human/non-human symmetry in socio-material reconstructions and challenging the idea of predetermined structures in society (Baiocchi, Graizbord and Rodriguez-Muniz 2013, p. 324). This led to a common critique that ANT is “apolitical”, a suggestion that has been consistently contested by diverse and adaptive interpretations of society that attend to the assembling forces of political processes that must be drawn out, examined and not presumed (Baiocchi, Graizbord and Rodriguez-Muniz 2013, p. 337; Latour 1990). To bolster my inquiry into the ARF/RHD network’s propensity for adaption over time, governmentality provides an analytical approach that attends to the ways that human behaviours are directed across diverse contexts, particularly by government (Foucault as cited in Rose, O’Malley and Valverde 2006). This lens will help me demonstrate the way interests that work to stabilise networks are not a constant state of reality, but rather a series of processes that are alterable. I will supplement ANT with governmentality and extend it to include non-human actors as both influenced and influencer in the political regions of this complex socio-material network.

Governmentality considers government as a complex of entities, institutions and tools that interact to enable political power to be exercised upon people (Foucault as cited in Rose, O’Malley and Valverde 2006, p. 86). This theory reflects an analytical shift in focus from traditional sovereign nations with central rule, to these “ensembles” of government associated with governable populations. Populations are understood in terms of their relationality with other people and things around them, like a network in ANT. These relational sites become a focus of intervention by governments who seek to first understand and then redirect people (and things) towards a particular goal via techniques and processes of power (e.g., knowledge derived through epidemiological data collection, see Collier 2009, pp. 86-87). The techniques of power are the tools mobilised to accumulate knowledge,

while the processes are political rationalities employed that shape the boundaries of thought and action for a population in a particular context (Rose, O'Malley and Valverde 2006). Political rationalities are ways of thinking about governing and how to distribute knowledge for that purpose (Rose and Miller 1992).

Rose, O'Malley and Valverde (2006, p. 98) identify that a key criticism of governmentality theory is the misguided "cookie-cutter typification or explanation" of a government program as being a particular political rationality, e.g., neo-liberal. They suggest that it is important to consider that political rationalisations are always developing and adapting. For example, to suggest that something is neo-liberal does not demonstrate the diversity and dynamism of neo-liberal forms across contexts, a perspective that makes the related issues seem unsurmountable. Rather, a "good" governmentality study breaks away from the structural perspective of the monolithic state with a "panoptic" vision over citizens, as originally theorised by Foucault (1979). It shifts instead to a more ANT-like symmetry in which the state is simply another actor, uniquely constituted in a web of associations drawn together by the "convergent" power of "translation" (Callon and Latour 1981, pp. 280-281). *Translation* is the way that goals are constructed and come to be understood broadly through the same language and logic (Rose and Miller 1992). This encapsulates a move towards the variety of authority, the multiple goals of multiple actors in network *ensembles*, and the different techniques employed to reach discrete political objectives (Rose, O'Malley and Valverde 2006, pp. 84-85). Further, governmentality highlights the constructive role of resistance in a network, creating a more open-ended, "transformational politics" than an analysis that simply discards resistance as a negative externality to network order (O'Malley 1996, p. 312).

As in ANT, governmentality examines the durability of the layout of actors in relation to each other, determined by the persistence of tools used to "enrol" network actors, and their ubiquity across the socio-technical space (Rose and Miller 1992; Latour 1990). For example, an electronically published procedural manual, dispersed systematically across multiple health clinics would play a stronger stabilising role than a single handwritten note. Some tools of "enrolment" are stronger than others as they disseminate readily and persist, arranging actors in a network based on effectively *translated* objectives that become

constructed as shared interests (Rose and Miller 1992, p. 184). In this context, government is no longer a central “State”, but is rather a “multi-centred” complex of techniques and tools which normalise, stabilise, and immobilise networks to comply with “rules at a distance” (Rose and Miller 1992, pp. 184-185). By combining this approach with ANT, power imbalances, theorised as durable asymmetries between actors, can be identified and strategies for realignment of network actors into a more equal arrangement can be considered.

Post-Colonial Challenges in ANT

Post-colonial STS operates to dismantle the dominant imperialist model embedded in the Modern world through critical decentring and disassembling of hegemonic epistemologies (Saïd as cited in Anderson and Adams 2007). It is important that this is distinguished from the dismantling of the network itself, as it is rather the organising processes that are the target for disassembly. This approach values collaboration with “views from elsewhere” (Anderson and Adams 2007, p. 183) to accentuate the spatialities and multi-sited nature of knowledge production processes. Just as decolonialism intentionally challenges colonial presuppositions and impositions in social processes and arrangements (Smith 2012), post-colonial STS highlights the need to challenge colonial functions that lead to unequal technoscientific assemblages. In this sociological project I am consciously seeking to engage with and elevate Indigenous perspectives, knowledges, and voices (Haynes et al. 2020). I will demonstrate that these are vital, practical, and meaningful epistemologies, not simply tokenistic political tools (Barnes et al. 2009, p. 444) and they demand an elevated space for expression within the ARF/RHD network. Smith (2012) identifies the Maori context of decolonial struggle, framing it as a critical awakening that challenges the established hegemonies of colonial social infrastructure. This challenge mediates the possibility of alternative thinking and action that could lead to the disruption of the status quo. Similarly, through applying a post-colonial focus in ANT, one can integrate explicit consideration of the historical processes embedding colonial knowledge and action in healthcare systems. By focusing on the concerns of marginalised peoples, I hope to contribute to the disruption and rearticulation of “racial-colonial entanglements” produced through disproportionate consideration of biomedical knowledges across institutional spaces (Sabati 2019, p. 1061).

ANT scholars have experienced criticism for both a lack of attention to power and for providing unbalanced attention to the high-status personalities and grand narratives of history; a process that has contributed to screening out the “invisible work” of understudied, marginalised associates in a network (Star 1991, p. 29). An ANT analysis, supplemented with governmentality and post-colonial critique, will ensure this is not the case, bringing greater symmetry to Aboriginal and Torres Strait Islander “work” towards resistance through diverse knowledges within the hegemonically constructed reality of endemic ARF/RHD.

Bringing it Together

Through combining ANT, ethics of care, governmentality theory, and postcolonial studies I will perform a unique sociological analysis of ARF/RHD in Australia. As a non-Indigenous researcher, I do not intend to assert my findings as an ultimate solution to be imposed. Rather, following Puig de la Bellacasa (2012), I hope to offer this unique analytical combination as a way of thinking that may be useful in addressing some associated issues. In the following chapters I attend to some of the ways normalisation of illness in Indigenous communities (Haynes et al. 2021) has led to a perpetually stabilised unequal network arrangement of ARF/RHD in Australia. In these situations of stability, power can be seen as an effect rather than a cause in the resulting unequal arrangement between human and non-human actors (Latour 1990). While political techniques of inertia have persisted under a regime of regulation and standardisation, a re-evaluation of these taken-for-granted realities could dynamise the ARF/RHD network into the future. Unequal network arrangements are contingent on past processes yet are not inevitable (Star 1991, p. 38). Endemic illness in Indigenous populations should not be considered normal, it is not just, and it is not unavoidable. By looking at the ways the socio-technical elements of ARF/RHD have been changed over time, there is less opportunity for naturalisation of chronic illness in Aboriginal and Torres Strait Islander peoples, and more possibility for a fundamental shift in approach that appreciates the localised concerns and knowledges of Indigenous ARF/RHD sufferers.

Data Tracing and Association Discovery

While remaining systematic, I have chosen to primarily adopt the ANT method of tracing the associations of the network (Latour 2005) for my data collection. To begin, I obtained a range of scientific and medical literature through Pubmed database searches. I used the broad search input “Acute Rheumatic Fever and Rheumatic Heart Disease Indigenous Australians”. This yielded 70 articles for consideration. After reading the abstracts of all articles I removed highly specific articles that did not align with my research questions e.g., in-depth studies of historical Group A Strep vaccine models. In addition, I collected other sources including sociological and policy documents to gain a holistic representation of the socio-material complexities and fluid assemblage of the ARF/RHD network. To achieve this, I drew on the “Document and Artefact Analysis” methodology described by Macleod et al. (2019a, pp. 181-182) whereby I examined written sources in terms of their potential role in the network as a tool that is created, dispersed, interpreted, and used by diverse actors. By examining texts in this way, I developed an understanding of the prominent actors and their durability, position, relationality, and effects in the network. I utilised reference lists from texts to trace related sources that addressed similar issues in texts conveying the same or differing viewpoints.

Figure 1 below is a simplified image of the three-dimensional ARF/RHD network resulting from this mapping process which enabled me to appreciate the previously inconceivable interconnectedness between disparate network elements (McCarthy and Martin-McDonald 2007, p. 90). This process revealed to me the extent of intellectual energy and multisectoral efforts that have been inserted into this network, particularly over the past decade in which the most prolific research has been produced in Australia. Through this process I have developed a comprehensive web of information, proportionate to the confines of an Honours thesis.

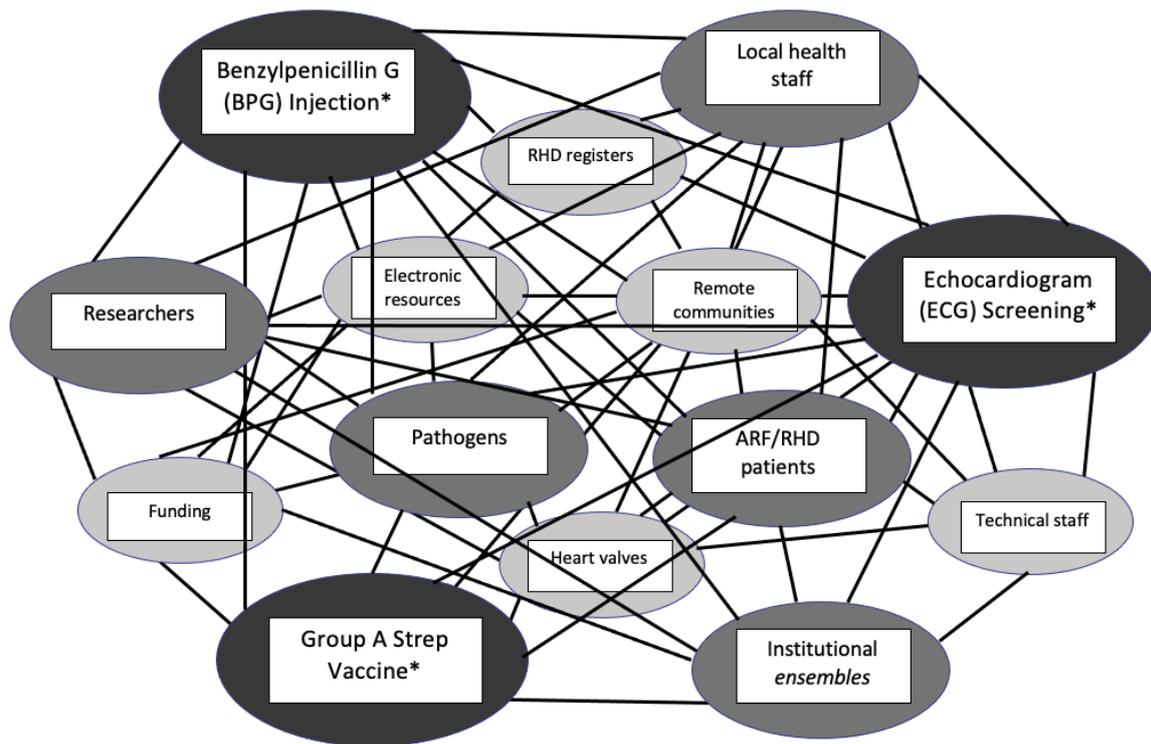


Figure 1. A simplified image of a possible ARF/RHD network. Image generated through mapping some of the key human and non-human elements that emerged during my analysis. Lines connecting network elements indicate energetic network processes such as power, knowledge, and communication. * Indicates technological nodes explained further below.

By subjectively considering this socio-technical assemblage, I was regularly drawn in by the gathering influence and stabilising role of various technologies involved in prevention and treatment. I made the decision to structure my research around three technologies that I deemed most influential or prolific. Using ANT terminology, I have called these analytical focuses technological *nodes*, being conspicuous points in the network that emerge as shaping actors. The next three chapters are based around these *nodes* including benzylpenicillin G (BPG) injections, echocardiograms (ECG), and Group A *Streptococcus* (Group A Strep) vaccines. While these sections are to be read linearly, it is best to consider them as contingent and interconnected as key issues in prevention, detection and treatment can be extracted and examined in association with other related concerns. It is my hope that through the careful consideration of the many parts of this network, constructed over time, real world change can be seen towards the elimination of this

endemic illness and the accompanying systemic inequalities that have persisted for so long in Australia.

Chapter 3: BPG Injections – The Mainstay for Prevention or a Transitional Tool?

Introduction

Acute rheumatic fever (ARF) and rheumatic heart disease (RHD) almost exclusively affect poor and marginalised peoples, often catalysing the onset of chronic cardiac diseases and lifelong dependency on biomedical health interventions (Haynes et al. 2020). For the past 70 years benzylpenicillin G (BPG) intramuscular antibiotics injections have remained a central intervention in the ARF/RHD network in remote Indigenous communities of Australia, used in primary prevention of ARF, secondary prevention of RHD, and treatment of RHD-related complications. In this chapter I highlight the ways that the predominant role of BPG injections in contemporary ARF/RHD programs has arisen and endured through innumerable resistances, negotiations, and consensuses flowing between actors. I will explore some of the ways that BPG injections shift their role across disparate network dimensions through “multiplicity” (McCarthy and Martin-McDonald 2007, pp. 86-88), pervade across temporal network regions, are influenced by the spatiality and knowledge systems of connected actors, and absorb a large responsibility for care in the ARF/RHD network of Australia. I conclude with a section addressing the ways that understanding BPG injections as a transitional actor, rather than a mainstay of prevention, could contribute to a socially just network rearrangement in the future.

BPG Injections and Multiplicity

Patented in 1950 by Wyeth Corporation (Wyber, Johnson and Patel 2015, p. 16), BPG technology has not seen any distinctive change over time in terms of its action in ARF/RHD prevention and treatment. However, the ways this actor is understood and performs various roles is vastly different across the internally multiple dimensions of the network. In the biological dimension, it remains a vital weapon against the continuing onslaught of bacterial attacks, demolishing the cellular peptidoglycan barriers protecting *Streptococcus pyogenes*, and slowing its infective advance through bodily tissues (Wyber et al. 2016). BPG injection is specifically designed to persist in the body of infected people, slowly releasing its germicidal defences to ensure a multi-wave, prolonged battle against Group A Strep over several

weeks through its low solubility in blood (Wyber, Johnson and Patel 2015). Despite a growing tide of antibiotic resistance in the contemporary era of medicine (Bowen et al. 2014), BPG has held strong, continuing to demonstrate high efficacy in the antimicrobial field (Currie 2006), solidifying its enduring relevance in the medical dimension of the ARF/RHD network.

BPG injection syringes comprise of an innocuous glass cabin connected to a protrusive steel spike, awaiting deep insertion into the gluteal muscle of a Group A Strep-infected patient by practiced clinical hands (Pfizer 2021, p. 10). The content of BPG injections have “a high concentration of suspended material” making a slow injection rate essential to avoid blockages (Pfizer 2021, p. 2) and severe pain (Mitchell et al. 2018, p. 46). At the same time and less tangibly, they are a lifesaving medium of antimicrobial defence, arising through their inextricable association with remote Indigenous ARF/RHD patients. The current arrangement of these actors in the network are contingent and interdependent: without BPG injections, a genetically susceptible ARF/RHD patient in a high-prevalence area remains vulnerable to repeated auto-immune attacks and chronic illness. Without the patient requiring treatment, a BPG syringe is simply a spiked vial of industrially reconstituted mould.

When these elements align through the act of clinical injection, a hybrid association is formed between human and non-human elements of the network. For example, individuals diagnosed with ARF are prescribed with injections of BPG every 28 days for up to ten years (Haynes et al. 2020). Through these durable connections, BPG injections remain prominent in the mainstream biomedical fight against Group A Strep and subsequent ARF/RHD. The biomedical view of BPG injection, conveyed widely in scientific, medical, and political arenas, formulates this tool as a central element in addressing this crisis of preventable illness (Dooley et al. 2021; Australian Institute of Health and Welfare 2019). By stepping into the scene of prevention and treatment, BPG injections assume the role of an immune agent; a role that in low-risk patients would generally be performed by their innate and adaptive immune systems, without any need for biomedical intervention.

A Painful Interaction

The human/non-human hybridity formed through BPG injection of remote Indigenous patients is problematized by the physical pain of the interaction. The procedure is known to injure in the absence of effective pain management, and sometimes symptoms of unwellness can persist for days, leading some patients to be fearful of this clinical interaction and avoid it (Amgarth-Duff et al. 2019; Mitchell et al. 2018). RHD Australia, a Department of Health funded multi-sectoral agency, in cooperation with the Aboriginal Health Council of South Australia, developed a brief visual guide for healthcare workers to highlight the appropriate preparation, application, and care required in a BPG injection interaction (Figure 2). This visual tool signals to educators and healthcare workers that BPG is a key intervention for people with ARF/RHD. Concurrently, it stresses the potential to cause distress or pain where the clinical application is performed without care and consideration. However, the onus of ensuring appropriate BPG injection administration is sometimes shifted into the patient dimension of the ARF/RHD sufferer and their family. The partial transference of responsibility for this clinical procedure is apparent in the patient information provided by the South Australian Government (Figure 3). This advises the best ways for patients and families to approach health staff to ensure appropriate clinical pain management techniques are applied. These two figures engage with BPG injection procedures across disparate dimensions of the network indicating to both health staff and patients that this crucial experience can be painful. Concurrently, they communicate to disparate actors that with effective and respectful interpersonal communication of a shared interest to minimise pain this life-saving interaction can be less burdensome.

Guide to Administering Penicillin Injections for RF/RHD

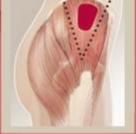
<h3>Before injection</h3> <p>Take time to make the client feel valued and relaxed. <u>Consider the following</u></p> <ul style="list-style-type: none"> Client's preferred site of injection Oral pain relief Topical anesthetic (<i>Emla</i> cream) Client privacy 	<h3>Prepare injection</h3> <ul style="list-style-type: none"> Prepare injection out of view of client Complete the "6 rights of medication administration" with a second clinical staff member Warm syringe to room temperature Attach a 21g needle (green needle) 	
<h3>Appropriate sites for injection</h3>		
<h4>Vastus lateralis (thigh)</h4> 	<h4>Dorso-gluteal (upper, outer bottom)</h4> 	<h4>Ventrogluteal (hip)</h4> 
<h3>Administer injection</h3> <ul style="list-style-type: none"> Position the client for comfort Provide appropriate distraction Apply pressure to site for 10 seconds Allow time for alcohol swab to dry Inject deep into muscle at a 90° angle Inject slowly over 2-3 minutes Dispose of injection equipment carefully 	<h3>After injection</h3> <ul style="list-style-type: none"> Encourage movement of affected limb Ice/cold pack to injection site Oral pain relief Document in client record Provide a reminder for next injection Notify SA Register that injection has been given (rhd@health.sa.gov.au) 	



Figure 2. Guide to administering penicillin (BPG/Bicillin/LAB). Poster developed by RHD Australia and the Aboriginal Health Council of South Australia Ltd. outlining summarised recommendations for administration of penicillin antibiotic injections by health practitioners. Available online from: <https://www.rhdaustralia.org.au/resources/guide-administering-penicillin-bpgbicillinlab>

Rheumatic Fever and Penicillin Injections

How to reduce pain

Information for patients

There are many options to reduce the pain of the injections and you have the right to know what these are. This information is to help you talk to health staff and to make a decision that is right for you.

- ✓ **Don't have the penicillin injection cold.** Ask the nurse or Aboriginal health worker to take the penicillin out of the fridge 15 minutes before the injection. Hold it in your hands to warm it up.
- ✓ **Ask for the injection to be given very slowly, over 2-3 minutes.**
- ✓ Take pain medicine before the injection, but only the amount recommended on the packet.
- ✓ Other options you can ask for include:
 - > An ice pack (wrapped in cloth) on the injection site before the injection.
 - > Lidocaine (a local pain blocking medication) added to the penicillin and given in the same injection.
 - > EMLA cream (a skin anaesthetic). It can go on the skin on the injection site 15-30 minutes beforehand but works best if it goes on 60 minutes before the injection.
 - > Ethylchloride (Cold Spray). It is sprayed onto the skin just before the injection.
 - > Buzzy4Shots device - a vibrating ice pack that goes on the injection site and stays on during the injection. Good for kids.
 - > Bionix Shot Blocker. It is a plastic disc with small bumps on the back. When it's pressed on the skin at the injection site, it distracts you from pain.

The penicillin injection needs to go into a big muscle, like your bottom, hip or thigh.

Don't have the penicillin injections into your arm.

The penicillin injection will stop the Strep germ from causing rheumatic fever for up to 28 days.

You should **not stop having the penicillin injections** without asking your heart doctor (cardiologist), or you could get rheumatic fever again.

Rheumatic fever can cause more damage to the heart if you get it again.

Always tell health staff if you have any allergies.

After the injection:

- ➡ Move around as soon as possible.
- ☀️ Apply heat packs/cold packs as per your preference.
- 📞 If you have any worries, talk to your doctor, nurse or Aboriginal health practitioner.

For parents and caregivers:

- ☺️ Reassure your child that the injection is important for them to be healthy.
- ☺️ Distract your child by talking, playing games, or looking at a phone, iPad or book.
- ☺️ Tell your child's teacher that your child needs the penicillin injections every month and that your child might be sore after the injection.
- ☺️ **Make an appointment at the clinic for your child's next injection, every month.**
- ☺️ Use the RHD phone app or calendar on your phone to remind yourself when the next injection is due (ask your Aboriginal health practitioner or nurse, or look at the RHD website: rhdaustralia.org.au).
- ☺️ **Is your child on the Rheumatic Heart Disease Register? Ask your Aboriginal health worker, nurse or doctor.**
- ☺️ If your child has a sore throat, skin sores, joint pain or fever – go to the clinic for treatment.

The best way to stop rheumatic fever is to:

- ✓ Have penicillin injections every 21-28 days.
- ✓ Wash your hands and body every day, clean your teeth in the morning and night. Wash bed sheets, towels and clothes regularly.



Treatment Tracker Free rheumatic fever treatment reminder app

Treatment Tracker is a reminder app for young people on penicillin injections for the prevention of rheumatic fever. Designed to:

- ✓ Remind users of their injection date
- ✓ Motivate them to get their injection on time

www.rhdaustralia.org.au/treatment-tracker-app

For more information
sahealth.sa.gov.au/rhd
rhdaustralia.org.au
 Telephone: 08 7425 7156 or 0401 124 013
 Public - R - AT

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<https://creativecommons.org/licenses/by/4.0/>

Figure 3. Rheumatic Fever and Penicillin Injections: How to reduce pain. Poster developed by RHD Australia and the Government of South Australia outlining patient communication tools for discussing pain management of BPG injections with health staff. Available online from: <https://www.rhdaustralia.org.au/resources/rheumatic-fever-and-penicillin-injections-how-reduce-pain-patients>

This BPG injection-clinician-patient-family nexus of the ARF/RHD network highlights complex relationality and multiplicity at a single socio-material interface. Examination of official educational resources (Figure 2 and 3) illuminates an area of the network where power differentials between predominantly white health staff and Indigenous patients have manifested in ARF/RHD health settings. In clinical settings poor adherence to long-term antibiotic programs is often attributed to individual patient non-compliance (Harrington et al. 2006). In parallel, Haynes et al. (2020) identify the theme of “collective trauma” in their systematic review of literature that attends to Indigenous experiences of ARF/RHD. They identify that “collective trauma” is sensed through processes of racism, fear, and anger in various culturally insensitive interactions with non-Indigenous health staff and institutions (p. 10). This emergent critique from academic actors exemplifies the complexities of the injection-patient interaction, beyond just physical pain, and highlights the difficulties arising from misapplication of biomedical models in Indigenous healthcare. While it is yet to *translate* into official health policy (Haynes et al. 2021, p. 2), this critique is developing as a key destabilising knowledge system in the ARF/RHD socio-technical space. Through inclusion in new national guidelines and strategies (Wyber et al. 2020; RHD Australia 2020), this social justice narrative is operating in opposition to the “business as usual” biomedical approach (Welch et al. 2020, p. 119) that continues to dominate knowledge flows in the ARF/RHD network.

The multiple identities of BPG injections across disparate ARF/RHD network dimensions highlights the ways that this one non-human actor is materially and functionally malleable, depending on who or what it is interacting with. While some actors see poor injection adherence as a complex experience of health injustice, others see the inadequacies of BPG programs as a procedural issue with implementation and patient engagement that can be optimised through education. By shifting between actor viewpoints, it is apparent that whilst the biomedical vision of bodily health and clinical efficiency is an integral part of addressing Group A Strep-related illness, complementary consideration of the socio-historical and political implications of hegemonic methods in healthcare is essential for a well-rounded perspective. Aligning these parallel views could be immensely beneficial to dislodging the health inequality of ARF/RHD via the driving *energies* of communication for a result of collaborative medical-patient hybridities. Øversveen (2020, p. 862) highlights the

potential of some health technologies to enhance existing and persisting health inequalities for those who are unable to “materialise and enforce institutional expectations” for the use of these healthcare approaches. I believe that BPG injections could move away from being seen as a matter of patient non-compliance in an exclusionary health system. Rather, its role could be shifted towards a community-owned tool of protection, in better grouping with Indigenous ways of being and doing than with biomedical knowledges that see it as an isolated clinical tool to be used on and by Indigenous peoples in prescriptive ways.

Effectiveness of BPG Injections Across Space and Time

BPG injections are generally considered both clinically- and cost-effective against endemic Group A Strep infections (Hardie, Ralph and de Dassel 2020). However, this scientifically reliable actor is often unable to deliver in its pivotal public health role for ARF/RHD prevention in the field, shown by ever-increasing case numbers despite its widespread implementation (Katzenellenbogen et al. 2020; Health Policy Analysis 2017). Its success is entirely contingent on coordination and interdependence with other network elements, many of which reject its constructed status as the solve-all solution to endemic chronic illness.

BPG injections are employed across all temporal stages of ARF/RHD disease progression in remote communities including primary, secondary, and tertiary prevention. To achieve this multi-stage dispersal and implementation involves the circulation of immense network *energies* (Latour 2005, p. 17). These *energies*, in particular communication, flow through the network spaces, acting to renegotiate pre-established healthcare and community roles in order to mobilise BPG injections across policy writing, medical practice, and patient education. For example, studies have identified Group A Strep skin infections can be treated with 80% efficiency through a single BPG injection as a form of primary prevention (Wyber et al. 2021); secondary prevention can be systematically implemented on a routine basis when coupled with active diagnosis of ARF/RHD using an echocardiogram (ECG) (Ralph et al. 2020); and tertiary prevention of complications relating to valve surgery, such as infective endocarditis, can be reduced through patient BPG injection adherence (Australian Institute of Health and Welfare 2019). Through activation across all temporal stages of disease in the

ARF/RHD network, BPG injections are imbued with an inordinate responsibility for care in ensuring the avoidance of chronic heart illnesses in contexts that have historically been systemically neglected and excluded by government institutions and health services (Bond et al. 2020).

The multi-sited temporalities of BPG injection places an excessive socio-political and historical load onto a small mould-filled-case-with-a-needle. One way in which BPG injections manage this load is through sharing accountability for care across network associates, thereby maintaining its elevated status in prevention and treatment. This sharing of responsibility is achieved via processes of *translation*. For example, BPG injections are linked to RHD Australia, a government *ensemble* that has developed and dispersed huge volumes of educational resources including: procedures, guides, flow charts, posters, songs, videos, and smart phone applications relating to BPG injection (RHD Australia 2021). An example of these resources is the short film entitled *Important Health Message: prevent rheumatic fever* (Moonshine Agency Pty Ltd 2014). This video is accessible in eleven Aboriginal and Torres Strait Islander languages and English and positions BPG injections as a necessary medication to “keep your heart good” and that “will stop rheumatic heart coming back” (Moonshine Agency Pty Ltd 2014). This wide range of resources and their diverse target audiences highlights the potential for heterogenous actors from disparate social, cultural, and geographical locations to be brought into closer association with BPG injection as a positive health actor. These knowledge tools and processes, stemming from BPG injections, have a gathering effect. They each draw on the empirically proven yet limited impacts of this actor’s biological and practical effectiveness in preventing RHD, and *translate* it across network regions via communicational processes, such as local languages, to increase their coherence and accessibility.

But somehow all these *energy* flows and attempts to convince connecting actors of the centrality of BPG injections do not result in ARF/RHD reduction. In ARF/RHD, health professionals often fail to follow recommended procedures due to poor training or a restrictive scope of practice (Harbridge 2016). Additionally, patients are unable to engage with technologies due to a suite of complementarity issues, similar to what Øversveen (2020) finds in the case of diabetes. Some of the complementarity issues contributing to this

disengagement include experiences of racism, pain, inaccessibility, or trauma (Haynes et al. 2020). Further, public funds do not address resourcing gaps that are essential for effective BPG program implementation across many diverse communities (Wyber et al. 2020, p. 10). Therefore, communication has a gathering effect to an extent, but the longevity of this coherence between actors is strongly influenced by the quality and reciprocity of the content. This concept is encapsulated by Jennings et al.'s (2018, p. 114) idea of “good caring talk” which highlights the way *translations* are understood and accepted by surrounding network associates in their own terms and not forcibly imposed from the outside in. In particular, Indigenous community acceptance of healthcare programs, such as BPG injections, is influenced by the ability of health professionals to display “respect and care for its Indigenous clients as human beings” (Jennings, Bond and Hill 2018, p. 114) and through self-reflection upon the shared colonial experience of Indigenous peoples in healthcare settings (Mitchell et al. 2021, p. 50).

The space for positive engagement in the network can be proactively facilitated through culturally appropriate outreach. A recent study by Hardie, Ralph and de Dassel (2020, p. 427) demonstrated that “in the NT, 76% of people diagnosed with RHD between 2014 and 2018 had no previous ARF diagnosis” and so community members were never given the option of receiving preventative BPG injections. Even so, BPG injections are held in place by health professionals as the principal element of primary, secondary, and tertiary prevention, against the advice of researchers who suggest a more holistic, engaged, and collaborative approach is necessary (Wyber et al. 2020; Hardie, Ralph and de Dassel 2020). In the face of a growing body of evidence, BPG injection continues to stand out from the surrounding elements through its durable ubiquity across prevention and treatment. This is despite surrounding actors challenging its ongoing significance by exposing its real-world insufficiencies (Hardie, Ralph and de Dassel 2020). Breaking down peptidoglycan cell walls of Group A Strep is an amazing biological feat. However, breaking down the systemic health inequalities leading to embedded ARF/RHD in remote Indigenous Australia requires proactive reciprocity and respect for difference, beyond the scope of a needle.

Changing Materialities and Intermittent Commitment

The application of BPG injections in remote communities is an immensely resource intensive project that demands economic investment, professional commitment, and community collaboration for its effective implementation (Wyber et al. 2020). Investments of time, money, and passion from various groups and individuals to ensure suitable administration of BPG to Aboriginal and Torres Strait Islander peoples have been only intermittently successful. This is due to various concerns such as poor healthcare delivery, failed community education projects, and diagnostic limitations (Hardie, Ralph and de Dassel 2020). These existing concerns are compounded further in periods of short supply of BPG (Wyber, Johnson and Patel 2015). Stock-out periods have occurred at least five times since 1995 and relate to shifts in corporate ownership and the associated movement of factory locations for production and distribution (Wyber et al. 2016, p. 21). These interruptions signal that, historically, BPG injections have not been stable enough to meet constant care requirements for effective prevention and treatment of ARF/RHD. It highlights that BPG injections are subject to outside influence and their appearance in the network is somewhat sporadic, demonstrated by material shifts over time: from a powder-based formula delivered via a “horse syringe”, to a smaller liquid injector, to occasional absences in the early 2000s that led to usage of a painful and problematic powder once again, and finally returning in the small liquid Bicillin L-A formulation that is now produced in Australia and owned by Pfizer Incorporated (Wyber, Johnson and Patel 2015; Currie 2006). The recent shift to local production of BPG injections by Pfizer has been beneficial, as shown by shorter interruptions that were more effectively managed (Wyber, Johnson and Patel, 2015). However, changeable material compositions accentuate that the success and stability of BPG injections is not only dependent on local conditions of clinical administration and patient adherence. It is also reliant on far-off corporate processes that do not always appreciate the need for constant BPG allocation to remote areas when economic and business imperatives dictate otherwise (Currie 2006).

The role of BPG injections in fighting Group A Strep infections remains important to ARF/RHD prevention and treatment, yet there is no recourse for periods of absence. Semi-regular shortages position BPG injection technology as an outside actor; its supply is derived

through processes external to the communities it is used in, and its production is owned by economically dominant actors that are somewhat disassociated from the needs of the people they are distributing medicines to (Currie 2006). Currently, the only active method of preventing development of ARF/RHD in Australia is dependent upon the actions of a single company and their corporate commitment to “empowering and equipping” (Pfizer 2020, p. 6) patients in their ongoing monopoly of BPG injection products. While their Corporate Social Responsibility slogan, “Pfizer CARES”, seems to align with this goal, perhaps the socio-political distance of any corporate *ensemble* from the lives of remote Indigenous patients is too great to overcome. If Pfizer Incorporated were to follow the recent historical pattern and shift their proclaimed responsibility of care for Indigenous remote patients on to another company, will the supply be interrupted again? For how long? As Wyber, Johnson and Patel (2015, p. 508) suggest, diversification of local suppliers and increasing transparency of supply communication could protect against these dislocations. However, the continuing reliance on BPG injection is not likely to eliminate ARF/RHD in Australia while ever extreme health inequalities persist (May, Bowen and Carapetis 2016).

By targeting the social determinants of health and raising standards of living to a level equal to that of other Australians, ARF/RHD could be effectively prevented along with a suite of other illnesses relating to the profound disadvantage of Indigenous Australians (Hardie, Ralph and de Dassel 2020). This could be achieved by enhancing the capacity of communities to establish ownership of the means to provide and share care to core network elements that are most greatly impacted by a sustained, responsible commitment to the health of Indigenous peoples (Carapetis and Brown 2020, p. 116). This does not preclude biomedical and corporate actors, but it does reduce their prominence and disperse their source of power throughout the network configuration. It is a demonstrably unsustainable practice to place all the responsibility for BPG supply on a single, historically fickle corporate assemblage. Through a gradual realignment of network *energy* flows via a coordinated long-term commitment to social justice, it may be possible to diversify BPG suppliers and enhance its reliable availability across remote Indigenous communities long-term.

Conclusion

To close this chapter I return to Puig de Bellacasa's (2011) concept of care as a dedicated "ethico-political" commitment to "matters of concern", such as endemic ARF/RHD in remote Indigenous Australia. Through this examination of BPG injections I do not wish to diminish the role of this antibiotic actor in the broader network. My intention is rather to expose some of the contingent processes that have led to the ineffective elevation of this biomedical tool above the many other diverse elements that hold the capacity to mobilise care in unique, dispersed and coordinated ways. ARF/RHD is a social justice issue as it is preventable via the manipulation of social determinants of health that could culminate in a healthy, safe, and secure environment where people are able to thrive. Instead, biomedical streams of knowledge and power stabilise the elements of the network that address the aftermath of inequality rather than the cumulative impacts of social, economic, political, and historical processes that have led to disadvantage in the first place. Prolific, durable, and systemic implementation of BPG injections is only required where endemic Group A Strep and other bacterial infections are widespread. By drawing on the existing relational power that pervades Indigenous communities, the respectful, reciprocal, and proportionate integration of BPG injections as a protective tool of care could be much more successful. Instead of acting as the temporal, spatial and political mainstay of ARF/RHD elimination, BPG injections could become a far more collaborative actor. They could become realigned as an integral yet transitional tool for Indigenous-led eradication of ARF/RHD by bolstering the health outcomes of communities while primordial prevention projects that address the root causes of health inequality are elevated as the priority.

Chapter 4: Echocardiogram –Visiblisation and De-Professionalisation?

Introduction

Echocardiograms (ECGs) are an ultrasound machine that converts sound bouncing off internal bodily structures into two dimensional (2D) images via a transducer wand. ECGs are an important technology for the diagnosis of ARF/RHD as they provide the means for viewing the internal structures of the heart that are otherwise unobservable. They are closely linked with BPG injections in the ARF/RHD network as they are used on people with a history of Group A Strep infection and to diagnose new ARF/RHD patients that then require antibiotics. While ECGs extend out from the ARF/RHD network of Australia in many ways, their controversial stabilisation as a technological *node* is contested by many actors. In this chapter I explore network discourses regarding ECGs to show the ways that the “potential and power of a technological device to shape an interaction is not pre-given but is realised in practice” (Timmermans 1998, p. 148). I consider how ECGs are ordered by techniques of standardisation that simultaneously visiblise and exclude actor groups, and the ways that ECGs are a professionalised tool associated with jurisdictional network boundaries in remote settings. I conclude by proposing that the standardised expert use of ECGs has played a key role in visiblising remote communities, and that de-professionalisation of diagnostic criteria could work to shift the network towards localised health management practices in the ARF/RHD network.

ECGs and Socio-Technical Exclusions

ECGs were developed into a medical tool for observation of heart valve disease in the 1950s (Krishnamoorthy, Sengupta and Khanderia 2007). Since ECGs were combined with colour-Doppler velocity imaging, developed in the 1980s, the direction and speed of flows of blood are also observable (Krishnamoorthy, Sengupta and Khanderia 2007). The use of ECGs has the potential to enhance the sensitivity of detection techniques for earlier treatment of ARF/RHD via a hybrid interaction of human technicians and non-human machine actors. Through active case finding programs (Francis et al. 2020) and subsequent diagnoses based on appropriately specific criteria, persons with ARF/RHD can be placed on registers, prescribed with antibiotics, monitored for disease progression, and referred to hospital for

life-extending surgical procedures. Importantly, the systematic *enrolment* of ECGs as either diagnostic, preventative, or both, is dependent upon network stability and acceptance of this technology, driven by *energies* that lead to consensus.

The *nodal* role of ECGs as a screening device has been elevated by multidisciplinary actors in the ARF/RHD network timeline over the last decade through durable network processes of *enrolment*. Revisions to both the Jones Criteria for ARF diagnosis by Gewitz et al. (2015) and the World Heart Foundation (WHF) criteria for ECG screening by Remenyi et al. (2012) have been influential in establishing new roles for the ECG, negotiating existing socio-technical relations in the network space. These criteria have been *enrolled* into the network by advocates through processes of lobbying, research, and persuasion to better encompass the endemic nature of ARF/RHD burdens in low-income regions of the world. These revisions reflect a shift in the official health narrative towards greater inclusion of the experiences of remote Indigenous communities. As official narratives often operate as an expression of the political rationalities of government *ensembles* (Latour as cited in Rose and Miller 1992, p. 183), these criteria exemplify the ways it “is often in the seemingly ‘technical’ matters that deeply relevant, social issues are ‘hidden’ – such as inclusion/exclusions of certain groups or voices, or the subtle restructuring of patients’ or professionals’ identities” (Timmermans and Berg 2003, p. 108). While previously only used to confirm clinically detectable cases, the shifting network arrangement mobilised by these revisions indicates the increasing importance of ECGs in visibilising under-recognised illness in remote Indigenous communities of Australia.

The Jones Criteria for ARF Diagnosis

The presentation of ARF/RHD in low resource settings differs greatly from established norms of disease progression observed in high resource settings (Steer 2015). I will argue here that differences across the multiple worlds of a network means standardisation and rules act as a source of order through “sameness and stability for many people”, whilst being a source of “chaos and trouble” for those that do not conform (Star 1991, pp. 41-42). The differences in disease manifestation across contexts demands a level of sensitivity in diagnostic assessments that reflects the heavier burden of ARF/RHD in some communities. That is,

assessments must be sensitive to the reality that disease is probable in high prevalence regions. Prior to the 2015 revision of the Jones Criteria, diagnostic attention was directed to high-income areas with low prevalence of ARF/RHD by health officials. The clinical focus on non-endemic areas drove the development and dispersal of specific diagnostic standards that were geared towards the improbability of ARF/RHD, unless a person had experienced preceding Group A Strep infection. The specificity integrated into these diagnostic criteria assumed that case numbers of ARF/RHD are low (as they are in high resource settings), so the standards became more restricted to avoid over-diagnosis of a largely declining illness (Beaton and Carapetis 2015, p. 7).

Through standardising knowledge processes, applied universally, the Jones Criteria contributed to the “*effacement*” (Prout 1996) of the high prevalence network regions with endemic ARF/RHD, including remote Indigenous communities of Australia and, more broadly, people of the Global South. *Effacement* is a network effect whereby some actors or *ensembles*, such as remote Indigenous communities, are isolated as a separate entity and made invisible to associated elements, rather than viewed as a contingent network component with related concerns (p. 201). This allows other regions of the network to function and flow uninterrupted, yet sometimes these invisible regions become visible, often when a key technology fails. In Australia, an assumption of low probability of ARF/RHD was not transferable to endemic regions and left people with sub-clinical illness undiagnosed through insensitive, highly specific measures of contextually inappropriate standards. Through this failure to prevent disease with existing criteria, some actors worked to re-introduce the high-prevalence network region into the mainstream agenda.

In Australia and New Zealand, inappropriate standards meant the replacement of the pre-2015 Jones Criteria with a unique set of diagnostic criteria in 2012 (Beaton and Carapetis 2015, p. 7). This bespoke set of national guidelines, relevant to the needs of diagnosing Indigenous peoples in remote areas, was a meaningful shift away from universalising historical standards. The previously *convergent* effects of the Jones Criteria as a *translative* device began losing traction and relevance in the network due to its localised appropriateness to non-endemic regions and its neglect of high prevalence areas. Actor opinions began to shift and the network’s fluid propensity for change was revealed through

adaption to new risk-stratified techniques of diagnosis that were more contextually appropriate to remote Indigenous communities and their experiences of disease.

In 2015, Gewitz et al. (2015) revised the Jones Criteria to incorporate ECGs as a crucial tool for detecting carditis for ARF diagnosis in high-risk populations. The significance of this revision is far-reaching as it encapsulates a network consensus on the validity of sub-clinical or under-recognised manifestations of disease that were previously a contested area of research. The dispersal of this new criterion exemplifies a “process of translating the images and concerns of one world into that of another, and then disciplining or maintaining that translation in order to stabilize a powerful network” (Star 1991, p. 32). In this case an image of ARF/RHD was *translated* from the world of researchers concerned with endemic disease in the communities of marginalised peoples, into the global health sphere.

However, while the 2015 criteria are more inclusive of remote Indigenous disease trends, the setting of standardised boundaries excludes the multiple lived experiences across a network that could never be fully captured in an homogenous format, such as criteria (Star 1991, p. 36). The criteria remain a normative prescription of potential presentations of ARF/RHD in endemic zones and could potentially exclude patients that fall outside these biomedically dictated patterns of disease expression. For example, an Indigenous patient from a moderate-high risk population that presents to a clinic with only the symptoms of carditis and a fever of 37.9°C does not meet the criteria for an initial diagnosis of ARF under this model. There are currently no additional tests available that would *enrol* this person into the network as an ARF patient as they did not have enough symptoms that match up with prescribed combinations of observable pathologies. However, this may change in the future through biotechnological developments such as the identification of biomarkers specific to ARF (RHD Australia 2020, p. 287). This area of scientific research highlights the ways that “Standards can stabilize some actions in a moving world, but when the world around the standard changes, the standard will quickly become outdated or altered as well” (Timmermans and Epstein 2010, p. 84). While increased sensitivity in the Jones Criteria and use of ECGs have improved case ascertainment for Indigenous peoples, there remains potential for cases to be missed via exclusive and standardising techniques. Despite the continuing potential exclusion of non-standard cases, the 2015 criteria revision has meant a

temporary stabilisation around new normative claims of ARF diagnosability and the integral role of ECGs in this process.

The WHF Criteria for RHD Diagnosis

In their 2012 revision of the World Heart Foundation (WHF) criteria for ECG diagnosis of RHD, Remenyi et al. (2012, p. 297) identify that the use of auscultation (listening with a stethoscope) as a method of carditis detection has led to underdiagnosis of many “silent or undetected attacks” of ARF/RHD. They demonstrate that the incorporation of ECG screening in high-risk areas would greatly increase the potential to intervene and treat people with sub-clinical manifestations of disease more readily, and thus reduce the economic and resource burdens of associated surgeries and acute care for advanced disease. Through this research these authors sought to rearrange and dislocate the elevated significance of auscultation in the ARF/RHD network through dispersal of new and influential criteria, highlighting the significance of sub-clinical diagnosis with ECGs.

Some clinical and research actors resisted this narrative; suggesting that the successful integration of ECG screening for the diagnosis of latent disease is contingent upon the development of robust BPG injection programs and broader health service delivery improvements in remote areas (Remond, Wark and Maguire 2013). These actors challenged the widescale integration of ECG screening as a diagnostic mainstay, attempting to shift network *energy* back towards existing BPG injection programs that remain inefficient and under-resourced. Hempenstall et al. (2021) raise related concerns derived from their ECG screening study of Torres Strait Islander children. In their study, the ECG emerged as a revelatory tool of “missed opportunities” for prevention of ARF/RHD as it exposed many previously unknown cases, while also highlighting the sub-optimal health service delivery, lack of antibiotics prescribed to patients presenting with symptoms in endemic regions, and poor access to dispersed populations of people for screening (p. 1211). Without associated system-wide improvements, this network *ensemble* of resistant research actors propose that the implementation of ECG screening is immutably dependent on the success of other evidence-based prevention programs, such as antibiotic administration, that have repeatedly failed in practice.

Despite this cautionary discourse, the need to identify sub-clinical ARF/RHD has been a growing area of interest, supported by the emergence of the WHF criteria in 2012. Sub-clinical carditis has been demonstrated as a significant manifestation of disease through an expanding suite of medical evidence and knowledge about ARF and its subsequent development into chronic RHD when left untreated (Watkins et al. 2018), yet “the power of standardization depends on whether standards are actually implemented” (Timmermans and Epstein 2010, p. 79). Through their research, pro-ECG actor groups have mobilised their professional and technical capacity to further stabilise the role of the WHF criteria in empirical research examples. While issues with preventative antibiotic administration and resource shortages persist in remote areas, these research actors have reinforced the importance of the ECG as a tool to prevent unnecessary disease progression through active interception of cases (Francis et al. 2020). While BPG injections are largely considered the only cost-effective approach to ARF/RHD prevention, Roberts et al. (2017) modelled several approaches to demonstrate cost-effectiveness of ECG screening. Their study included 80 different remote Indigenous communities in the NT and showed that comprehensive screening rotations by a small team of highly mobile ECG experts in remote areas could achieve substantial monetary savings by identifying RHD cases one to three years earlier than they are currently. In concurrence with this view, Francis et al. (2020) promote the substantial benefits of pro-active asymptomatic detection of ARF/RHD, uncovering “an unprecedented burden of undiagnosed RHD” in their study based in a single remote community of the NT. These various approaches demonstrated the cost-effectiveness of ECGs and their useful alignment with the 2012 WHF criteria as the new gold standard for RHD diagnosis.

Professionalisation and Readjusting Boundaries

While contested in many ways and often unavailable for use where they are most needed, ECGs perform as an invaluable tool of visibilisation, superseding the role of the stethoscope as the official instrument for detection and diagnosis in the ARF/RHD network. However, in remote Indigenous communities of Australia, their rarity means they remain somewhat dissociated in practice, withheld from these areas by economic and professional barriers. In

many of these remote communities, ECGs are a passive tool of confirmation, used where a patient with suspected RHD, identified by auscultation, is transferred to regional clinics off-Country to have their clinical diagnosis confirmed by ECG technicians (Walsh and Kangaharan 2017). ECGs are generally a specialty piece of equipment in this association, managed by a team of multidisciplinary experts that are qualified to diagnose patients through interpretation of ECG-Doppler colour imagery (Francis et al. 2020). The restricted access and expertise involved in ECG operation is indicative of processes of professionalisation in the ARF/RHD network.

Professionalisation of ECG operation demarcates the practice of ARF/RHD diagnosis as a separated expertise that has arisen alongside the ECG as a diagnostic technology. The result of such “jurisdictional claims” to expert knowledge and practice is often struggle (Abbott as cited in Pickard 2010, p. 1074); struggle to maintain a legitimate position as an expert, or a struggle to de-professionalise a particular role by destabilising and shifting network boundaries. Despite updated criteria prescribing ECG diagnosis, the technical knowledge and qualifications generally required to perform scans and interpret images mean that in low-resource, high prevalence ARF/RHD areas, the use of ECGs is restricted or non-existent. The network connections of ECGs to remote regions remains largely a technical recommendation rather than a lived reality for many Indigenous peoples. However, these boundaries are beginning to shift.

In remote settings, the professionalised status of an echocardiographer as a medical specialist is problematic due to the reduced capacity of local healthcare workers to perform diagnoses on-site and progress to the prescription of BPG antibiotics where appropriate (Harbridge 2016). Bicudo de Castro (2020, p. 471) identifies that professionalisation processes in an actor-network are heterogenous, undertaken by diverse actors with various goals, strategies, and outcomes that either weaken or support certain activities, such as non-expert echocardiography in ARF/RHD diagnosis. When the practical and material aspects of the machine-human interaction of ECG screening are broken down into constitutive elements, there seems to be insufficient reason for such selective operation of this imaging technology. Any healthcare actor trained in the use of a transthoracic ECG could, in theory, use an ECG machine. The difficulties arise in the interpretation of images

collected and the technology available. When compared to a healthy heart (Figure 4 a, b), “definite RHD” cases (Figure 4 c, d) have clearly defined features in the WHF criteria and the differences in morphology and function are pronounced on an ECG-Doppler image. However, these pathologies signify two possible points on a continuum of disease and health and the ability to obtain a clear image is heavily dependent on the quality of the machine itself, not only on the person operating it. For example, employing handheld portable devices results in much lower detection rates for borderline RHD, “even by experts” (Watkins et al. 2018, p. 1403). The failure to diagnose ambiguous cases is then, not an issue for experts vs non-experts, but is rather a contingent issue that occurs in materially disadvantaged settings that cannot afford high-end machines.

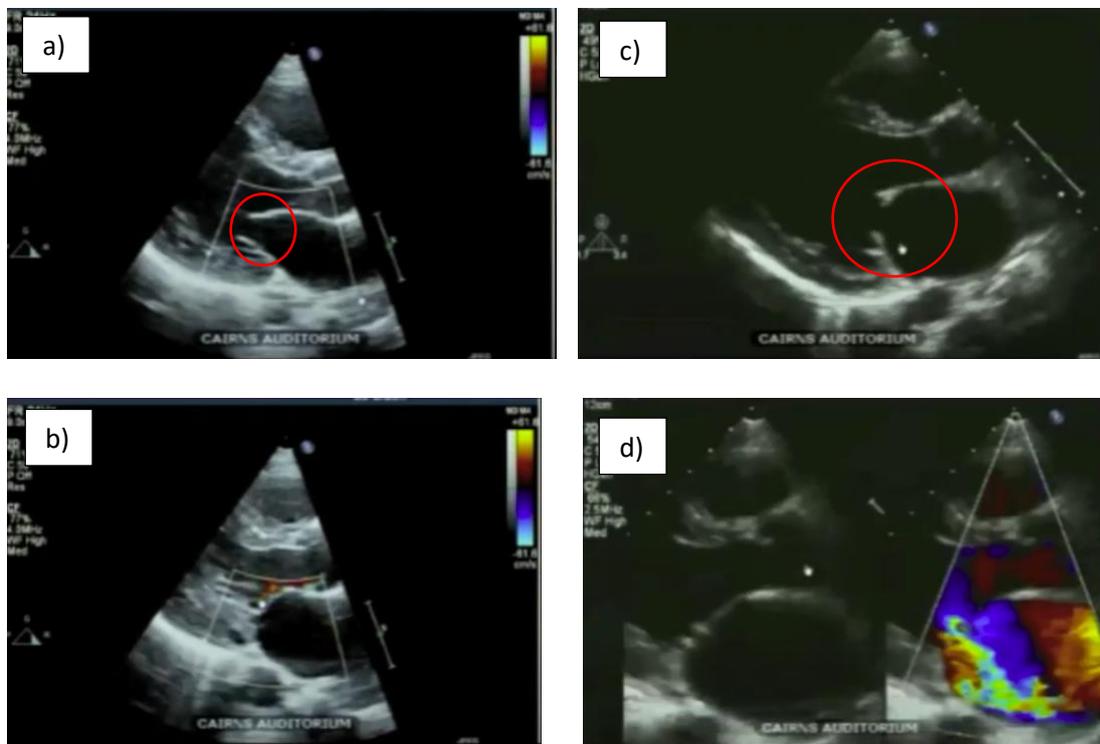


Figure 4. Echocardiogram images collected by echocardiographer Ben Reeves showing patient with healthy heart vs patient with valvular regurgitation due to rheumatic heart disease (RHD). a) Healthy heart with long smooth valve structure upon opening b) Healthy heart with closed mitral valves and minimal regurgitation detectable via Doppler colour imaging c) Definite RHD affected heart with damaged mitral valves upon opening indicated by nodules on ends of valve leaflets d) definite RHD heart with mitral valves closed and high levels of regurgitation detected via Doppler colour imaging. Images available from: <https://www.rhdaustralia.org.au/resources/echocardiography-rheumatic-heart-disease-ben-reeves>

In response to the increasing availability of affordable, portable ECG technology there has been growing interest in the de-professionalisation of ECG imaging to shift network boundaries away from dislocated technical staff and towards local empowerment of communities through ownership of health management activities. In a recent government evaluation of echocardiography for detection of heart failure and RHD, some of the key recommendations were to ensure the ECG is performed close to a person's home and in a timely manner (Australian Institute of Health and Welfare 2020, p. 15). However, there is no dependable supply of trained technical staff or ECG machines in remote clinics and other low resource regions to enable such an intention to manifest in practice (Watkins et al. 2018, p. 1403). By training "non-expert screening personnel" in a simplified approach to ECG examinations on portable devices, Francis et al. (2020, p. 121) infer there is potential for more efficient use of this technology in high-prevalence areas that could benefit immensely from early intervention. This viewpoint arose in response to the professionalised exclusivity found in the 2012 WHF criteria that is geared towards experts using quality machines in clinical settings (Watkins et al. 2018, p. 1403). Evidence-based guidelines are an example of the ways that expert work is becoming increasingly organised through processes of standardisation (Timmermans and Berg 2003, p. 109). This has been an ongoing barrier to effective integration of ECGs across the ARF/RHD network conformation and Watkins et al. (2018) suggest there is a need to create abbreviated screening criteria. Introduction of simplified standardisation would contribute to a de-professionalisation process that repositions distinctive expert boundaries of the network, enhancing efficiency and ubiquity of the technology through a growing association with non-expert operators (Pettrakaki, Barber and Waring 2012, p. 430).

Globally, RHD is one of the most underfunded and under-resourced areas of public health in relation to its health burden (Macleod et al. 2019b). As a materially neglected health concern, several network actors have performed investigations into the potential for more widespread ECG use within remote and low-income areas. In any heterogenous network space, *translation* is a crucial process that aligns disparate elements, asserts professional boundaries, or moves them into new locations through standardising tools (Star and Griesemer 1989, p. 404). These standards coordinate action in a network as they set shared expectations, when communicated effectively, across network dimensions. Facilitated by

the Telethon Kids Institute, the focused cardiac ultrasound (FoCUS) screening project explored the feasibility of training non-experts in ECG operation to increase access to these devices in low-resource, high-risk areas of Fiji (Engelman et al. 2016). The training involved an eight-week program for the detection of mitral and aortic regurgitation. The results demonstrated high levels of sensitivity, specificity, and accurate diagnosis of RHD using simplified criteria. These were promising results; however, they are ungeneralisable to contexts in the Torres Strait and mainland Australia without local research. In 2018 a non-expert ECG study was performed in Maningrida, NT by Francis et al. (2021). In this study, local health workers were trained in an abbreviated approach to echocardiography. This training was delivered in English for six days and, like FoCUS, involved identification of regurgitation as a key pathology of RHD. This study showed high sensitivity and specificity; however, the accuracy was not as high as desired by investigators. These technical, community, and non-expert actor groups demonstrated the ways that technologies and their related guidelines are fluid and adaptable, seen through shifting boundaries of professionalisation and de-professionalisation. Standards have been adapted with varying success across non-expert studies, highlighting the potential flexibility of the professionalised boundaries of ECG use in low-resource settings into the future.

Conclusion

The successful implementation of ECGs as a technological *node* has been an area of controversy due to unknown benefits in the detection of sub-clinical RHD. Additionally, the expense of supplying specialised machines and people to low-resource, remote settings has been a major barrier to ubiquitous ECG use in prevention. Despite these concerns, research into the benefits of sub-clinical diagnoses and the emergence of more affordable portable machines have allayed many of these fears and ECGs have been integrated into the network through standardised expert criteria for use in diagnosis. The remaining concerns largely surround network access to this sought-after preventative tool and its successful implementation across diverse communities, currently restricted by professionalised boundaries and poor-quality machines where available at all. Through consideration of recent studies, the potential to train local health workers to manage screening protocols could re-align these network boundaries, mediated through the *translative* effects of

simplified standards for diagnosis. This process of de-professionalisation could reduce reliance on distant technicians and reassert community ownership of health outcomes through localised screening programs run by local health workers.

Chapter 5: Group A Strep Vaccine - A 'Game-Changing' Solution?

Introduction

In 2019 the World Health Organisation (WHO) released an “actionable framework for vaccine development”, aimed towards mobilisation of a global campaign to bring a Group A Strep vaccine into being (Vekemans et al. 2019, p. 877). Two years later, I explore the network processes that have led to the dynamic integration of Group A Strep vaccines as a technological *node* in the ARF/RHD network of Australia over time. This vaccine technology has not been developed into a safe product for human use, nonetheless, it remains a central promissory actor that drives funding, decision-making, and carries the hopes for future eradication of ARF/RHD globally. In this chapter I examine vaccine development by attending to the materialities of Group A Strep bacterium, exploring the discursive evolution of vaccine development in Australia, and reflecting on the ways that the configuration of a network, while sometimes temporarily stabilised, is flexible and dynamic. I conclude by arguing that retrospective consideration of network actor discourses reveals changing perspectives over time and subsequently exposes opportunities for network shifts to be imagined as a contingent evolution of ideas for socially just change.

A Sociology of Expectations in the ARF/RHD Network

The anticipation of success and efficacy of a Group A Strep vaccine accentuates the need to engage with the future of technologies as a charged temporal space that plays an organising role in current network processes (Brown and Michael 2003). I integrate a sociology of expectations analysis into this chapter, drawing on ideas from Brown and Michael (2003), to examine the ways the actor-network is shaped around hopes for innovative technologies that offer imagined solutions to current concerns. This approach orients this analysis towards the examination of technological innovations in terms of how actors' views of success and failure of a technology shift over time. These views move along a narrativized continuum of “optimism-disappointment” as actors retrospectively consider past failings, and prospectively ponder hopes for success (p. 14). The power of prospective hope enables actors to assemble in unique ways around an innovation that would possibly have never emerged, had it not been for this optimistic imagined future. In cases of disappointment,

retrospectively derived expectations of future failure can preclude the construction of technoscientific arrangements from ever eventuating. Through this lens, I consider ways that a network is materially constructed by discursive production processes that *translate* knowledge over time, making and unmaking connections through consensuses and resistances (Baiocchi, Graizbord and Rodriguez-Muniz 2013, p. 337) in ARF/RHD prevention.

Group A Strep Vaccine: The Hundred-Year Promise of Disease Eradication

Development of a Group A Strep vaccine has a long history with many challenges and obstacles to the emergence of a viable product for human use (Steer et al. 2009, p. 544). Since the 1920s researchers have investigated various features of Group A Strep as potential vaccine targets (RHDAustralia 2020, p. 286). One issue contributing to the slow progress in vaccine development is the role of Group A Strep itself. Group A Strep is a devious, adaptable, and complex microbial being. It is the cause of many human diseases that vary greatly in terms of impact, site of infection, duration, and long-term effects (Mills and Ghosh 2021). It attacks many sites of the human body, commonly entering via the nasopharyngeal passage or the skin, and can become deadly through invasive colonisation, such as in infective endocarditis (RHDAustralia 2020, p. 286). This bacterium does not act alone, sometimes joining forces with other pathogens, such as ectoparasitic scabies that open wounds in the skin, easing bacterial passage and transmissibility in overcrowded and unhygienic settings (Swe, Reynolds and Fischer 2014, p. 585; Thornley et al. 2018). Group A Strep is well adapted to its pathogenic role and has evolved to respond to immune defences adeptly (Mills and Ghosh 2021), using the human body against itself by causing autoimmunity and mutating rapidly to avoid immune recognition (Reglinski and Sriskandan 2015).

Scientists have segregated two main categories of Group A Strep characteristics that perform as the targets for vaccine research. These are “M-protein” and “non-M-protein” research (Steer et al. 2009). M-proteins cover the surface of Group A Strep and collect immune agents as a shield against clotting factors and other immune cells that would otherwise seek to clear the bacteria from the human body (Mills and Ghosh 2021). There are many types of M-proteins, and they are associated with the autoimmune reaction

leading to ARF/RHD complications (Gray et al. 2017). These virulent characteristics make the M-protein a difficult target for vaccine research due to associated safety risks of unintended cross-reactivity with host tissues (Kumar and Tandon 2013). Alternately, non-M-protein targets include other bacterial components that are significantly less studied (Steer et al. 2009). Non-M protein characteristics are generally more conserved across Group A Strep types and do not appear to impact cross-reactivity. By challenging almost every aspect of standard vaccine development through its multi-strain, mutational, virulent, and covert qualities, the material and functional characteristics of this bacterial actor has strongly contributed to repeated failed vaccine innovations for one hundred years.

Failed Pasts and Optimistic Futures for a Vaccine

In the ARF/RHD network, processes of knowledge and power emerge through discourse, shaping expectations and imaginations of what the future network arrangement could look like with a vaccine. The significance of examining future expectations lies in the rising optimism for a vaccine over time and its various commercial and practical failures that permeate, yet do not weaken, the strength of that narrative from advocates. The future network is hence a charged space, not a vague undefined region, but rather a tangible subject of analysis (Brown and Michael 2003). To examine the phenomenon of evolving perspectives that mobilise network actors, I explore discursive changes seen across the three editions of the Australian guidelines for ARF/RHD including the 2006, 2012, and 2020 publications. The ways these guidelines address interrelated issues of vaccine development and disease prevention indicates changing hopes, driven by the accumulation of knowledge and tools over a fourteen-year period. These expectations reflect the pressures, resistances, and accelerations derived through the authors' fluctuating interactions with other elements within the dynamic sociotechnical web of ARF/RHD relations.

The First Edition: Mobilising Action

In the summarised version of the 2006 guideline, *Diagnosis and management of acute rheumatic fever and rheumatic heart disease in Australia*, the authors present the first national, evidence-based approach to addressing endemic ARF/RHD (Carapetis et al. 2007). The focus of this publication is on detection and treatment of ARF/RHD and does not

address primordial prevention strategies. The reason for not including these “is because the key to primordial prevention is reducing exposure to GAS, which requires dramatic improvements in housing, hygiene infrastructure and access to health care for Indigenous Australians” (Carapetis et al. 2007, p. 582). At the time, these objectives were presented as unattainable without systemic change and extensive resourcing and so were not a central priority, unlike in later editions. This omission demonstrates the ways that material factors, such as funding and resourcing, can play into perceptions of possible realities and futures. In this edition, the focus lies on discrete and entrenched biomedical interventions that had already been practically applied for some years, such as BPG injections as a secondary prevention technique.

Further, the language used regarding Indigenous communities was restricted to the need “to provide education and health promotion for individuals, families and the community” (Carapetis et al. 2007, p. 585). This framing positions Western knowledge-holders as the deliverers of essential information, indicative of a one-sided knowledge *translation* from researchers to communities within the network. This unidirectional communicative technique situates Aboriginal and Torres Strait Islander peoples within the deficit model of healthcare knowledge (Heard et al. 2019, p. 872), emphasised by the absence of Indigenous voices and viewpoints in this early agenda.

The absence of discourses of expectations from authors regarding the involvement of vaccines as a technological actor in this edition can be attributed to several temporally significant network processes. An extended moratorium was imposed by the Food and Drug Administration (FDA), halting human vaccine trials involving Group A Strep in the United States from 1979 to 2006 (Food and Drug Administration 2005). This ban was imposed due to an experiment that seemingly caused ARF in several participants (Steer et al. 2009, p. 548). Group A Strep is a pathogen specialised to attack only human hosts and the restriction of investigations to inappropriate non-human animal models contributed to successive failures to deliver a viable vaccine (Oslowicki et al. 2019, p. 3486; Rivera-Hernandez et al. 2019). While scientific research continued throughout the FDA ban era, there was a lack of regulatory support, commercial interest, and prioritisation of Group A Strep as a global health concern. This meant that the prospects of a successful vaccine emerging were

uncertain until a consensus could be reached and regulatory barriers removed (Bisno et al. 2005). Rather than focusing on an imagined future actor, the Rheumatic Fever Guidelines Writing Group of the National Heart Foundation of Australia (NHFA) aligned their focus upon seemingly attainable goals for 2006. A vaccine was not presented as a major player in the ARF/RHD network of Australia at this time. Instead, the focus was on projects that could be started or improved immediately, including the implementation of coordinated control programs, registers, and standardised diagnostic and treatment regimens.

The Second Edition: A Preventative Shift

In *The Australian guideline for prevention, diagnosis and management of acute rheumatic fever and rheumatic heart disease (2nd edition)* published in 2012, there were significant changes from the previous release, indicating shifting expectations over time, particularly surrounding vaccine development and primary prevention.

In 2009, following extensive advocacy from a specialty group of researchers and clinicians, the Commonwealth Government established RHD Australia (RHD Australia 2019b), which emerged as an effect of many relations between human and non-human actors. This *ensemble* of stakeholders included researchers, research, money, health professionals, health resources, and Aboriginal and Torres Strait Islander peoples, interested in the reduction of the preventable burden of ARF/RHD in remote communities. The establishment of this heterogeneous body shifted the Australian ARF/RHD network from a somewhat disjointed, fragmentary conformation into a more solidified arrangement, stabilising across shared intentions to prevent disease in remote communities. Coupled with the Rheumatic Fever Strategy (Health Policy Analysis 2017), this amalgamation of interested parties accelerated national efforts to establish register-based control programs in order to share data across jurisdictions. Additionally, the assemblage of the National Coordination Unit (NCU) signalled a joint commitment for the eradication of ARF/RHD through dissemination of evidence-based guidelines direct to communities, in close partnership with National Aboriginal Community Controlled Health Organisations (NACCHO). Professor Jonathon Carapetis, the then Director of RHD Australia, celebrated the novelty of this coordinated venture saying there is “no other equivalent of RHD Australia in any other

country” and suggested that these united efforts are looked upon as an example to aspire to in other ARF/RHD burdened regions of the world (RHDAustralia 2019a).

The RHDAustralia writing group prepared the 2012 edition of the Australian guidelines with a focus on prevention that had not been addressed in the 2006 NHFA version. The language used in this edition indicates the changing shapes of future expectations surrounding ARF/RHD eradication via development of a vaccine actor as a preventative agent, as well as new opportunities for enhancing community understanding of ARF/RHD risk factors.

Vaccines are first mentioned in this text as the “ideal solution for the primary prevention of ARF/RHD” through their potential to protect against Group A Strep colonisation (RHDAustralia 2012, p. 22). Following this statement, the idea of a vaccine is constructed as utopian due to the long history of “scientific and regulatory obstacles” and safety risks resulting in the failure to deliver on the promise of this preventative actor over many years. The authors then describe a pertinent concern with vaccines in development: that targeting the Group A Strep strains present in North America will not address ARF/RHD in endemic regions elsewhere that have extensive strain diversity. This section is then closed with the following quote; “While the development of a safe and effective GAS [Group A Strep] vaccine to prevent ARF/RHD is yet to be realised, it should remain a priority in ARF/RHD prevention” (RHDAustralia 2012, p. 23). The “optimism-disappointment narrative” of a sociology of expectations (Brown and Michael 2003, p. 14) emerges in this statement as authors of the guideline indicate the co-existence of disappointment in past failures and concurrent optimism for the future of a vaccine that will prevent Group A Strep colonisation from the outset.

Throughout this text Indigenous communities are discussed by the authors as groups requiring “awareness” (p. 12, 30, 60), “education” (p. 16, 53, 67, 68, 69), and “involvement” (p. 25, 71) in recommended programs. The added focus on prevention is a meaningful transition from the previous edition as it acknowledges the growing importance of health promotion, communication, and resourcing required to equip Aboriginal and Torres Strait Islander communities with access to the biomedical knowledge of Group A Strep management. However, similar to the first edition, writing about Indigenous peoples and their participation in terms of a unilateral knowledge transfer again infers a knowledge-

holder vs knowledge-receiver relationship, rather than “the reciprocal process of co-creating knowledge” in genuine, empowering partnerships (Haynes et al. 2019, p. 42). The 2012 edition thus demonstrates network stabilisation around both the idea of a new vaccine and the promise that educating Indigenous peoples about biomedical techniques of prevention could lead to a reduction in the burden of ARF/RHD.

The Third Edition: ‘Game-Changing’ Technology and Transformative Collaboration

RHDAustralia recently released *The 2020 Australian guideline for prevention, diagnosis and management of acute rheumatic fever and rheumatic heart disease (3rd edition)*. In the eight-year period between this version and the second edition, major changes occurred in the ARF/RHD network, both in Australia and globally, with the *convergent* release of a roadmap for the achievement of a vaccine (Vekemans et al. 2019).

In the years since, there has been an electrifying effect across the Australian ARF/RHD network with actors gathering to enable the production of conditions that would facilitate a successful and safe vaccine. The third edition echoes this renewed enthusiasm and the innovative potential within the existing ARF/RHD network arrangement. Consequential aspects of this evolution are signified by the integration of a new stand-alone chapter for “New Technologies” which introduces the Group A Strep vaccine as a key player in the network future. In addition, a chapter dedicated to “Primordial prevention and social determinants of acute rheumatic fever” was introduced, signalling a concurrent network shift towards addressing root causes of endemic illness in remote Indigenous communities.

The “New Technologies” chapter indicates that the authors align strongly with the WHO priority for developing “Key Capacities” for vaccine development. An example of this is the need to develop a human model of Group A Strep infection for “proof of concept evaluation” in future clinical vaccine trials (Vekemans et al. 2019, p. 878). In the guideline, investigations for a novel model of Controlled Human Infection for Vaccination Against *S pyogenes* (CHIVAS-M75) by Australian researchers Osowicki et al. (2019), is presented as an indication of emerging key capacities. Osowicki et al (2021), successfully developed the first

safe and efficacious model of experimental Group A Strep pharyngitis for study of the disease in humans a year after the release of the 2020 edition. This was a major step towards the achievement of at least one WHO priority and sewed hope back into the ARF/RHD network fabric. This meaningful finding confronted, and scientifically controlled, many unpredictable aspects of Group A Strep infection and recovery, moving the network one step closer to eventuation of a vaccine.

The “New Technologies” chapter of the 2020 guidelines emphasises persistent hope and co-occurring reflection upon past failures in the vaccine narrative. Acknowledgement of failures is not always disastrous and maintaining narratives of future success can sometimes perform as a “self-fulfilling prophecy” (Pollock and Williams 2010, pp. 528-529). The authors emphasise the wide-reaching positive impact that a Group A Strep vaccine would have for some of the most “severe and frequently fatal invasive disease” affecting vulnerable people in endemic areas, such as “pregnant women and newborn babies” (RHDAustralia 2020, p. 286). They then acknowledge past failures of other programs for primary prevention, saying “antibiotic treatment for Strep throat and skin infections have not been able to achieve large and sustainable reductions in the subsequent development of ARF or RHD” (p. 286). They suggest that a vaccine would be a more sustainable form of long-term intervention and a short-term primary prevention solution as well.

Overall, the authors remain overwhelming optimistic that a vaccine “will help eliminate disease” (p. 286). This future-focused enthusiasm is bridled by reflection upon multiple past failures driven by “scientific, regulatory and commercial obstacles” (p. 287). This demonstrates that over time the socio-political and material contingencies linked to vaccine success or failure have become increasingly apparent. As Borup et al. (2006, p. 286) argue, we see here that “expectations are both the cause and consequence of material scientific and technological activity”. The insertion of \$35 million from the Federal Government towards Group A Strep vaccine research bolstered a growing hopefulness across the research dimension of the network. This “catalytic” investment (Telethon Kids Institute 2021) has demonstrated that accelerated hopes are linked inextricably with material associations. Brown and Michael (2003) suggest in relation to other novel technologies, that multi-sectoral, institutional engagement can feed into the actual success of a technology in

the future. As this guideline seems to suggest, without the necessary resourcing through funding and institutional support, the vaccine remains a far-off dream yet through substantial monetary, regulatory, and governmental backing, the network alignment around a vaccine is better protected against future unknowns.

The influence of material network elements on innovative change becomes more apparent through consideration of the discourses that accompanied the third edition. At a conference in 2019 the Chief Executive Officer of NACCHO, Pat Turner, a key collaborator in RHD Australia initiatives, emphasised simultaneous support for vaccine research and the need to address material concerns of poverty and illness saying, “A Strep A vaccine would be a game-changer, but developing it will take years and people are dying now – we need to make sure that the really exciting investments in science are coupled with on-the-ground action,” (NACCHO Aboriginal Health News Alert 2019). This need for primordial action before the pursuit of a technological solve-all is demonstrated through the near-eradication of ARF/RHD in mainstream, non-Indigenous Australia, where standards of living are generally high and easy access to services is the norm (Steer 2015, p. 22). The inclusion of a new chapter attending to the social determinants of health signals that the emerging discourse in 2020 has evolved through the integration of multiple knowledges and the elevation of Indigenous voices. An example of this is in the Foreword prepared by the newly appointed Director of RHD Australia, Vicki Wade. In this section, Wade, a Noongar woman of South-West Western Australia, highlights that ARF/RHD “challenges are more than biomedical and are driven by the social, cultural and environmental determinants of health” (RHD Australia 2020, p. 2). This rising emphasis of the systemic causes of illness hints at the emergent social justice narrative that attends explicitly to the role of “cultural and structural barriers for Aboriginal and Torres Strait Islander peoples” (p. 14) and the ongoing impacts of colonisation that have become increasingly important considerations in ARF/RHD health programs (Haynes et al. 2021, p. 8). Additionally, language used in relation to Indigenous communities has shifted immensely since 2012 to become more collaborative and less paternalistic. For instance, instead of a predominant preventative approach of educating and prescribing Western knowledge, this edition focuses more on Indigenous community “capacity and governance” (p. 9), “relationships” and “partnerships” (p. 10), “holistic” views of health wellbeing and care (p. 9, 10, 36, 249, 252), “priorities and preferences” (p. 40),

“trust” (p. 50, 112, 160, 200), and “ownership” (p. 60, 275). This language signals a move towards a transformative narrative of empowerment through reciprocity, emphasising the need to engage in community-led approaches beyond biomedical understandings of disease management into the future.

Conclusion

In this chapter I considered the ordering influence of material elements and the future as a charged temporal space within the ARF/RHD network. By examining Group A Strep as an actor with intentions to evade immune defences and evolve beyond the grips of vaccine protection, I highlighted some of the fundamental historical issues that have slowed the innovative processes for vaccine development. However, as techniques for scientific exploration expand, the investigation of new, conserved targets that are found across multiple strains could be the key to newfound scientific discoveries. This scientific enquiry is contingent on the many associated actors and material realities of the ARF/RHD network that either support or hinder the pursuit of a vaccine. To demonstrate this ongoing dynamic struggle, I explored the discursive development of three editions of the Australian guidelines for ARF/RHD and how they evolved over time. The prospective hopes for a vaccine have changed in profound ways since 2006 that highlight the effects of network processes, shifting related actors into a state of convergence and stabilising them around support of a vaccine by 2020. Perhaps most crucially, the emergent role of Indigenous leadership in the recent edition encapsulates a radical turn in narrative structure from a heavy focus on surveillance in 2006, to a growing emphasis on prevention in 2012, and finally towards a concerted effort to convince the readership that primordial prevention presents the best prospects for holistic, sustainable health improvements for remote Indigenous communities of Australia in 2020. By retrospectively considering prospective discourse surrounding vaccines and how this has developed over time, it becomes clear that optimistic ideals for change have the potential to shift network flows and conformations in the future, stabilising around actors that promise a world with less ARF/RHD.

Chapter 6: Conclusion

In this thesis I have undertaken a sociological analysis of some of the socio-technical and material aspects of the acute rheumatic fever and rheumatic heart disease (ARF/RHD) network in Australia that have led to the endemic and ongoing presence of disease in remote Aboriginal and Torres Strait Islander communities. Further, I have considered how the construction of the ARF/RHD network has changed over time through movement of actors and dynamising processes that pervade the network space, shifting actor positions around emerging and retrospective opinions, perspectives, and expectations. These assembling processes and arrangements were examined through an actor network theory (ANT) perspective, supplemented with ideas from ethics of care, governmentality theory, and post-colonial studies. Through this combination of analytical lenses, I have contributed new insights to the sociological literature on this topic through investigations of key technological *nodes* in the ARF/RHD network, illustrating the ways that the seemingly disparate human and non-human elements of technoscientific assemblages are contingent and dependent on related actors and do not arise in isolation. This contingency illustrates the ways that network formation is a dynamic, cumulative process of flowing network *energies* that are shifted, interrupted, reversed, or enabled over time through discursive and material inputs from diverse actors.

As the scope of this inquiry was confined to an Honours thesis, I have focused on three network *nodes*, however, there are countless possible focuses, both human and non-human, that could be considered. Future research into this topic could involve; (1) analysis of primordial prevention *nodes* such as housing, water, and nutrition; (2) consideration of the racialised and gendered aspects of ARF/RHD through contraceptive, pre-natal and post-natal interventions; and/or (3) exploration of Aboriginal and Torres Strait Islander peoples' systems of governance, knowledges, and management of ARF/RHD and other illnesses across diverse communities.

By investigating network associations linked with three technologies, I have exposed some of the ways that the ARF/RHD network has been historically developed through a

biomedical lens of healthcare that is heavily reliant on discrete technological interventions for the management of ARF/RHD in remote Indigenous communities. In considering benzylpenicillin G (BPG) injections I was sensitised to the issues that can emerge through culturally incongruent *translations* of knowledge during healthcare interactions and the reliance on unsustainable systems of prevention dictated by distant corporate *ensembles*. However, I identified that this can be changed through the sharing of responsibility for care across other actors and with engagement characterised by reciprocal communication. Through contemplation of the diverse sources of care available in the ARF/RHD network, I suggest that attempts to realign the position of BPG injections as just one of many preventative actors, rather than as a mainstay of prevention could facilitate a transitional move towards primordial prevention strategies that address root causes of disease. By looking at echocardiograms (ECGs) I found that the standardisation tools, such as criteria, that emerge to visibilise historically obscured network elements of ARF/RHD in remote communities, are often contested despite their apparent *enrolment* as the gold standard of diagnosis. Additionally, standardisation can lead to the establishment of jurisdictional network barriers through professionalisation processes that become a site of resistance as actors work to facilitate non-expert empowerment via localised education of health staff. Finally, the exploration of Group A *Streptococcus* (Group A Strep) vaccine development then drew my inquiry into the future of the ARF/RHD network as a charged temporal space of investigation, whereby the narratives of success in the future and disappointment in past failures collided with the contingent material elements required for the construction of a hopeful discourse. This led me to understand that the current expectations for a future free of ARF/RHD is contingent on complex socio-material interactions of the past. This opening up of the network to an optimistic future of collaborative change is ever-evolving as new actors and knowledges are introduced and shift existing network flows and arrangements over time.

Overall, my investigation has demonstrated that the ARF/RHD network is a dynamic sociotechnical space that has been subject to immense energetic fluctuations that pervade the network and shift actors based on contested and emerging understandings of best practice for prevention and treatment of this endemic disease. While many policy makers and health practitioners consider ARF/RHD as an intractable, stationary reality, I believe this

inquiry has exposed the vast potential for change to occur into the future of the ARF/RHD network, through both material and epistemological rearrangements. The stabilisation of the network conformation around various historical and emergent interventions is a key feature of this health issue. These semi-solid conformations can be fluidified through *convergent* communicational and material inputs from diverse actors that see the potential for a holistic shift. By confronting the assumptions underlying the biomedical knowledge processes systemically diffusing the current entrenched network assemblage, resistant actors can redirect *energies* to reverse the flow of power and knowledge, reassembling the network into a more socially just conformation, built around community-led projects for collaborative primordial prevention of ARF/RHD. This does not preclude new and established technologies and biomedical insights. Rather, it asserts the value and elevates the importance of Indigenous knowledges, cultures, and leadership in the future configurations of the ARF/RHD network of Australia.

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