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Care, Connect, Cure: Constructing Success for Health Consumer Organisations

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Sydney Business School of the Faculty of Business

Care, Connect, Cure:

Constructing Success for Health Consumer Organisations

Dianne Prince

"This thesis is presented as part of the requirements for the award of the Doctor of Business Administration of the University of Wollongong"

31/08/2016

CERTIFICATION

I, Dianne Prince, declare that this thesis, submitted in fulfilment of requirements for the award of Doctor of Business Administration, in the Sydney Business School, Faculty of Business, University of Wollongong, is wholly my own work unless otherwise referenced or acknowledged. The document has not been submitted for qualifications at any other academic institution.

Dianne Prince
31/08/16

ABSTRACT

In Australia, Health Consumer Organisations (HCOs), also known as Patient Support Groups, play an important role in supporting people facing a shared health condition. This research aims to identify and illustrate factors mediating the success of formally structured Australian HCOs. An understanding of what enables or inhibits 'success' for such organisations will inform HCOs and stakeholders seeking to work with them, and assist them in the development and evaluation of their strategic plans.

This research identifies factors mediating the success of HCOs operating in Australia through a study involving four separate organisations. Organisations were selected purposefully to illustrate differences and similarities across the broad range of HCOs that provide support for people facing specific health challenges or for those caring for others. Each organisation participating in this research has a national presence or affiliation, and has been operating for a minimum of 10 years. All are registered with the Australian Charities and Not-for-Profits Commission and are members of the Australian Health Consumer Forum.

The concept of 'success' is contestable depending on who defines it and this influenced the choice of a qualitative research design. Semi-structured interviews were conducted with members of each organisation and with other stakeholders. Key documents, including Annual Reports over a 5 year period were reviewed, along with literature on Health Consumer Organisations and Not for Profit groups. Thematic analysis of interview transcripts and content analysis of key documents revealed factors believed by stakeholders to influence success of Health Consumer Organisations in Australia.

Stakeholder Theory was the primary lens used in the analysis and interpretation of the data collected during this research. In addition, Social Capital Theory was helpful when seeking to understand the contribution of volunteers, and Kaplan and Norton's 'Balanced Scorecard' along with Mitchell's framework of stakeholder salience and utility, useful models for strategic planning and performance measurement.

As revealed in this research, success for HCOs is described in three categories: Profile, Performance and Purse. The research also identifies seven factors mediating HCO success including Clarity, Contribution, Credibility, Connectedness, Capital, Capacity and Creativity.

There are two main research outcomes. Firstly, it presents a practical framework to assist HCOs in Australia in planning and evaluating stakeholder relationships and strategy. Secondly, by illustrating the application of Garriga Cots' (2011) stakeholder social capital concept and Knox and Gruar's (2007) integrated model for marketing strategy development in the non-profit sector to HCOs in Australia, it makes a modest but new contribution to the extant literature on stakeholder theory.

ACKNOWLEDGMENTS

This study started life as an initial curiosity about a particular genetic disorder affecting about 1 in 200 Australians of European background. As I began to search for information on the condition, I made contact with committee members of HCOA who over time inducted me into their fascinating world. During the years since I started on this endeavour I have come to appreciate the very great generosity of people who volunteer their time in such organisations and my first acknowledgement is to them. I'd like to express my gratitude to all the participants in this study who gave generously of their time answering my questions and providing background information. Without them, there would be nothing to write about, but more importantly without them there would be a huge gap in what our community offers for those facing great personal health challenges, whether these be acute and urgent, or chronic and long term.

Next, I'd like to thank the staff at the University of Wollongong's Sydney Business School and the Australian Health Services Research Institute (AHSRI) for their guidance and support in the time I've been working on this. In particular, I wish to thank Professor Helen Hasan for agreeing to supervise the final stage of writing up following Emeritus Professor John Glynn's retirement. John was Executive Dean of the Sydney Business School when I started this adventure and together with Associate Professors Grace McCarthy and Gary Noble provided great support and advice along the way. Saturdays on campus were fun because of the great company of friends in my DBA cohort. Ann, Marianna, Louise, Peter, Andrianni and Malcolm were never short on laughs or words of encouragement. They made the trip down Mt Ousley very worthwhile.

The very last words of thanks belong to Brian Smole, my best friend and partner. For more than 40 years he has been a constant source of encouragement in all my endeavours and no less so than in this most recent. As a scientist, he has a huge appetite for understanding why things are and how things work, bringing a wonderful discipline to whatever project he undertakes. He has been a great interrogator, constantly challenging my assumptions and beliefs, asking essential questions for a researcher.

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CHAPTER 1: INTRODUCTION

1.1 Introduction

Health Consumer Organisations (HCO), also known as Patient Support Groups, play an important role in supporting people facing a shared health condition. HCOs in Australia vary in scope, size and structure, ranging from very small groups representing and supporting individuals within a local community, to alliances representing smaller groups advocating on behalf of individuals with rarer conditions. Groups such as the Genetic Alliance and Rare Voices Australia represent the interests of a number of smaller groups or networks sharing information and resources. Individuals who want to support others experiencing the same condition often establish HCOs. Some of these remain informal self-help groups while other 'condition-based groups' (Allsop, Jones and Baggot, 2004) seek to connect in 'formal alliance organisations' advocating for change in the way the condition is treated or the way the individual is treated. While it is difficult to know how many HCOs are in Australia, the Consumer Health Forum of Australia (CHF) lists more than 100 HCOs as member organisations and the ACNC has 833 charities registered with 'Advancing Health' as their primary purpose and 'the general Australian public and people with chronic disease or terminal illness' as their beneficiaries. We might assume that the number lies somewhere in between.

Applying Brown and Zavestoski's 2004 typology of Health Social Movements (HSMs), the HCOs in this study can be defined to some extent as Health Access Movements in that they seek to influence the provision and quality healthcare services. Two HCOs can be described as Constituency Based Movements as they represent the interests of women and the aged. None matched Brown and Zavestoski's HSM criteria for Embodied Health Movements (EHMs). In terms of Allsop, Jones and Baggott's alternative typology (2004), each of the HCOs in this study could be described as 'condition-based groups', while two could be described as 'population-based' groups. None of the HCOs participating represented 'formal alliance organisations' although one was exploring an alliance with another organisation.

1.1.1 The purpose and aim of this research

The purpose of this study was to identify factors mediating success as defined by formally structured Australian HCOS in order to make a practical contribution to their planning and administration processes. An additional aim of the study was to develop a framework to identify and illustrate expectations of HCO stakeholders, for strategic planning purposes. The identification of factors contributing to HCO success may also assist stakeholders seeking to work with them, and enable benchmarking between HCOs and similar organisations.

To my knowledge no studies have to date specifically investigated factors enabling or inhibiting HCO success, nor according to Huyard (2009) has there been interest in researching 'the inner structure, resources and functioning of (patient organisations)' Huyard (2009:980). Figure 1.1 illustrates the gap addressed in this research.

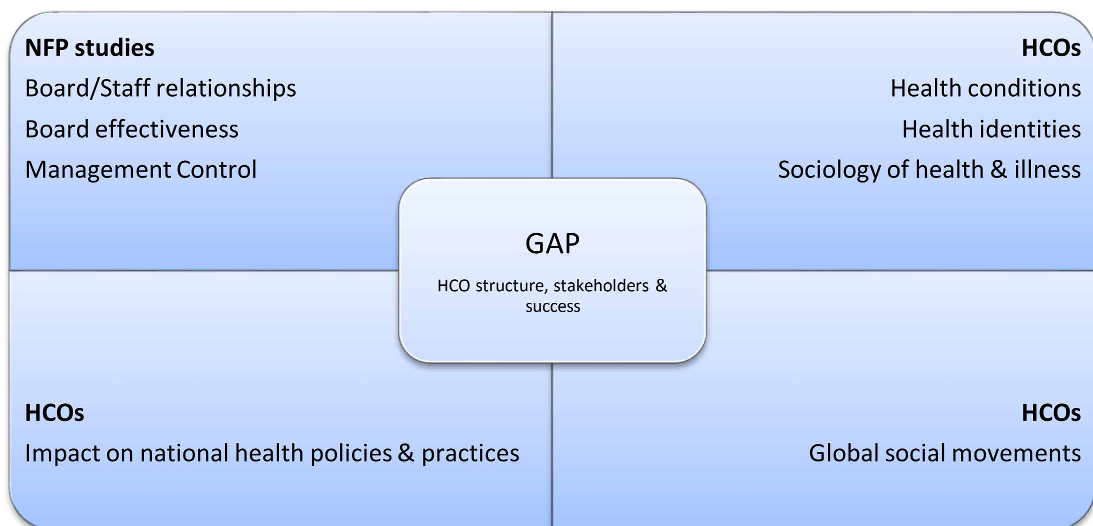


Figure 1.1 Research areas and gaps

1.1.2 The Value of this research

This research has two primary practical outcomes. Firstly, presenting a framework for planning and evaluating stakeholder relationships and strategy, will contribute to enabling the success of HCOs in Australia. Secondly, by illustrating the application of Garriga Cots' (2011) stakeholder social capital concept and Knox and Gruar's (2007) integrated model for marketing strategy development in the not-for-profit sector, to HCOs in Australia , this research makes a modest but new contribution to the extant literature on stakeholder theory.

In addition to this thesis, a full report is available to participating organisations on request and a summary report of the research findings available to all participants.

HCOs are important to a variety of stakeholders for different reasons. Firstly, they are important to those who join them for personal support and advice. They are also important to governments as providers of community services funded by them and as sources of consumer input on policy. In addition, they are of interest to both public and private sector healthcare providers seeking input on their services from consumer representatives. Finally businesses seeking to engage with consumers where 'direct to consumer' communication is highly regulated, have demonstrated increasing interest in sponsoring HCOs. Each stakeholder has their own view of HCO success and each has an interest in measuring HCO effectiveness in terms of their views.

During this research, I was continually drawn to explore the nature of changing relationships between doctors and patients. While a basic understanding that these relationships have changed and continue to change is integral to this study, my research does not specifically explore those relationships. Rather it is located within business and organisational studies with the intent to understand what makes these organisations effective and successful in the eyes of their stakeholders, and to apply this understanding to managing strategic relationships.

1.2 The research process

1.2.1 Research design and methodology

Since the concept of success is socially constructed and contested, qualitative methods were selected as most appropriate to this research and debates surrounding the work of grounded theorists Corbin (1998), Glaser (1999, 2007), Bryant (2007, 2009), Charmaz (2004, 2014), Denzin (2008, 2009) and Walsh et al (2015) informed it. Data from 29 interviews was synthesised with information from other sources to construct overarching concepts of 'success' and to identify factors mediating success for these organisations.

This research identifies characteristics contributing to the success of formally structured HCOs operating in Australia through a study of four separate organisations, selected purposefully to illustrate differences and similarities across the broad range of HCOs supporting people facing specific health challenges. Each participating organisation has operated on a national basis for a minimum of 10 years. All are registered with the Australian Charities and Not-for-profits Commission, and are members of the Australian Consumer Health Forum.

Seeking answers to 'how' and 'why' questions in relation to contemporary issues within real-life contexts (Yin, 2009), this qualitative research Is informed by case vignettes rather than detailed case studies, drawing on their experiences to illustrate the range of HCOs active in Australia. As illustrated in Figure 1.2, the purpose of these vignettes was to provide the backdrop to, and context for, data collection and analysis.

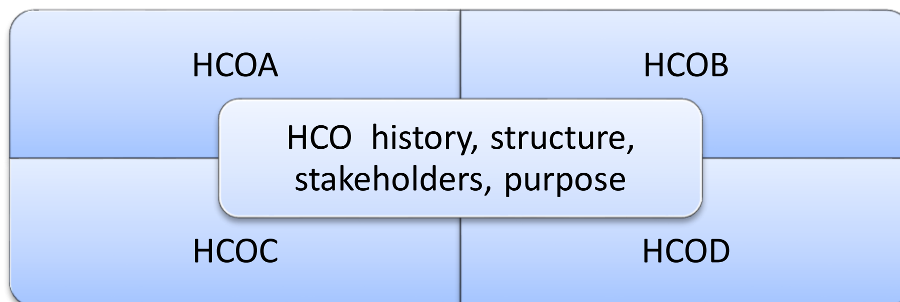


Figure 1.2 Descriptive Case Vignettes

Semi-structured interviews were conducted with members of each organisation, and with stakeholders from industry, research and medical communities. Key documents, including Annual Reports over a period of five years, were reviewed along with literature on Health Consumer Organisations and Not for Profit groups. Thematic analysis of interview transcripts and content analysis of key documents were undertaken, to reveal factors influencing success of Health Consumer Organisations in Australia.

Data collected included interviews and documents, website material, social media reports and annual reports. The literature review includes works from a wide range of academic fields including the history of medicine, sociology of health, illness and organisations, business studies, organisation theory and marketing.

Eisenhardt (1989), Sandelowski (2002, 2006, 2010), Eisenhardt and Graebner (2007), Tracy (2010), Malterud (2012) and Ellingson (2014) provided insights on the challenges of undertaking qualitative research, and guidance on specific methodological strategies such as conducting semi-structured interviews and using memos to record observations and questions for follow up and further investigation, and coding and analysing data.

1.2.2 Research questions

My research set out to answer two main questions: (i) what does success mean for HCOs in a changing health environment and (ii) why do some HCOs appear to be more effective than others? Guided by three basic questions identified in Anheier and DiMaggio's "road map" for non-profit sector research, *"Why do non-profit organizations exist? How do they behave? What impact do they have and what difference do they make?" (cited in Anheier, 2005),* my research focused on the first two levels of analysis, organisation and field/industry, detailed in Table 1.1.

Table 1.1 Anheier's Basic Third Sector Research Questions

Level of analysis and focus			
Basic question	Organisation	Field/Industry	Economy/country
Why?	Why is this organization nonprofit rather than for profit or government? *Organizational choice*	Why do we find specific compositions of nonprofit, forprofit and government firms in fields/industries? *Field-specific division of labour*	Why do we find variations in the size and structure of the nonprofit sector cross-nationally? *Sectoral division of labour*
How?	How does this organization operate? How does it compare to other equivalent organisations? *Organizational efficiency etc; management issues*	How do nonprofit organizations behave relative to other forms in the same field/industry? *Comparative industry efficiency and related issues*	How does the nonprofit sector operate and what role does it play relative to other sectors? *Comparative sector roles*
So what?	What is the contribution of this organization relative to other forms? *Distinct characteristics and impact of local organization*	What is the relative contribution of nonprofit organizations in this field relative to other forms? *Different contributions of forms in specific industries*	What does the nonprofit sector contribute relative to other sectors? *Sector-specific contributions and impacts cross-nationally*

Anheier (2005: loc 2879 of 12375) Table 6.1 Basic third sector research questions

1.2.3 Background Literature

This research draws on literature from the broader category of non-profit organisation (NPO) effectiveness focusing mainly on management control, board/staff relationships, and the impact of the board of directors (MacMillan et al, 2005; Mwenja & Lewis, 2009; Reid & Turbide 2012; Tucker & Parker, 2013), and on a broad range of literature more directly related to HCOs.

Studies on the growth of health consumer movements (Bastian 1998; Baldry 1992; Rabeharisoa 2003, 2006; Allsop, Jones and Baggott 2004; Brown and Zavestoski 2004; Klawiter 1999, 2008; Landzelius 2006; Archibald 2008; Borkman and Munn-Giddings 2008; Callon and Rabeharisoa 2008; Baggott and Forster 2007; Huyard 2009; Baggott and Jones 2011; Rabeharisoa et al 2012; Brown 2013; Rabeharisoa and O'Donovan 2014), provided insights on relationships between HCOs and their stakeholders.

The work of Klawiter (2002), Lofgren (2004), Batt (2005), Busfield (2006), O'Donovan (2007) and Jones (2008) examining the nature of relationships between consumer groups and the pharmaceutical industry, reflects the process of medicalisation described by Conrad (1992, 2005) and Conrad and Leiter (2004),and provides insights on the pharmaceutical industry as stakeholder.

Studies on the role of patient support groups in Australia (Boyle et al 2003, 2007, 2009, 2011, 2016), and in Germany (Kofahl et al, 2014), identified opportunities and challenges for 'better engagement between CHOs [Consumer Health Organisations] and the formal health system that is underpinned by accurate information about how CHOs can contribute' to self-management of chronic conditions (Boyle et al, 2016:402). These studies highlight the interests of medical practitioners and health consumers as HCO stakeholders.

A summary of the background literature for this research is depicted in Figure 1.3

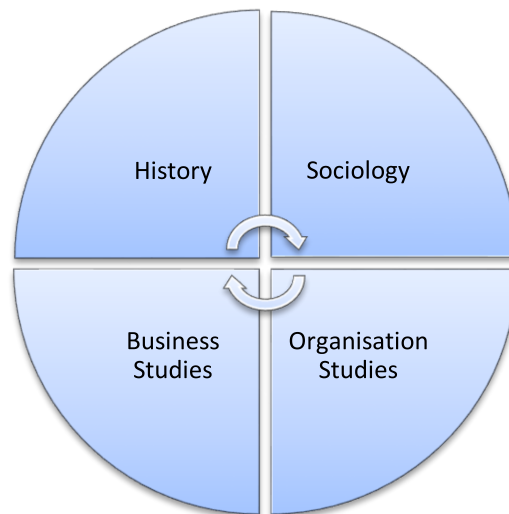


Figure 1.3 Sources of research literature

1.2.4 Theoretical lenses

While a number of different theoretical lenses and frameworks including Resource Dependence Theory and Founder Syndrome Theory are applicable to an examination of influences on the success of Health Consumer Organisations, Stakeholder Theory became the primary lens because it presented the opportunity to examine the HCOs from a wide variety of perspectives. In addition, Social Capital Theory was helpful when seeking to understand the contribution of volunteers and employees, as well as the benefits arising from collaboration and alliances. Organisation Theory in relation to not for profit organisations and Kaplan and Norton's 'Balanced Scorecard' as a framework for measuring performance were also used to make sense of the data.

Figure 1.4 Theoretical lenses

1.2.5 Researcher bias or potential conflict of interest

A personal background in education, teaching English as a Second and Foreign language and experience learning other languages and living in other cultures provided me with a framework for 'listening to', 'reflecting on', 'interpreting' and 'translating' what was said in interviews. While I had no recent history in the not-for-profit sector or with health consumer organisations at the time of commencing my research I joined the volunteer management committee (board) of a local community group while I was completing my data analysis. I believe this involvement enhanced my understanding of the broader NFP sector and the challenges facing NFP organisations in general.

At the time of finalising my thesis, I accepted the role of president with one of the HCOs involved in this study.

I began this research with almost 20 years' experience in the pharmaceutical and medical devices industries and considerable knowledge of business operations and strategic sales and marketing practices. In that time I observed changes in the way the industry firstly evaluated the salience of significant stakeholders namely patients, payers and prescribers (Ferrandiz, 2001), and then subsequently managed the different key relationships.

In the end three categories of 'success' and seven mediating factors emerged from distilling the data sourced from a limited number of HCOs, and synthesising contributions from the literature and my own observations and reflections, borne from personal and professional experiences. (Charmaz, 2014).

1.3 Summary of findings

This research revealed three categories of HCO success: Profile, Performance and Purse. Success was also defined in terms of a HCO's sustainability, its financial resources and the ability to transform or re-invent itself, sometimes through alliances and networks with other organisations. Only one HCO defined success as goal attainment or mission accomplishment, expressed as there no longer being a need for the organisation. Its work would be complete once awareness was raised to the point where testing or screening and appropriate interventions became commonplace. One external stakeholder informant wryly observed that some HCOs appeared to have lost sight of their mission while others were led by 'old fogeys' more interested in 'self-preservation', rather than transforming, innovating or designing exit strategies, for when their mission was accomplished.

In addition to the three categories of success defined, the research also identified seven mediators (enablers or inhibitors) of success. These are Clarity, Connectedness, Contribution, Credibility, Capital, Capacity and Creativity.

Reported measures of success include growth in membership, continuing or increased funding, media mentions, positive evaluations of service provision, growth in service provision, research, community recognition and feedback.

1.4 Research Outcomes

This report presents a snapshot of the work of a selection of HCOs in Australia HCOs fulfil three main missions: to care for and support people with specific conditions affecting their health, to connect with others who may influence their mission and in doing so build community and social capital, and to 'cure' the circumstances impacting their members by influencing decision-makers on health policy and practices, and supporting scientific research. Figure 1.5 depicts a summary of what HCOs do.

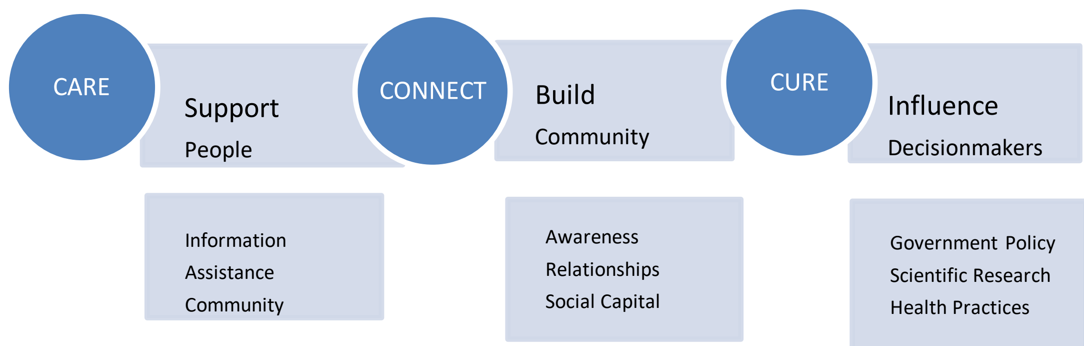


Figure 1.5 Principal Activities of HCOs

This research identifies what success means for HCOs in Australia and describes characteristics contributing to success. By illustrating the application of Garriga Cots' (2011) stakeholder social capital concept and Knox and Gruar's (2007) integrated model for marketing strategy development to HCOs in Australia, it makes a modest but new contribution to the extant literature on stakeholder theory.

It presents (i) a process for evaluating stakeholder relationships and for planning strategy based on stakeholder analyses and (ii) a framework for measuring performance to the plan. It is hoped that these tools will contribute to the success of HCOs in Australia.

1.5 Thesis structure

Chapter 1 outlines the aims and significance of this research and presents a roadmap for navigating its path from research design through to outcomes.

Chapter 2: Literature Review
This chapter situates this research in the broader Australian healthcare context, providing an overview of Medicare, the Pharmaceutical Benefits Scheme and the Therapeutic Goods Administration (TGA). The role of the Australian Not-for-profit and Charities Commission (ACNC) and challenges facing not-for-profit organisations in Australia are also discussed. This chapter reviews literature on not-for-profit effectiveness, Health Consumer Organisations and health social movements, the history of medical marketing practices, contemporary marketing practices, and the theories used in explaining the data and research findings.

Chapter 3: Research Methodology and Design
This chapter presents the philosophical foundations underpinning this research and explains my reasons for undertaking qualitative research. It describes the research methodology, providing explanations of each phase. The rationale for selecting participants, and data collection and analysis methods are detailed in this chapter.

Chapter 4: Research Findings Part 1
This chapter presents case vignettes describing each participating HCO, outlining its history, purpose, structure, governance and funding arrangements. It presents the first part of the research findings, exploring what success means for HCOs in terms of Profile, Performance and Purse.
Together with Chapter 5, Research Findings Part 2, it draws together research data, stakeholder and social capital theory and not-for-profit effectiveness literature, as the foundation for the CPC framework presented in Chapter 6.

Chapter 5: Research Findings Part 2

This chapter presents the research findings that relate to factors identified as mediators of success, providing thick descriptions of Clarity, Contribution, Credibility, Commitment, Connectedness, Capital, and Capacity. Together with Chapter 4, Research Findings Part 1, it draws together research data, stakeholder and social capital theory and not-for-profit effectiveness literature, as the foundation for frameworks presented in Chapter 6.

Chapter 6: Research Outcomes

This chapter presents practical guidance for HCOs based on the research findings - a process for stakeholder analysis and strategic planning, and a series of frameworks for evaluating success.

Chapter 7: Conclusion

This chapter summarises the contributions of the research. It explores implications for HCOs, governments, industry and other stakeholders, acknowledging the limitations of the study and identifying opportunities for further research.

CHAPTER 2: LITERATURE REVIEW

This chapter begins with an overview of the approach taken and key fields investigated in this research. This is followed by a critical presentation of the literature in specific fields of relevance.

2.1 The Approach to the Literature Review

As depicted in Figure 2.1, literature from many fields of study informed this research, including sociology and social movements (patient support or self-help groups and health social movements), strategic management and business performance, the non-profit sector, marketing (contemporary marketing practices including relationship marketing within the non-profit sector and the medical and pharmaceutical industry .

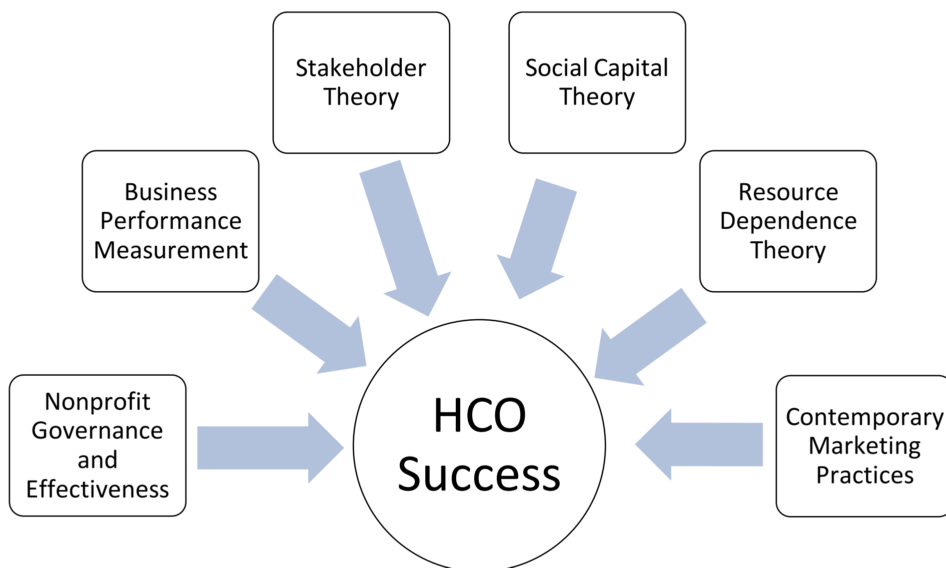


Figure 2.1 Fields informing this research

Histories of health and medical marketing and the development of the pharmaceutical industry, together with research on contemporary marketing practices and relationship marketing, provided insights into the changing relationships between consumers, medical practitioners and other players within the healthcare industry.

The application of different theoretical lenses helped with the analysis and interpretation of the constructs and enablers of success. Stakeholder literature contributed to understanding ‘connectedness’, ‘contribution’ and ‘clarity’; social capital literature informed discussion of ‘connectedness’, ‘creativity’ and ‘capital’, and resource dependence literature ‘connectedness’, ‘credibility’ and ‘capacity’.

The development of the stakeholder analysis and strategic planning frameworks resulting from this research benefitted from the strategic management, business performance and non-profit effectiveness literature.

Literature was reviewed continually through the entire research process. A series of searches was conducted to uncover literature in three main areas: the patient as consumer or advocate, the not-for-profit sector, and pharmaceutical marketing practices. Searches using key words including ‘patient support groups’, ‘health consumers’, ‘consumer health organisations’, ‘ self-help groups’, ‘health social movements’, patient advocacy’, ‘consumer advocacy’, ‘doctor-patient relationships’, were undertaken to identify previous research related to patient support.

Searches to uncover work on non-profit effectiveness used key words including ‘non-profit organisations’, ‘not for profit organisations’, ‘non-profit effectiveness’, non-profit success’, ‘social capital theory’ ‘stakeholder theory and non-profit’. It should be noted that the terms ’non-profit’ and ‘not-for-profit’ are used interchangeably in this literature review.

Further searches used key words including ‘relationship marketing’, ‘contemporary medical marketing practices’, ‘direct to consumer marketing and pharmaceutical’ and ‘medicalisation’, to identify studies on pharmaceutical marketing practices.

A snowballing technique emerged for achieving ‘theoretical saturation’ of the literature whereby meta-analyses identified through each search were in turn checked for key references, with these papers also checked for references. Final checks were done of the contents of high impact journals across different fields of study from 1990 - 2016. Figure 2.2 illustrates the search process. Appendix 1 lists key journals accessed in fields relevant to the research. A detailed presentation and analysis of the literature is contained in the following sections of this chapter, and additional relevant research is discussed throughout this report.

Figure 2.2 Representation of Literature Review

2.2 Public Health Care in Australia

The Australian public health context matches Conrad and Leiter's (2004) 'mediated markets' where 'there is an indirect relationship between consumers, on the demand side, and medical producers or providers, on the supply side, with third party payers occupying an intervening role'. In the Australian context the Federal Government via Medicare or private health insurers 'intervene[s] in the exchange relationship between consumers and [healthcare] providers', 'by defining what is "medically necessary" and then paying for only those goods and services that they have deemed medically necessary' (2004:161).

Established in 1984, 'Medicare is the Commonwealth funded health insurance scheme that provides subsidised healthcare services to the Australian population'. In addition to covering some or all of the cost of general and specialist 'out of hospital' medical services, Medicare provides for fully subsidised hospital treatment for public patients in public hospitals and covers the cost of most medicines in full or partially, through the Pharmaceutical Benefits Scheme (PBS). The Medicare Benefits Schedule (MBS) lists the range of services covered by Medicare and recommended fees.

Decisions about which new services to publicly fund and list on the MBS are made by the government on the advice of the Medical Service Advisory Committee (MSAC) , an independent non-statutory committee established by the Minister for Health in 1998. MSAC recommends listings on assessments of safety, clinical and cost effectiveness and total cost. Reviews are undertaken periodically to remove and add services. 'The MBS is an uncapped, demand-driven programme. In general, once a particular service is included on the MBS, its utilisation is largely a matter for health professionals and their clinical decision-making in consultation with their patients'. (http://www.msac.gov.au/internet/msac/publishing.nsf/Content/factsheet-03 accessed 220816)

The Pharmaceutical Benefits Scheme (PBS) provides government subsidised medicines to the Australian public. Before an application to the Pharmaceutical Benefits Advisory Committee (PBAC) to list a medicine on the Pharmaceutical Benefits Scheme (PBS) can be made, the drug must first be approved for use in Australia by the Therapeutic Drugs Administration (TGA).

Listing on the PBS is critical to decisions made by pharmaceutical and biotechnology companies to market new therapies in the Australian market. Prior to listing a drug on the PBS, the Commonwealth Government and the pharmaceutical company will sign a commercial 'deed of agreement'. Deeds of agreement are designed to reduce government exposure to the risks associated with subsidising medicines, namely uncertainties in estimating usage and overall cost to the PBS, as well as uncertainties around cost and health outcomes. Usage and overall cost uncertainties relate to the number of patients accessing the medicine, daily dose and/or duration of therapy. (DOHA, Deed of Agreement Guidelines 2009).

Pricing submissions may supported by consumer input from groups or individuals likely to benefit from the supply of the medicine at the government subsided price. These individuals may have been receiving the drug through participation in clinical trials or special access schemes. (See Appendix 2 for a sample record of consumer hearing). Pharmaceutical and biotechnology companies have established close relationships with patient organisations with stakes in their therapeutic portfolios.

2.3 Non-profit organisations

2.3.1 For profit vs non-profit organisations

In seeking to answer the question, ‘are non-profit organizations different?’ Brody (1996) adopted a legal-economic approach to her comprehensive examination of the similarities and differences between non-profit and for profit organizational forms, concluding, ‘in many ways, all firms, non-profit and for profit, bear more resemblance to each other than their organizational differences suggest. Because all firms operate through people, firms arise and behave similarly in response to economic forces’. (1996:465).

Despite these similarities, NPOs have a unique relationship between operations and revenues (Weerawardena et al, 2010:347). ‘A non-profit pursues a mission that is neither financially sustainable using a for-profit business model, nor for which there is sufficient public support to move government to action and the expenditure of taxpayer funds (Hansmann, 1980; McDonald, 2007; Valentinov, 2008)’. They ‘emerge to satisfy a need that neither the business nor public sectors satisfy (Etzioni, 1972; Kotler & Murray, 1975)’, (in Weerawardena et al, 2010:347). Abzug (1999) maintained that ‘strict sectoral boundaries become less meaningful’ (1999:139) ‘if ‘non-profits help to promote and legitimate for-profits (Abzug and Webb, 1996) while for-profits help to fund non-profits’ (1999:139).

2.3.2 The Australian Charities and Not-for-Profit Commission

The Australian Charities and Not-for-Profit Commission defines a not-for-profit organisation as one ‘that does not operate for the profit, personal gain or other benefit of particular people (for example, its members, the people who run it or their friends or relatives).’ A not-for-profit may however make and accumulate a profit ‘as long as there is a genuine reason for this and it is to do with its purpose, for example ... building new infrastructure or accumulating a reserve so it continues to be sustainable.
If an organisation continues to hold onto significant profits indefinitely, without using them for its charitable purpose, this may suggest that the organisation is not working solely towards its stated charitable purpose (and is not operating as a not-for-profit)’.
http://www.acnc.gov.au/ACNC/Register_my_charity/Who_can_register/What_is_NFP/ACNC/Reg/NFP.aspx downloaded 18/07/16

The Australian Charities and Not-for-Profits Commission (ACNC), was established in 2012 as the national charity regulator, as a means of providing ‘some level of accountability to the public, and meet community expectations in relation to entities in receipt of public monies and support (Commonwealth of Australia, 2012, p. 28)’, (Saj, 2015 in Hoque and Parker (Eds) 2015:301-302). ‘While registration was voluntary, tax concessions and government funding were to be made available only to registered entities’. (Saj, 2015: 301-302). Registered entities are required to provide an annual financial report and annual information statement outlining the organisation’s activities, as well as formal documents that include a charity’s purpose, activities and processes.(accessed from ACNC website 18/07/16)

Of 43,153 entities currently registered as charities by the Australian Charities and Not-for-Profit Commission, 3,377 or 7.8%, list health as their primary purpose and of these 3,050 list their main activity as aged care activities; mental health and crisis intervention, or ‘other’. Only 327 list their primary activity as hospital service rehabilitation. (http://australiancharities.acnc.gov.au/visualisations/explore-all-charities accessed 18/07/16).

2.3.3 The Not for Profit environment in Australia

It is worth noting Furneaux and Ryan’s (2014) advice that ‘there is a proliferation of names for NPOs (Lyons 1998), due to a lack of specific Australian legislation defining non-profits or charities (Lyons and Dalton 2011) with different laws passed on a piecemeal basis. This means that all ‘charities are non-profit organisations, but not all (or even most) non-profits are charities (Lyons and Dalton 2011, 242)’. (Furneaux and Ryan, 2014:1116).

Saj (2015) notes ‘such is the significance of the role played by Australian charities that it has been acknowledged to be one of co-responsibility with government (Beilharz, Considine & Watts, 1993; Graycar & Jamrozic, 1989; IC, 1995; Robbins, 1997)’.
The sector is ‘thoroughly integrated into the fabric of Australian political, social and economic life’, receiving funding from taxpayers via government contracts and grants and direct donations, and providing essential daily services that would otherwise not be provided. In addition, charities ‘contribute significantly to the development of social capital through marshalling the effort of volunteers, and by participating strongly in the public policy debate’. (Saj, 2015 in Hoque and Parker (Eds) 2015:288).

According to Kong and Prior (2008) the non-profit environment in Australia has changed significantly since the 1980s with the introduction of 'new public management' 'a reform agenda aimed at overturning the traditional bureaucratic model of public administration (Hughes, 2003)' for a for-profit sector style of management (Weerawardena and Sullivan-Mort, 2001) (2008:120). A study by The Public Interest Advocacy Centre at the University of Western Sydney (Sidoti et al, 2009) examined 'the government-not-for-profit relationship' and the 'radical transformation in the way that governments do their business' in light of the introduction of 'new public management *(*George and Wilding 2002; Melville 2005)', (Sidoti et al, 2009:3).

Sidoti et al (2009) citing Darcy (2002), Brown and Keast (2005), and O'Shea (2006) amongst others, noted the increase in outsourcing of government services and 'dramatic changes in the relationship between government as purchaser and not-for-profit organisations (NFPOs) as providers of 'government' services as a result of the NPM implementation. (Sidoti et al, 2009: 8-9). Furnaux and Ryan (2014) citing Lyons and Dalton (2011), reported the relationship between government funders and NPO service providers had 'soured' under the NPM (2014:1117) as a result of underfunding service provision, increased reporting requirements and the use of competitive tendering for funding (Brown and Ryan 2003; Lyons and Passey 2006)' (2014:1117).

2.3.4 Non-profit Effectiveness

The literature on non-profit effectiveness, comprehensively reviewed by Forbes (1998), Lecy et al. (2012) and Liket and Maas (2015), generally presents effectiveness in terms of three models (Forbes, 1998). The three models are the goal attainment model (Bernard, 1938; Price, 1972), the systems resource model (Georgopoulos and Tannenbaum, 1957; Yuchtman and Seashore, 1967), and the reputational model (Jobson and Schneck, 1982; Herman and Renz, 1997). Herman and Renz (1997, 1999) argued that most research has focused solely on the goal attainment model (cited in Liket and Maas, 2015:270-271). These three models are reflected in the categories of success identified in this research: Performance (goal attainment), Purse (systems resource) and Profile (reputation) discussed in Chapter 4.

Accepting that 'non-profit organizational effectiveness is a social construction' (Herman and Renz, 1999:107) 'created by the actions and interactions of stakeholders', understandings of success for Health Consumer Organisations and ways of measuring effectiveness (where they exist) will continue to change. 'Effectiveness is stakeholder judgment, formed and changed in an ongoing process of sense making and negotiation... the social construction of NPO effectiveness is not necessarily stable or complete.' (Herman and Renz, 1999:118). While their previous research showed stakeholder judgments of NPO effectiveness often differed (Herman and Renz, 1997b), Herman and Renz (1998) 'found consistent judgments of effectiveness much more common among those NPOs that all stakeholder groups agreed were highly effective (1999:119). They also found that 'stakeholders are more agreed about what high performing NPOs are than about what middling or poor performers are' (1999:119).

Herman and Renz (2004) assert that 'the social construction of non-profit organizational effectiveness is not necessarily stable, (and) nor is it inevitable that constituencies will differ in their judgments' (2004:696). 'The social processes resulting in judgments of non-profit organizational effectiveness may lead different constituencies to develop the same criteria and to evaluate the information relevant to those criteria in the same way.' (Herman and Renz, 2004:696).

In their study of 64 non-profit organisations, Herman and Renz (1998) found the following indicators of effectiveness or success: a mission statement, a recent needs assessment, a planning document (Clarity); a measurement of client satisfaction, a formal CEO and employee appraisal process (Performance), an independent financial audit (Purse), and a statement of organizational effectiveness criteria (Clarity). In addition, they found that the more effective organizations more often employ strategies of seeking new revenues (Purse) and strategies to enhance legitimacy (Profile) (Herman and Renz, 1999:118). Measures proposed by Paton and Foot (1997) and Baruch and Ramalho (2006), and indicators identified by Herman and Renz (1999) are closely aligned to the concepts of success and its enablers as identified in this study. Paton and Foot's (1997) measures include short term and long-term performance of each activity/program (Performance), financial and management soundness (Purse), renewal or decline and the impact of organizational development initiatives (Capital) (Herman and Renz, 1999:111).

Baruch and Ramalho (2006) also found that studies of NPOs reported the use of both ‘nonfinancial criteria (for example, employee satisfaction, customer orientation, quality, and public image)’ and financial criteria with efficiency (conceived as an input-output ratio), stated as the most common measure (Herman and Renz, 2008:401). Arguing for a multiple-constituency (stakeholder) approach to effectiveness, Herman and Renz (1997, 1999, 2004) suggested measuring ‘responsiveness’ (to the needs and expectations of current and potential stakeholders) (1999:123), later defining ‘best practice’ as ‘regular and effective communication in a variety of ways with significant stakeholders. The critical interest is to engage in ongoing dialogue with those constituencies whose judgments of the organization’s effectiveness are likely to be important to the organization.’ (Herman and Renz, 2004:702).

Referring to the salience and utility of specific stakeholders Herman and Renz (2004) noted, ‘unlike in baseball, there is no single umpire in NPOs. All stakeholders are permitted to “call” effectiveness; some stakeholders will be more credible than others, and some will be more influential than others’ (2008:404). Citing research by Balser and McClusky (2005) supporting the importance of managing stakeholder relations, Herman and Renz (2008) suggested it is also important ‘to respond to and honestly challenge or debate (stakeholder) expectations’ when appropriate (Herman and Renz, 2008:410).

A summary of stakeholders of non-profit organisations is outlined in Table 2.1 based on the work of Van Puyvelde et al (2012).

Table 2.1 Stakeholders of a Non-profit Organization (Van Puvelde et al, 2012)

Stakeholder type	Description
Interface stakeholders	
Board members	The board of directors is the governing body of the non-profit organization. It represents the organization to the outside world and makes sure that the organization carries out its mission (Anheier, 2005).
Internal stakeholders	
Managers	Management of the non-profit organization
Employees	Other paid staff of the non-profit organization
Operational volunteers	Volunteers who are directly involved in the provision of goods and services offered by the non-profit organization
External stakeholders	
Funders	Individuals or organizations that donate to the non-profit organization and governments or government agencies that give subsidies to the organization
Beneficiaries	Consumers, clients, or members of the non-profit organization
Suppliers/contractors	For-profit, non-profit, or governmental organizations that provide goods or services to the non-profit organization
Competitors	For-profit, non-profit, or governmental organizations that compete with the non-profit organization in the same market or industry.
Organizational partners	For-profit, non-profit, or governmental organizations that collaborate with the non-profit organization
Others	Other external stakeholders such as the media, community groups, and persons or groups who are affected by externalities produced by the non-profit organization

Herman and Renz (2008) assert the importance of inter-organisational networks and network effectiveness to the effectiveness of individual organisations, urging for more research into the relationship between network effectiveness, NPO effectiveness and sustainability. 'As more NPOs collaborate to deliver services through networks of service delivery, network characteristics and effectiveness will become increasingly important to understand for their relationship to organizational effectiveness' (Herman and Renz, 2008:409). HCO network effectiveness was not addressed in this research presents an opportunity for further study.

The next section explores what Health Consumer Organisations (HCOs) do, describing their mission in three primary focus areas: Care, Connect and Cure. It also identifies potential stakeholders who might share an interest in their work. Detailed examination of 'health identities' was beyond the scope of this research but this section does briefly acknowledge the range of health identities from patient to health activist, by further defining participating HCOs in relation to location along the continuum of health identity practices.

Comments from interviewees begin to appear from Chapter 2 and have been coded to protect the identity of the interviewee and the HCO. HCO and interviewee codes are summarised in Table 3.2 included in Chapter 3.

2.4 Health Consumer Organisations

'I've never heard the term health consumer organisation.
I've always heard of them as support groups, patient support groups
or support organisations.
Health consumer organisations is probably a better term
for the world we live in, and political correctness' (A2)

2.4.1 What are health consumer organisations and why do they exist?

As A2 notes, the expression 'patient support group' may be more common to some than 'health consumer group' but 'health consumer group' and 'consumer health group' have gained currency in Australia since the Consumers Health Forum was started in the late 1980s with Federal Government funding in the 1986/1987 budget.. For the purposes of this research, Health Consumer Organisations are defined as organisations formed to support individuals with specific medical conditions and/or their families and carers, through education, service delivery and advocacy. In the interest of brevity, the acronym 'HCO' is used throughout this thesis.

In seeking to develop an understanding of success for Health Consumer Organisations from the perspectives of multiple stakeholders, it is important to examine what is meant by 'Health Consumer'. In this research, the term 'health consumer' refers to individual members of the organisations studied, their carers and others seeking information and support, when confronted with a specific condition affecting their health. Emergence of the notion of 'health consumer' has coincided with perceived shifts in the locus of power in relationships between doctor, patient and other stakeholders across the broader health and medical environment and changes in medical marketing which are discussed later in Section 2.5

A substantial body of research literature on contested 'health identities' and health social movements exists, but detailed explorations of contested 'health identities' and health social movements were considered beyond the scope of this research, which was limited to groups identifying themselves as 'health consumer organisations' in Australia and which were recognised by their stakeholders as such.

While the field of medical sociology provided a rich source of background information on the development of health identities and health social movements, it became clear that a gap exists in researching ‘the inner structure, resources and functioning of (patient organisations)’ across health movement research, medical sociology and organisation studies (Huyard, 2009:980). This research contributes to narrowing that gap.

2.4.2 Health Consumer, Patient, Expert Patient, Advocate, Activist?

“We prefer to use the term ‘consumers’ rather than ‘patients’. There are a few reasons behind this. A ‘consumer’ tends to choose and get involved in decision making whereas traditionally a ‘patient’ tends to be a person who receives care without necessarily taking part in decision making. Also the term ‘consumers’ includes carers who often have an important role in health care decision making and care giving.”
HealthConsumersNSW downloaded 2/11/15

A continuum of meanings exists for ‘health consumer’. Bastian (1998) supported the adoption of a broad meaning for the notion of health consumer, one which encompasses ‘scientific approaches (consumers as subjects of research); market solutions (consumers as informed users of goods and services); legal approaches (consumers as citizens with rights); and democratic participation (consumers as equal partners and citizens)’ (1998: 4). Hess (2004) referring to ‘the rise of disease-oriented HSMs’ (health social movements), noted the ‘death of the patient’ in the original, etymological sense of the term ‘patient’ as someone who endures... to knowledge-challenging activist” (2004:697). Zoller (2005) drew a distinction between health activist and health advocate when she defined health activism (and by default health activist) as ‘a challenge to existing orders and power relationships that are perceived to influence negatively some aspects of health or impede health promotion. Activism involves attempts to change the status quo, including social norms, embedded practices, policies, and power relationships’ (2005:359), whereas health advocacy operates ’within the existing system and biomedical model, usually with a focus on education’ (Brown et al, 2004), (2005:359). Health social movements were defined as ‘collective challenges to health policy and politics, belief systems, research, and practice, which may include numerous formal and information organizations and networks that develop over time with ongoing action, often organised from the bottom up’ (Zoller, 2005:360).

Acknowledging the work of Charmaz (1983), Herzlich and Pierret (1986) and Baszanger (1992), Fox and Ward (2006) examined 'ways in which health (a socially constructed phenomenon), the body (an entity that is both physical and social in character), and identity (the emergent, always 'becoming other' reflexive sense of self), flow together in the practices of individuals and groups' (2006:462).

Citing descriptions of patient/consumers as 'resourceful' (Muir Gray and Rutter, 2002), 'autonomous' (Coulter, 2002) or 'involved' (Hjortdahl, 2004), Fox and Ward (2006) suggested 'a continuum of identity practices, from a relatively medicalized 'expert patient' to an independent consumer of health information and products, often constructing notions of health and illness in contrast to a biomedical or professional perspective' (2006:464). HCOs participating in this research are located more towards the 'expert patient' end rather than the activist (Zoller, 2005) end of Fox and Ward's (2006) continuum of identity practices.

As stated earlier, until relatively recently Health Consumer Organisations were named 'Patient Support Groups' and this term continues to be commonly used within both the medical and general communities. Williams (1970) used the term 'health consumer' in his presentation of a potted history of voluntary health movements in the USA. 'While these organizations are commonly thought of a citizens' movements or campaigns, and while they frequently involve a great deal of lay participation and involvement, and usually depend for their success on this characteristic of mass appeal and support, the original inspiration, initiative, and leadership has tended to come from physicians. In other words, the germination is not directly and primarily that of consumer demand; rather it constitutes professional recognition of a need and then mobilisation of support' (1970:534).

Over the past decade, Health Consumer Organisations have become recognised as belonging to a new social movement, the health consumer movement (Allsop et al, 2004). Originating from within the broader consumer social movement, health advocacy and activism are increasingly researched in their own rights, especially within the fields of medical sociology and the sociology of health and illness.

Key contributors to the study of health social movements, and to the sociology of health and illness include Bastian (1998), Rabeharisoa (2003, 2006), Rabeharisoa and O'Donovan (2014), Allsop et al (2004), Brown and Zavestoski (2004), Brown et al (2004, 2011), Brown (2013), Archibald (2008), Baggott and Foster (2008), Baggott and Jones (2011), Borkman and Munn-Giddings (2008) and Huyard (2009).

The breadth of social and political action evident in a single condition social movement was illustrated by Klawiter (1999) in her description of different 'cultures of action' (Klawiter, 1999:106), adopted by three separate grass roots organisations involved in Breast Cancer activism in one specific geographical area. The three different foci for action respectively adopted by 'Race for the Cure', 'Women and Cancer Walk' and 'Toxic Tour of the Cancer Industry' were to promote 'biomedical research and early detection', to 'promote social services and treatment', and to advocate for corporate regulation and cancer prevention (Klawiter, 1999:104). The third 'culture of action', advocating for regulation and prevention, is also represented in community-based participatory research (CBPR) coalitions, active in the Asthma community working in the area of social and environmental justice (Keirns, 2009:S244).

Indicative of the types of changes patient organisations have been able to effect, are changes to diagnostic labelling. Jason (2012) cited two advocacy campaigns that changed the way the medical community viewed and named specific conditions. Multiple Sclerosis (MS) was previously known as hysterical paralysis, a term used to 'discredit the legitimate medical complaint of predominately female patients', until action by the Chronic Fatigue Syndrome (CFS) advocacy movement resulted in the condition being renamed the more scientific Myalgic Encephalopathy (ME). (2012:310). To some extent these 'cultures of action' are reflected as the primary purposes of HCOs participating in this research, illustrated in Figure 2.3.

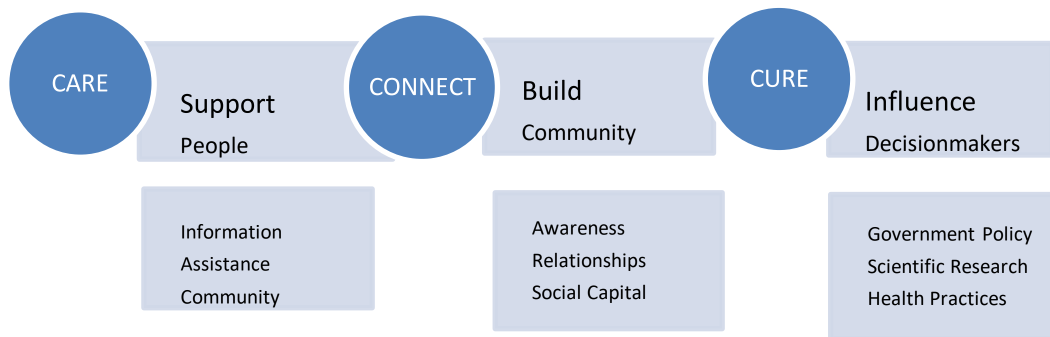


Figure 2.3 HCO Missions

2.4.3 Influencing Decision-makers

Rabeharisoa (2003) characterised patient associations in terms of their engagement with research, naming two types of patient organisations as either ‘auxiliary’ or ‘emancipatory’, depending on their role in advocating for, initiating or simply supporting research activities. The EPOK (European Patient Organisations in Knowledge Society) Study (Rabeharisoa et al, 2012) examined the emerging role of patient organisations, representing four conditions across four countries, in knowledge production and research related activities in a pan-European context.

Huyard (2009) categorised patient organisations according to stakeholder engagement specifically in relation to goal setting. The term ‘pluralistic’ was used for organisations in which a range of different stakeholders were engaged to achieve multiple shared goals (Care, Connect, Cure), and ‘monistic’ for organisations which were represented by a single category of stakeholder with a singular goal (Cure) (2009:980).

Brown and Fee (2014) documented the value of health social movements, identifying their origins in the early 1800s. Referring to the positive impact of three movements on urban living conditions, the health of children and the prevention of substance abuse, they urged public health workers and social activists to continue form alliances and to work together for advances in global population health concluding ‘there is real power, often for good, in social movements and collective political action’ (2014:395).

2.4.4 HCOs in Australia

Studies by Bastian (1984) and Baldry (1992) provide insights into the development of the Consumer Health Movement through their histories of the Consumer Health Forum. Lofgren (2004, 2011) explores the nature of relationships between the pharmaceutical industry and consumer organisations and Sav et al (2014) investigates reasons for individuals joining HCOs. Boyle et al's studies (2003, 2007, 2009, 2011), focus on referrals from general practitioners to HCOs, identifying the potential value to healthcare of more formally recognised HCO involvement in the self-management of chronic conditions.

Health Consumer Organisations across Australia vary in scope, size and structure ranging from very small groups representing and supporting individuals within a local community, to alliances representing smaller groups advocating on behalf of individuals with rarer conditions. In addition to single focus groups that focus on specific health conditions at state and national levels, peak organisations have been established to represent the interests of all health consumers at either state or national levels. The latter are sometimes set up by governments as vehicles for getting consumer input and feedback on issues affecting the health system. Examples include state based Health Consumers NSW, Health Consumers Queensland, Health Consumers Alliance of SA, Health Care Consumers Association ACT, Health Consumers Council in WA and the national Consumer Health Forum of which the various state peak bodies are also members. Members of these peak bodies include 'condition specific' groups, which in turn may be state based organisations, state based affiliates of federated organisations or national organisations. Groups such as the Genetic Alliance and Rare Voices Australia were formed to represent the interests of a number of smaller groups or as networks for sharing information and resources. Figure 2.4 illustrates the range of HCO types active in Australia.

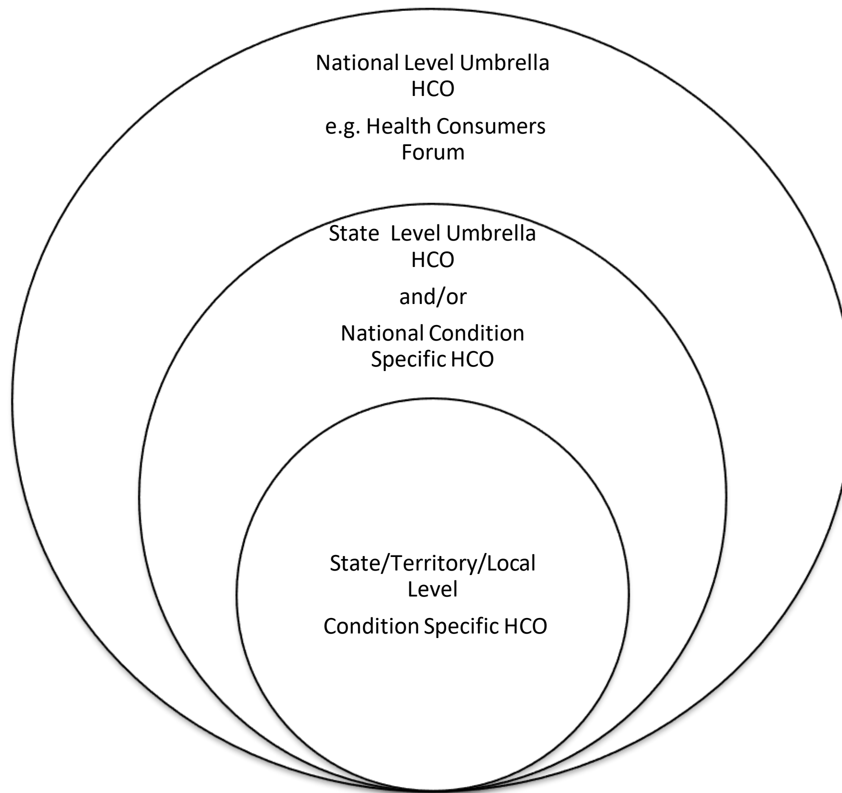
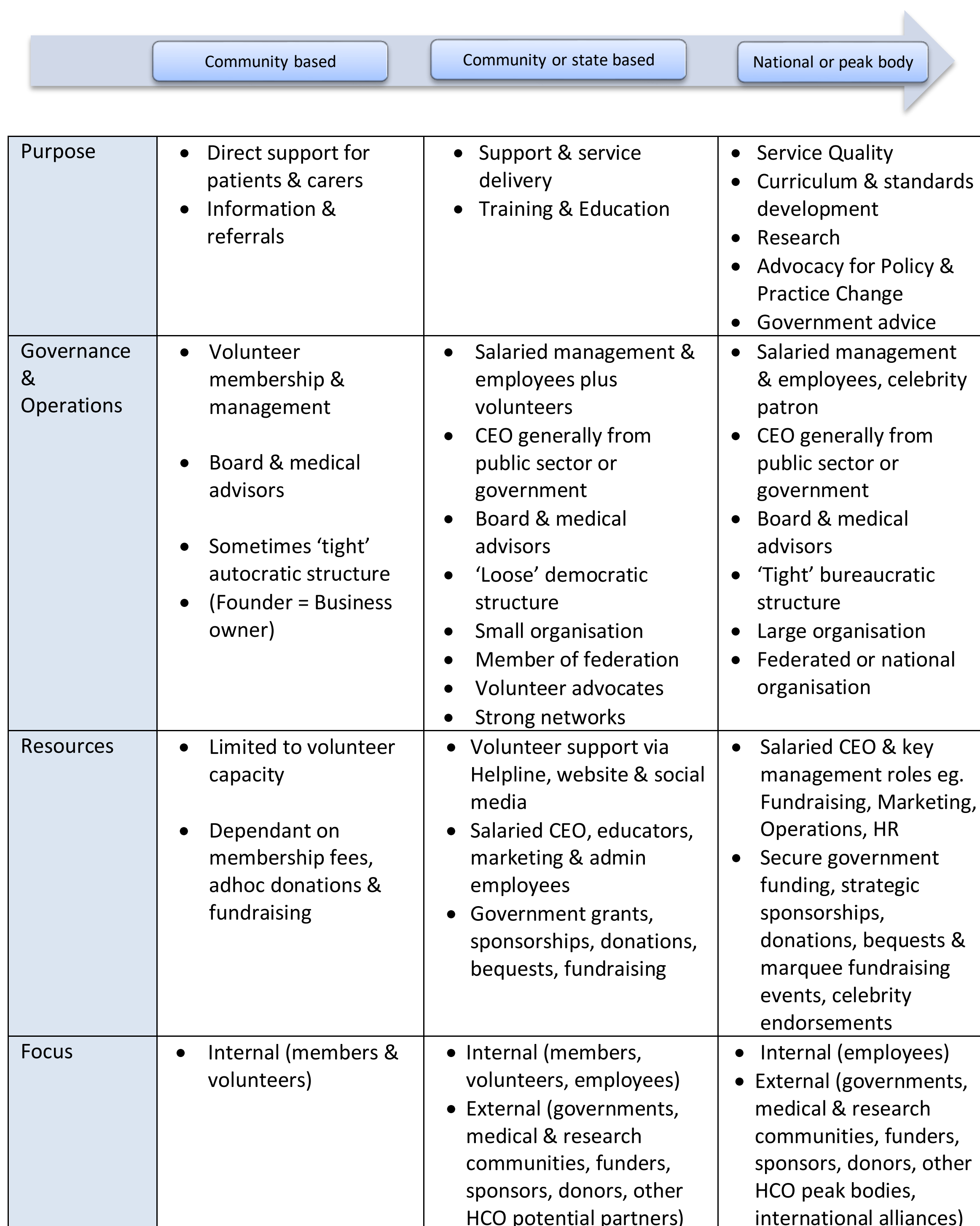


Figure 2.4 Types and scope of HCOs in Australia

HCOs may be completely volunteer run or operate with a mix of volunteers and paid employees. Volunteers usually have first-hand knowledge of the condition through their own personal experience or as the carer of someone else with the condition. Paid employees are recruited for specific roles, and selected on the basis of their professional expertise, as well as on their empathy for those dealing with the condition. Most HCOs have a board responsible for governance and/or a medical advisory committee providing advice on research and quality medical information for the members, as well as supporting HCO submissions to government and funding bodies. Features of HCOs operating at local community, state or national levels in Australia are illustrated in Table 2.2.

Table 2.2 Features of different types of Health Consumer Organisations



	Community based	Community or state based	National or peak body
Purpose	• Direct support for patients & carers • Information & referrals	• Support & service delivery • Training & Education	• Service Quality • Curriculum & standards development • Research • Advocacy for Policy & Practice Change • Government advice
Governance & Operations	• Volunteer membership & management • Board & medical advisors • Sometimes 'tight' autocratic structure • (Founder = Business owner)	• Salaried management & employees plus volunteers • CEO generally from public sector or government • Board & medical advisors • 'Loose' democratic structure • Small organisation • Member of federation • Volunteer advocates • Strong networks	• Salaried management & employees, celebrity patron • CEO generally from public sector or government • Board & medical advisors • 'Tight' bureaucratic structure • Large organisation • Federated or national organisation
Resources	• Limited to volunteer capacity • Dependant on membership fees, adhoc donations & fundraising	• Volunteer support via Helpline, website & social media • Salaried CEO, educators, marketing & admin employees • Government grants, sponsorships, donations, bequests, fundraising	• Salaried CEO & key management roles eg. Fundraising, Marketing, Operations, HR • Secure government funding, strategic sponsorships, donations, bequests & marquee fundraising events, celebrity endorsements
Focus	• Internal (members & volunteers)	• Internal (members, volunteers, employees) • External (governments, medical & research communities, funders, sponsors, donors, other HCO potential partners)	• Internal (employees) • External (governments, medical & research communities, funders, sponsors, donors, other HCO peak bodies, international alliances)

2.4.5 HCOs and the ACNC

All of the HCOs in this study are registered with the Australian Charities and Not-for-profit Commission (ACNC), the national charity regulator established by the Federal Government in 2012. Upon registering with the ACNC an organisation identifies its purpose and selects a subtype which may be changed if the purpose changes. Although the guidelines to selecting a subtype explicitly state a charity must actively pursue a specific subtype noted in its governing documents, there is considerable diversity in the subtypes selected by HCOs, making it difficult to determine the number of organisations that might fit the category of HCO as defined in this research.

The subtypes of greatest relevance are Advancing Health, Health Promotion Charities and Public Benevolent Institutions. Two of the HCOs in this study identified as a Health Promotion Charity (HPC), defined by the ACNC as 'a charitable institution whose principal activity is to promote the prevention or control of diseases in people'. While many of the activities that HCOs carry out are included in the ACNC description of HPCs, promotion activity must be the principal activity. (http://www.acnc.gov.au/ACNC/Pblctns/Factsheets/FS_HPC/ACNC/FTS/Fact_HPC.aspx?hkey=04556437-4357-4df8-bd13-79b946f8a264 downloaded 180716).

The other two HCOs identified themselves as a Public Benevolent Institution (PBI), defined by the ACNC as 'a type of charitable institution whose main purpose is to relieve suffering that is serious enough that it would arouse a feeling of pity or compassion in members of the community. Such suffering could be caused by conditions such as poverty, sickness, helplessness or distress'. (http://www.acnc.gov.au/ACNC/Pblctns/Factsheets/FS_PBI/ACNC/FTS/Fact_PBI.aspx?hkey=6a34688c-da31-4dc8-9424-50aac699aa21 downloaded 180716)

Three of the HCOs in this study listed Advancing Health as a subtype. ‘Advancing health includes preventing and relieving sickness, disease or human suffering’ and examples provided by the ACNC included associations, foundations and support groups for people with particular illnesses or diseases. The ACNC Registry showed multiple listings for the conditions represented by HCOs participating in this research with the exception of HCA where HCOA was the only organisation registered. 17 separate charities associated with HCOB were registered; 21 separate charities associated with HCC and 27 separate charities were registered for HCD were registered.

Of the 43,153 charities registered with the ACNC as at 18/07/16, 833 indicated ‘Advancing Health’ as their primary purpose and listed the general Australian public and people with chronic disease or terminal illness as their beneficiaries. These organisations employed 136, 845 staff and were assisted by an estimated volunteer cohort of 71,200. 85% had DGR (deductible gift recipient) status. The total annual income reported ($12.9 b AUD) was generated by 450 large to extra-large organisations, with none reported by the remaining 383 small to medium organisations in this category. ‘In general, larger Charities are more likely to be Companies or Incorporated Associations, be Public Benevolent Institutions or Charitable Institutions, and are more likely to have DGR status (70% for "Large" Charities up to 85% for XXL). Smaller Charities are more likely to be Unincorporated Associations; to be Charitable Institutions (84%) and NOT to have DGR status (67%)’.

A summary of the ACNC entries for HCOs participating in this research is included in Table 2.3.

Table 2.3. HCO by ACNC registry

ACNC Data \ HCO		HCOA	HCOB	HCOC	HCOD
Subtype	Public benevolent Institution		✓	✓	
	Advancing Health		✓	✓	✓
	Institution whose principal activity is to promote the prevention or the control of diseases in human beings (definition of HPC)	✓			✓
Beneficiaries	General community in Australia	✓	✓	✓	
	People with Chronic Illness	✓	✓	✓	✓
	Others	✓	✓	✓	✓
States	All	✓	✓	✓	✓
Size	S/M/L	S	L	L	L

2.4.6 The Consumer Health Forum

The Consumer Health Forum (CHF), the peak organisation in Australia, was established in 1987 with Federal Government funding as a 'forum, made up of representatives of community groups to advise the government on health issues affecting consumers'. (https://www.chf.org.au/history.php accessed 231015). It lists 108 member organisations of which 56 are voting members, 50 are organisational members, and 5 are corporate members. (https://www.chf.org.au/our-members.php accessed 231015). In 2010, CHF was registered as a not-for-profit company and the Governing Committee became the Board. Its current Strategic Plan (2015-2018) lists the following objectives:

1. Develop and promote consumer-centred health system policy and practice to governments, stakeholders, providers and clinicians.
2. Engage with the members of CHF to ensure collective consumer voices are involved in the co-design of health system changes and innovation.
3. Generate and harness existing evidence to shape and co-create consumer-centred health policy and practice.
4. Partner strategically to achieve a consumer-centred health system
5. Sustain and grow a member-driven, value based, reputable and well governed organisation.

Baldry's account of the history of the CHF (1992) listed 16 member organisations of the first General Committee, representing the broad range of social movements active in Australia at that time. Since broad representation of community and consumer groups was considered important for the forum to be successful, members included the Australian Consumers Association and the Australian Federation of Consumer Organisations, as well as groups with a more specific focus on health consumer issues such as the Health Issues Centre and the Australian Women's Health Network. (Smith, 1989 cited in Baldry, 1992).

Members of the original CHF Governing Committee represented a wide range of organisations. They included the National Aboriginal and Islander Health Organisation, the Victorian Mental Illness Awareness Council, the Australian Community Health Association, the Australian Council on Rehabilitation of the Disabled, the Collective of Self Help Groups and Disabled Peoples' International Australia, the Australian Conservation Foundation, the Australian Pensioners' Federation, the Federation of Ethnic Community Councils of Australia, the Youth Affairs Council of Australia, the Australian Council of Social Services, and the Australian Council on the Ageing (Baldry,1992:154).

Current CHF members include only three of the original member organisations: the Australian Council of Social Services, the Australian Council on the Ageing and the Health Issues Centre. Other member organisations representing broader community interests are the Association of Independent Retirees, the Association of Participating Service Users. (https://www.chf.org.au/our-members.php accessed18/07/16)
Member organisations also include a number of primary health networks, professional associations representing allied health services and industry (e.g. Medicines Australia) and corporate members mainly from the pharmaceutical industry.

Corporate members have been listed separately since 2004. Before then, they were listed along with other Associate members. Pfizer is the only pharmaceutical company listed since 2001, the year from which annual reports are published on CHF's website. Table 2.4 shows corporate members from 2010 - 2014.

Table 2.4. Corporate CHF members from 2010 - 2014

2014	2013	2012	2011	2010
GlaxoSmithKline	GlaxoSmithKline	GlaxoSmithKline	GlaxoSmithKline	GlaxoSmithKline
Janssen-Cilag P/L	Janssen-Cilag P/L	Janssen-Cilag P/L	Janssen-Cilag P/L	Janssen-Cilag P/L
Merck Sharpe & Dohme (Australia) P/L	Merck Sharpe & Dohme (Australia) P/L	Merck Sharpe & Dohme (Australia) P/L	Merck Sharpe & Dohme (Australia) P/L	Merck Sharpe & Dohme (Australia) P/L
Pfizer (Australia)	Pfizer (Australia)	Pfizer (Australia)	Pfizer (Australia)	Pfizer (Australia)
ROCHE Products P/L	ROCHE Products P/L	ROCHE Products P/L		
	Novartis Australia	Novartis Australia	Novartis Australia	Novartis Australia
	Bayer Australia Ltd	Bayer Australia Ltd		
		NPS Better Choices, Better Health		
			National Prescribing Service (NPS)	National Prescribing Service (NPS)

2.4.7 Who is interested in HCOs and why? (Stakeholders)

HCOs attract the interest of a number of stakeholders for different reasons and each has different stakes or claims on them. Primary stakeholders as the name suggests, are consumers, those individuals confronted by a condition affecting their physical or mental health who may seek information and/or advice from a HCO. In the absence of a support group, they may attempt to establish one with the intent of helping others.

Government stakeholders are interested in HCOs as sources of consumer input on policy and as providers of outsourced community services. Van de Bovenkamp and Trappenburg (2010) found substantial government influence on organizational structure, activities and ideology of HCOs in the Netherlands as a result of significant government funding (2010:329). In contrast, the relationship between HCOB and the Australian government was reported as unique.

> *'They were astonished about the government funding relationship with us'* (B2)

The relationship between medical practitioners and HCOs varies across practices and is, to some extent contingent on the profile of the HCO, which in turn depends on its credibility. Medical practices value evidence-based information provided by HCOs and some practitioners refer their patients to HCOs for support but as Boyle et al (2003) indicate, there is potentially a stronger role for HCOs working with general practitioners to support self-management for patients with chronic conditions. Fox and Ward (2006) suggest that the relationships between medical practitioners and patients will continue to evolve and be different from the 'active-passive', guidance-co-operation' and 'mutual negotiation' relationships identified by Szasz and Hollender (1956), since the notion of 'expert' patient is neither categorically defined nor universally accepted (Fox and Ward, 2006:463).

Business stakeholders may be motivated to sponsor HCOs to demonstrate 'corporate social responsibility' (CSR) however this is not the only reason for engaging with HCOs. According to Bastian (1987) *'the pursuit of consumer groups ... can be more than the usual legitimating role sought from many kinds of groups by a service or industry wanting a better, more selfless image ... indeed, it is common for players with the health care system to believe, and claim, that their interests and consumers' interests are the same'* (1998:7).

This is evident in the case of pharmaceutical companies interested in building relationships with HCOS when undertaking clinical trials in Australia or when submitting applications to the Therapeutic Goods Administration (TGA) to register a new drug for use in Australia or to the Pharmaceutical Benefits Advisory Committee (PBAC) to list a drug on the Pharmaceutical Benefits Scheme (PBS). Pharmaceutical companies also value these relationships as a channel for communicating with consumers where 'direct to consumer' advertising is restricted.

Herxheimer (2003) reported on links between the pharmaceutical industry and 'two prominent international federations, IAPO (International Alliance of Patients' Organisations) and GAMIAN Europe (Global Alliance of Mental Illness Advocacy)' (2003:1209). Noting the European Commission's preference to hold discussions with federations because of their claim to represent patients across different countries, he suggested the IAPO's claim to patient representation did not appear legitimate since it 'was founded and is funded by Pharmaceutical Partners for Better Healthcare, a consortium of about 30 major companies' (2003: 1209).

Established in 1994 and representing 250 member organizations in 67 countries and 47 disease areas (downloaded from https://www.iapo.org.uk/key-facts, 1/5/16), IAPO still receives most of its income from 'partnerships with pharmaceutical companies' (IAPO Annual Report, 2014:11). Its financial dependence on industry partners was strongly articulated when defending reserves of 6 - 12 months. 'IAPO is dependent on the corporate sector for the majority of its funding and the corporate sector itself is subject to market fluctuations, and to restructuring such as mergers, which may make funding more precarious' (2014:11). Interestingly the next sentence states 'this level of reserves also means that IAPO is free to refuse funding (from any organization) that might [comprise] (sic) IAPO's work or values' (2014:11).

EULAR (European League Against Rheumatism) another patient support organisation, lists 25 pharmaceutical companies as corporate members on their website at 29/4/16 and 36 of the 78 organisations listed in the PARE (People with Arthritis/Rheumatism in Europe) directory are also EULAR members. PARE websites reveal additional corporate sponsorship from some or all of the pharmaceutical companies listed as EULAR members.

Buckley (2004) in her discussion of marketing strategies employed by pharmaceutical companies, also highlighted business interest in health consumer organisations, as did Batt (2005) reporting on relationships between pharmaceutical companies and patient groups in Canada. Ball et al (2006) noted the potential for pharmaceutical companies to compromise the independence of patient organisations they fund (2006), citing several examples from the UK, Denmark and the Netherlands in relation to influencing governments to widen access to drugs. (Ball et al, 2006).

O'Donovan (2007) however cautioned against assuming an outright 'corporatisation of health activism' by pharmaceutical companies in Ireland, asserting that 'recognition must be given to the possibility that health advocacy organizations can both disturb orthodox understandings of health, illness and patienthood' while simultaneously contributing to 'the commodification of health activism' (2007: 730). The suggestion of 'a strong cultural tendency in Irish health advocacy organizations to frame pharmaceutical corporations as their friends and allies in their quests for better health' (2007:728), is likely to be not limited to Irish organisations.

Australian research (Hall, Jones and Iverson, 2011) into consumer perceptions of sponsors of disease awareness advertising reported that pharmaceutical companies collaborate with HCOs on ‘condition branding’ (Moynihan and Cassels, 2005; Fox et al, 2006 and ‘Disease Awareness Advertising’ (DAA) (Hall et al, 2011), sponsoring activities where they have a related pharmaceutical product. While there is ‘evidence that DAA increase prescriptions and sales’ (Basara, 1996; t’Jong et al., 2004) (2011:7-8), Hall, Jones and Iverson (2011) noted that there is also ‘growing scepticism regarding pharmaceutical industry influence over health NPOs (Angell, 2006; Jacobson, 2005; Moynihan and Cassels, 2005)’ and cautioned that joint promotions might be negatively viewed (2011:7-8).

Given the considerable resource restraints on HCOs in Australia, corporate sponsors represent a valuable source of funding support. How the relationship between business and the HCO is managed and more importantly perceived, by other stakeholders is critical to its Profile. Researchers and research organisations are also interested in HCOs not only as a source of study participants and project collaborators, but also as potential competitors for research funds.

Each stakeholder has their own view of HCO success and each has an interest in measuring HCO effectiveness in terms of their own interests.

2.5 20th Century medicines marketing practices (1900-2015)

This section firstly presents a historical overview of developments within the pharmaceutical industry in order to provide background for understanding (i) the interests of pharmaceutical and biotechnology companies as HCO stakeholders, and (ii) shifts in marketing practices adopted to support different stakeholder relationships.

2.5.1 Key milestones and stakeholders

The changing nature of healthcare stakeholder relationships is contingent on the development of the global medical and pharmaceutical industries. While differences in the global industry are evident in distinct cultural settings, marketing practices are more closely aligned between developed markets such as USA, Europe and the UK, than with 'developing markets' as in Russia, India and China. The Australian industry is strongly aligned with the industry in the USA, Europe and the UK. This is reflected in the membership of Medicines Australia, the peak organisation representing the interests of the pharmaceutical industry in this country. Of the 34 'Class 1' member companies in 2015, 16 were of European heritage, 8 were of USA heritage, 3 were of USA/European heritage, 2 were of British heritage, 1 was of British/European heritage, 1 was Australian/European heritage and 3 were Japanese.(accessed from MA website 021115). For this reason, discussion of modern marketing practices is limited to practices deployed in developed markets.

Histories of the modern medical industry generally start with the 1938 Federal Food, Drug and Cosmetic Act in the USA and outline legislative and economic changes over the next five decades. Written by economists and political scientists they are highly instructive in developing an understanding of the recent past. Historian Nancy Tomes (2001) nominated the late 19th century as the starting point for the modern industry as it was around the 1880s when the medical profession sought to improve 'its competitive position vis-a-vis alternative healers by aligning itself with laboratory science, reforming medical schools, and lobbying effectively with state legislators' (2001: 524).

Temin (1979) took the 1938 Federal Food, Drug and Cosmetic Act, as the reference point for contrasting the pre-World War II and post-war industry, describing the impact of the passage of the 1938 Federal Food, Drug, and Cosmetic Act on the American industry, its structure and marketing practices.

Before 1938, drugs could be and were for the most part, purchased in the US without prescriptions, and companies did not advertise to doctors. After 1938 new drugs required pre-registration with the FDA and a new requirement around labelling information 'created for the first time a distinction between over-the-counter drugs (which had detailed labels) and prescription drugs (which had limited labels and could not be sold except by a doctor's prescription).' (Temin, 1979: 434)

The 1938 Act created a unique feature of this industry, known as the trilogy (Ferrandiz, 2001:1). The trilogy refers to the three main players within the industry: the prescriber, the government (in the Australian context) or insurer (in the US context) and the consumer or patient. The uniqueness of the trilogy lies in the roles of each and the relationship between them. The prescriber, the one who decides, neither pays nor consumes; the government or insurer, the one who pays neither decides nor consumes; and the patient, the one who consumes, neither pays nor decides (Ferrandiz, 2001:1). The new regulations changed the way prescription or ethical drugs were marketed, resulting in a shift to prescribers being identified as the 'customers', rather than the patients or consumers.

Temin (1979) identified the 1950s as the period in which the American pharmaceutical industry was transformed into its (current) modern configuration, described by Conrad and Leiter (2004) as 'mediated markets' where ' there is an indirect relationship between consumers, on the demand side, and medical producers or providers, on the supply side, with third party payers occupying an intervening role. Third party payers ... intervene in the exchange relationship between consumers and providers or producers in two ways: by defining what is "medically necessary" and then paying for only those goods and services that they have deemed medically necessary' (2004:161). In the Australian context, Third Party Payers are government gatekeepers including the Therapeutic Good Administration (TGA), which regulates and approves drugs for sale in the Australian market, the Pharmaceutical Benefits Advisory Committee (PBAC), which approves drug listings on the Pharmaceutical Benefits Schedule (PBS) and Medicare, which authorises government subsidies for medical treatments and diagnostic tests.

Following the 1938 Federal Food, Drug and Cosmetic Act the next significant piece of legislation was the 1962 Kefauver-Harris Drug Amendment, which called for Food and Drug Administration (FDA) regulation of prescription drug advertisements.

This legislation, requiring advertisements to outline side effects, contraindications and effectiveness, essentially limited promotions to print media, given the difficulties in presenting such details in broadcasts. Tomes (2001) suggested that the rise of the consumer culture in the USA in the early 20th century was as evident in healthcare consumption as it was in the consumption of other promoted goods. 'Americans sought not only "health in a bottle," through expenditures on over-the-counter drugs, but also "health-in-a-book," through avid consumption of health advice'.

At the same time, 'print media and later radio began to cover health issues more widely; they also became increasingly dependent on revenue from health-related advertising, which constituted its own powerful form of commercialized advice.' (2001:531). Through her examination of two critical ideas namely the 'patient-as-consumer' and 'medical exceptionalism', a concept raised by economist Kenneth Arrow, Tomes (2001) provided a rich insight into the parallel development of modern medicine and consumerism. Arrow (2001) maintained 'the behaviour expected of sellers of medical care is different from that of business men in general' because they are 'governed by a concern for the customer's welfare which would not be expected of a salesman' (cited in Tomes 2001:525).

Starr (1982) notes that as the market took shape key questions arose. 'What sort of a commodity is medical care? Do doctors sell goods (such as drugs), advice, time or availability?' (Starr, 1982:22). As Tomes put it 'neither patients nor doctors behaved as "normal" consumers and suppliers did. From the patient side, illnesses were usually unexpected and potentially life-threatening, diminishing the chance to shop for care; patients also lacked the information and expertise to compare doctors or balance treatment against price (what economists refer to as the "shopping problem" and the "information problem")' (Tomes 2001:525).

The impact of the Kefauver-Harris Drug Amendment was lessened dramatically with the introduction of the FDA's 1999 *Guidance for Industry on Consumer-Directed Broadcast Advertisements.* This enabled companies to provide more product information through toll-free numbers and the Internet, resulting in an increase in overall advertising spend and greater investment in Direct to Consumer (DTC) television advertising.

According to Conrad and Leiter (2004), 'annual spending on direct-to-consumer advertising for prescription drugs tripled between 1996 and 2000 [and is] by far the fastest rising segment. Much of this increase has been in television advertising after the Federal Drug Administration Modernization Act of 1997 made it easier to advertise drugs to the general public (Lyles 2002). This change allowed broadcast ads to name both the disorder and the drug so long as they also contain limited risk and benefit information, making television drug advertising more feasible and more attractive to the pharmaceutical industry. Spending specifically on television advertising increased six-fold between 1996 and 2000, to $1.5 billion dollars (Rosenthal et al. 2002)' (Conrad and Leiter, 2004:161).

According to Bonaccorso and Sturchio (2002) and Lyles (2002), pharmaceutical companies claim that direct-to-consumer advertising enables patients to make better choices, because they are better informed (Conrad and Leiter, 2004:161). However research conducted on content analyses of television ads for prescription drugs indicated that the educational value of these ads was limited while emotional appeal was widespread (evident in 95% of ads). 'Television ads were often ambiguous about whether viewers might legitimately need the product. They offered limited information about risk factors, prevalence of the condition, or the subpopulations at greatest risk. By ambiguously defining who might need or benefit from the products, DTCA implicitly focuses on convincing people that they may be at risk for a wide array of health conditions that product consumption might ameliorate, rather than providing education about who may truly benefit from treatment'. (Frosch et al, 2007: 9 -10)

Ta and Frosch (2008) cited several studies which demonstrated that as a result of patients seeing drug advertisements 'discussions (with their) physicians are altered and that patients who see drug advertisements often discuss and request these brands (Lyles 2002; Wilkes, Bell, and Kravitz 2000)' (Ta and Frosch, 2008:100). According to Daubresse et al (2015) there is 'a preponderance of evidence' that DTC advertising increases consumer demand (Vogel et al, 2003), as well as physician diagnoses, the number of prescriptions and prescription sales (Zachry et al, 2002; Penson et al, 2006; Basara, 1996; NIHCM Foundation, 2000) (Daubresse et al, 2015:44). Increases in pharmaceutical sales were quantified in a Kaiser Family Foundation study in 2003 which found that in the year 2000, every one dollar spent on DTC advertising yielded an additional $4.20 in additional pharmaceutical sales in that same year. (The Henry J. Kaiser Family Foundation, 2003, cited in Ta and Frosch, 2008:98).

In their study on the impact of DTC on sales of four asthma drugs from 2005 - 2009, Daubresse et al (2015), found 'each additional televised advertisement was associated with 2% higher rate of prescriptions dispensed within the population of interest during the study period. (2015:42).

Although Direct to Consumer Advertising of prescription medicines is not allowed in Australia, a number of pharmaceutical marketing practices targeting consumers directly are evident. Several Australian studies (Miller & Waller, 2004; Vatjanapukka 2004; Hall, 2010, Hall & Jones 2007, Hall, Jones & Iverson 2011) have contributed to our understanding of these promotional practices and there is evidence that pathology and diagnostic companies are also engaging 'directly' with consumers in Australia through public awareness campaigns such as 'Know Pathology'.

Disease awareness advertising (DAA) has become commonplace (Hall 2007, Hall, Jones and Iverson, 2011) and 'while manufacturers refer to these advertisements as 'disease education' they can reasonably be considered 'de facto DTCA' (Vitry 2009).' (Doran and Lofgren, 2013:25). Hall et al (2010, citing Angelmar et al, 2007), suggest pharmaceutical companies use DAA as a form of promotion in 'condition branding'. They note that 'condition branding' is 'considered by some as socially responsible action for the pharmaceutical industry that aims to generate awareness of a disease or condition in order to improve its recognition and treatment'. Consumers International (2006) and Hall and Jones (2008b) see DAA as a strategy 'to increase brand share for products and the total number of prescriptions (Hall et al, 2011:7). Hall et al (2011) conclude that DAA is 'particularly effective for brands where a company has the only treatment for that condition or a large market share (Angelmar et al, 2007)' (2011:7). In their study of consumer perceptions of sponsors of disease awareness advertising, Hall et al (2011) found 'it is possible that participants felt less positive attitudes towards pharmaceutical companies because there was no acknowledgement of the benefit to the companies. In DAA, pharmaceutical companies do not disclose their commercial intent to sell prescription medicine products, and often position advertisements as "community service announcements" (Medicines Australia, 2006). Recent research indicates that consumers can become sceptical of corporate societal marketing if the consumer perceives that the advertiser is deceiving them as to the commercial or other benefits accrued by the corporation in undertaking the marketing activity (Forehand and Grier, 2003).' (Hall et al, 2011:15)

2.5.2 Changing roles: Medical Authority vs the informed patient

Starr described medical authority as 'a resource for social order' (1982:15), and identified the 'emergence of a market for medical services (as) originally inseparable from the emergence of professional authority'. He suggested that the transformation of medical care from an obligation filled by family, social network or community to 'the conversion of healthcare into a commodity' was 'one of the underlying movements in the transformation of medicine' (1982:22).

This 'professional dominance' gave medicine 'the jurisdiction over virtually anything to which the label 'health' or 'illness' could be attached' (Conrad, 1992:214 citing Freidson, 1970:251). Tomes (2001), citing a long list of medical historians including Starr (1989), Brown (1979) and Burrow (1977), also acknowledged this professional dominance, referring to the years between 1920s and 1960s as 'the "golden age" of American medicine, due to rising physician incomes and respectability and organized medicine's strength as a political lobby'. (2001: 524).

2.5.3 20th Century Marketing practices - medicines and health

Until recently marketing practices of western pharmaceutical companies have mostly reflected their view that doctors are the most powerful members of the healthcare 'trilogy' (Ferrandiz, 2001:1) of patients, payers and prescribers. Perceived changes in the respective power of each member of the 'trilogy' has influenced how pharmaceutical companies introduce and market their products over the past two decades.

Face-to-face product detailing by sales representatives, advertisements in medical journals, and sponsorships of medical conferences and educational events are some of the promotional activities still used by the industry. In the past, sales representatives offered product reminders such as pens, sample packs, and other more substantial rewards in the form of travel and conference subsidies or generous hospitality at educational events, as inducements for brand loyalty. Product reminders are no longer allowed in Australia, and the Australian Competition and Consumer Commission (ACCC) requires pharmaceutical companies to publicly report expenditure on sponsorship for medical practitioners and health consumer organisations, via the Medicines Australia website.

The notion of 'informed patient' was identified as one of the most significant factors driving change in the pharmaceutical industry (Therriault, 2007) with the IMS Health Forecast Report suggesting 'in this market environment, building relationships directly with patients as they become better educated and take a more active role in their own healthcare … is essential'. As Illert and Emmerich (2008) illustrated in Figure 2.5 'direct-to-consumer' advertising accompanied the rise of the notion of 'the informed patient' and a shift in power from physician to patient and payer. (2008:25).

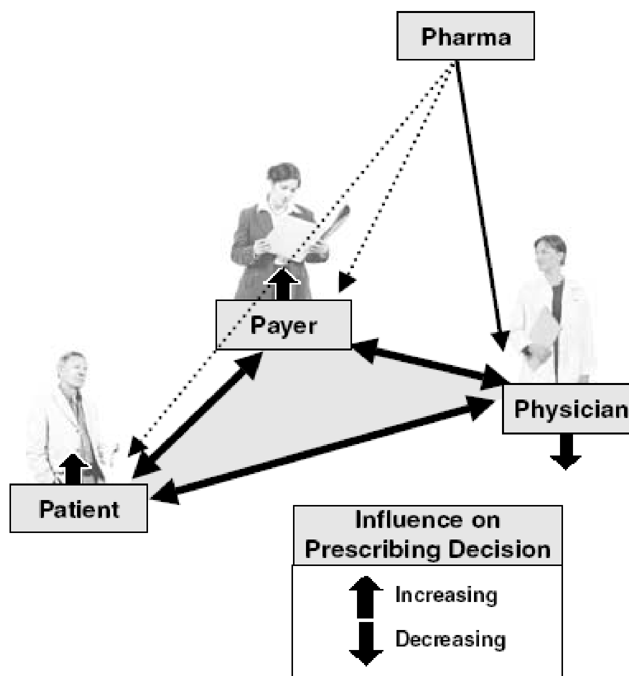


Figure 2.5 Key players' relationships within healthcare (Illert and Emmerich, 2008:25)

Illert and Emmerich (2008) suggested that pharmaceutical companies should focus more on the needs of payers *and patients* (my italics), in light of their increased interest and involvement in health outcomes. They highlighted the need for companies to market and promote their products differently in light of the changing environment, and described several initiatives to illustrate the practical application of their theory.

Their ‘patient management concept’ developed for an international company, aligned activities and services to address specific needs of patients at different phases of a disease, thus creating and ensuring on-going demand for their products.

In her overview of “push’ and ‘pull’ pharmaceutical marketing practices, Buckley (2004) identified ‘Direct to Consumer Advertising’ (DTCA), and the building of relationships with patient support groups, as two examples of ‘Pull’ strategies.

Buckley maintained there was a greater need for regulation around the ‘Push’ strategy and activities than around Pull activities, agreeing with Maguire (1999) that ‘despite the boom in consumer ads, doctors are still king’ (Maguire 1999, cited in Buckley 2004:96). Buckley’s view is not supported by research undertaken between 2000 and 2002 by Alt and Puschmann (2005). Their study of nine international pharmaceutical companies over the two-year study period, identified a need for more attention to patients and payers, rather than prescribers. They suggested a redesign of pharmaceutical business processes and developed a methodology for re-engineering customer relationships within the industry.

Alt and Puschmann’s (2005) recommendations to re-engineer customer relationships were reinforced by Sachs et al (2010) who developed a process based on the ‘stakeholder view’ (Post et al, 2002) to ‘tap stakeholder potential’ (2010:149). ‘The ‘Stakeholder View’ relates to a firm’s interactions with its stakeholders. It emphasizes the fact that the linkages between the corporation and its multiple stakeholders are important vehicles for creating, sustaining, and enhancing the corporation’s wealth-creating capacity (Sveiby, 1997)’ (Sachs et al, 2010:149).

Sachs et al’s ‘Stakeholder View’ process provides a framework for understanding the differences and similarities between its own and its stakeholders’ perceptions (Wartick and Mahon, 1994) (2010:149), recognising the need for a firm to be aware ‘the many actors’ in the value creation process, and of their interrelatedness in the stakeholder network (2010:152).

2.5.4 Individualised healthcare

Advances in individualised healthcare enabling industry to 'identify predispositions for major diseases … based upon a combination of genetic and environmental risk factors' (Humer, 2004:108) are now coming to fruition and as a result we are beginning to see major changes in the way treatments are targeted to individuals as illustrated in Figure 2.6. These changes will influence the way that companies market their products to consumers.

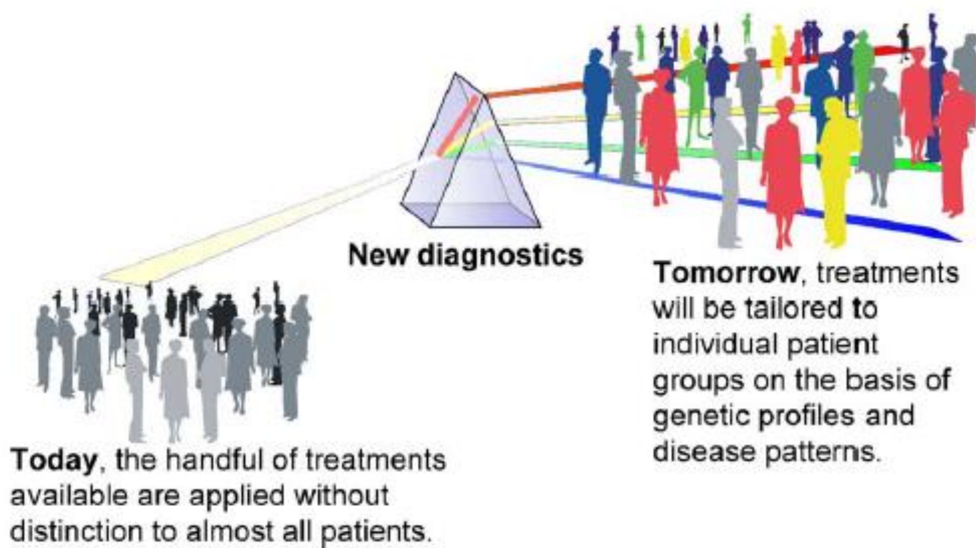


Figure 2.6 Towards individualized healthcare (Humer, 2004:108)

Companies are now refocusing their marketing strategy to account for both the new locus of power, and the advent of individualised medicine. Their support of Health Consumer Organisations is one example of the shift in marketing strategy. Another is the use of Social Marketing. Domegan (2008) cited exploratory case studies of science-society programmes aimed at the general public, and established to drive knowledge-based society. The case of PharmaChemical Ireland (represented by an umbrella non-profit organisation) shows how pharmaceutical companies are extending their marketing activities from their traditional focus on products into new ventures promoting science and the industry.

2.5.5 The modern pharmaceutical industry

An understanding of today's global pharmaceutical industry provides the foundation for addressing questions related to the future marketing and supply of drugs. In an assessment of changing market dynamics Floyd (2008), drawing on Porter (1990) and Dunning (1993), identified the following key drivers for change within the industry:

(i) increased demand for healthcare products from ageing populations (not only in the US and Western Europe but also in Japan, Hong Kong & eventually China);

(ii) political factors encouraging new entrants to the market to reduce costs;

(iii) improvements in technology & communication enabling globalisation of the industry;

(iv) alliances, mergers and acquisitions to enhance research and development capability.

The modern pharmaceutical industry is renowned for its high profitability with a reported average return on equity of 18.4% for the 30 year period between 1960 and 1991, compared to 11.9% across other industries (Scherer, 1993:98). However, this level of profitability is debated. Scherer maintains that these returns are overstated because of the way that research and development, and new product marketing costs are accounted for as current year expenses, rather than capital. 'Under standard accounting practice, R&D and new product marketing outlays both of which are atypically high in pharmaceuticals, are written off as current expenses. Since both, and especially R&D, affect revenues for many years to come, it would be more accurate in principle to capitalize the outlays and then depreciate them over appropriate time periods. Otherwise, the rate of return on "investment" is calculated using an asset base that improperly excludes accumulated intangible R&D and marketing capital. Accounting figures tend to overstate the true rate of return on investment under these conditions. Most studies attempting to correct for this accounting bias have reached the same conclusion: reported drug company returns on stockholders' equity are overstated (for example, Helms, 1975, Part Two; U.S. Office of Technology Assessment, 1993, pp. 96-103)' (Scherer, 1993:104).

The pharmaceutical supply chain is complex and highly regulated. The drug development process is lengthy and expensive. It takes 10-12 years typically to bring a new drug to market and in general, companies have approximately 3-5 years to maximise financial gain from the new drug before a patent expires and generic competition enters the market.

In addition to the direct costs associated with the development of the drug, the costs of bringing a new drug to market include costs of clinical trials, opportunity costs associated with financial resources committed to the development process not being available to invest, and the costs associated with reimbursement delays.

Over the past decade, acquisitions and mergers have seen the rise of larger pharmaceutical companies. As they look for ways to strip waste out of their supply chain, pharmaceutical companies are globalising their businesses and rationalising manufacturing. Older manufacturing facilities in developed countries have been closed and new high tech facilities built in countries with more favourable tax environments, for example in Ireland and Singapore. Back office support functions including information technology, human resources, operations, logistics, customer service and finance have been centralised and/or outsourced to third party companies operating from developing countries such as India or the Phillippines. Increasingly the only presence a pharmaceutical company has in developed countries is limited to Marketing and Sales functions, and Medical Access and Patient Relations teams, focused on specific stakeholders, whether medical practitioners (prescribers), or government and regulators (payers) or consumers (patients).

2.5.6 Medicalisation, Markets and Consumers

In their examination of changes in the medical marketplace Conrad and Leiter (2004) considered the impact of direct-to-consumer advertising (DTCA) of prescription drugs and the role of consumers and pharmaceutical corporations in medicalization, which 'narrows the definition of health and widens the definition of sickness'. (2004:171).

Critics believe that advertising which encourages consumers to consult their doctors if concerned about symptoms, contributes to the medicalisation of normal conditions (Mintzes 2002; Rosenthal et al. 2002) (Conrad and Leiter, 2004:161). Medicalisation in turn creates demand for prescription medicines. Examples cited included Viagra and the case of 'male sexual dysfunction', and Paxil and the creation of 'anxiety market' (including panic disorder, 'obsessive compulsive' disorder, social anxiety disorder (SAD) and generalized anxiety disorder (GAD). Following the medicalisation of normal 'emotions such as worry and shyness' (Conrad and Leiter, 2004:163), and FDA approval for the use of Paxil for SAD and GAD, the pharmaceutical company focused on marketing the conditions through disease awareness campaigns.

According to Conrad and Leiter (2004) the disease awareness advertisements 'relied upon a mixture of "expert" and patient voices, simultaneously [giving] the conditions diagnostic validity and [creating] the perception that it could happen to anyone (Koerner 2002)'. (Conrad and Leiter, 2004:164). Conrad and Leiter (2004) suggest that 'while prevention of disease is a major market for drugs and interventions, the relatively common problems of life, on the margins of medicine, hold the greatest potential for market expansion and medicalization.' (2004:171).

Medicalisation, an 'epistemic challenge' facing the medical profession and research communities since the 1960s (Hess, 2004:697), could be seen as the flipside to the recognition of 'contested illnesses'. Citing Light (2000), Hess (2004) noted 'the decline of professional dominance and the rise of countervailing powers' in response to knowledge challenges presented by health social movements (HSMs) and others (Hess, 2004:697). Tomes (2001) suggested that these movements 'laid the groundwork for a deep-seated suspicion of organized medicine that would flourish in the 1950s and 1960s' (2001:540).

Crompton (2007) details examples of patient organisations that have driven research through collaboration with biotechnology companies in competition with pharmaceutical companies following years of frustration by lack of research in areas of interest. Crompton (2007) cited the example of the Cystic Fibrosis Foundation (CFF), which created a revolutionary new business arrangement with Aurora Biosciences Corporation, leading 'at least a dozen formal collaborations [between] biotechnology companies' and patient groups. (Fleischer-Black, 2002)' (2007: 205). These new collaborative ventures co-own the intellectual property and royalties for the treatments they develop. (Fleischer-Black, 2002: 1 cited in Crompton, 2007:205 -206). According to Crompton (2007) this enables biotechnology companies to establish 'an independent strategy with a willing and confident patient base for possible clinical trials [with] little requirement for marketing costs' (2007:205-206).

Crompton's observation of 'connectedness' where 'people and organizations can now search for information, link up with others and interact globally in networks connecting 'who knows who' (social networks) to 'who knows what' (knowledge networks) through a trans-border spacio-temporal compression of communicative action' (Crompton, 2007: 207), illustrates Garriga Cots's (2011) notion of stakeholder social capital, discussed in Section 2.6.

Another interesting development has been the recent entry of Australia's first 'for benefit' pharmaceutical company in 2015. The company 'For Benefits Medicines' has committed to directing all of its profits to patient support and medical research. According to Professor Bruce Mann, Director of the Breast Service at Royal Melbourne and Royal Women's Hospitals, and Board member of Breast Cancer Network Australia (BCNA) and Breast Cancer Institute Australia (BCIA), 'FBM is pioneering a new era of social enterprise in pharmaceutical healthcare in which companies will operate exclusively for social causes, patient benefit and medical innovation. FBM represents the perfect hybrid of a formally structured commercial entity that distributes products that improve quality of life, while directing profits to beat diseases. By choosing an FBM product, the medical community will be investing in local patient support programs today, and facilitating medical research to improve treatments tomorrow." (FBM national media release (25/11/2015).

It is clear from these changes, that pharmaceutical and biotechnology companies are seeking closer relationships with HCOs funding activities such as on-line patient support tools, conferences and education programs as a way of indirectly marketing their own products and services. In Australia, companies are obliged to report their sponsorship of HCOs on the Medicines Australia website. 33 companies reported supporting 260 HCOs in 2014 and 276 in 2015 across 390 projects each year, with an average expenditure of $9,500,000 per annum. A summary of types of activities supported is included in Appendix 3.

2.6 Theoretical Lenses: Examining HCO Success

2.6.1 Overview

Of the many different theoretical lenses that could have been applied to this research, Stakeholder Theory and Social Capital Theory were selected as principal lenses. Although the origins of stakeholder theory are firmly based in the commercial or for-profit arena (Freeman 1984, Mitchell et al 1997, Jones 1995; Gioia 1999; Frooman 1999; Jones and Wicks 1999), stakeholder theory was selected over resource dependence theory because it offered wider scope for discussion of success and its enablers for Health Consumer Organisations.

By demonstrating the practical application of Stakeholder Theory in the context of non-profit organisations, this research makes a small but different contribution to the substantial body of knowledge in the stakeholder and non-profit effectiveness literature, challenging Donaldson and Preston's (1995) view that applying stakeholder theory in non-corporate settings is problematic. Furthermore, focusing on a limited number of purposefully selected health consumer organisations has enabled a rich description of success and its enablers, as constructed by research participants from this subset of non-profit organisations.

In addition to the two principal lenses, Resource Dependence Theory, Business Performance and Not-For-Profit Effectiveness literature informed the discussion, and Kaplan and Norton's 'Balanced Scorecard' was applied as a way of framing strategic management concepts for Health Consumer Organisations. Literature on Relationship Marketing and Contemporary Marketing Practices further supported the application of Stakeholder concepts.

Stakeholder Theory helped establish the external context for Health Consumer Organisations and was applied to the examination of each of the three areas of success constructed by participants, namely Profile, Performance and Purse. Social Capital Theory provided insights on the contribution of volunteers and employees, and the social value created through collaboration and alliances. Resource Dependence Theory supported the discussion on Purse.

Theoretical contributions to this research are illustrated in Figure 2.7.

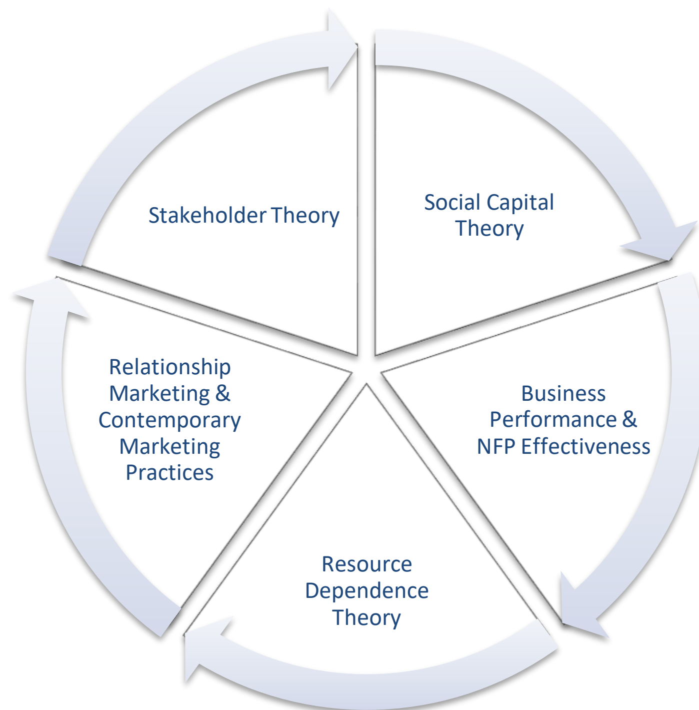


Figure 2.7 Theoretical lenses

Although there is an extensive body of research literature on non-profit effectiveness, and a smaller body of research on health consumer organisations, none to my knowledge has examined factors influencing success for health consumer organisations.

Stakeholder theory was applied to firstly identify HCO stakeholders, that is those individuals or groups who, in the resource dependence sense, could provide or withhold resources to help the HCO achieve its objectives (Aldrich and Pfeffer, 1976; Pfeffer et al, 1976; Salancik 1984), as well as those currently and potentially affected by the achievement of the organization's purpose or objectives.

Stakeholder Theory framed the discussion of the influence of Clarity, Contribution, Capacity and Connectedness and on a HCO's overall success in terms of its Profile, Performance and Purse. Once identified, stakeholders for each of the participating HCOs were mapped against each of the dimensions in the framework developed by Mitchell, Agle and Woods (1997), to assess their salience or importance to HCO. Resource Dependence Theory provided insights into the influence of Credibility, Capacity and Connectedness on adequate resourcing or the HCO's Purse.

Social Capital Theory guided the discussion around the value created within the HCO and its network for its different stakeholders and stakeholder connectedness and engagement. Questions explored in this discussion from a Social Capital Theory perspective relate to what success means for stakeholders, how it may be different for different stakeholders, and how it is created through connectedness. Social Capital Theory contributed to understanding the way Connectedness, Contribution, Capital and Creativity influence HCO Performance. Table 2.5 summarises questions raised when applying different theoretical lenses to HCO success.

Table 2.5 Insights from theoretical lenses

Resource Dependence Theory	• what does the HCO need to succeed (goal achievement)? • who can help the HCO achieve its objectives by providing resources? • what control do they have to provide or with-hold resources?
Stakeholder Theory	• who affects or is affected by the HCO? • how important are they to the HCO? • what is success for them? • how do we engage & manage them?
Social Capital Theory	• what contribution does the HCO make to the 'social good'? • how do stakeholders benefit from being connected to the HCO?

2.6.2 Stakeholder Theory

The following review briefly summarises the major aspects of stakeholder theory discussing stakeholder identification and salience, stakeholder affiliations, networks and social capital in the context of non-profit organisations. Simply put Stakeholder Theory seeks to explain how firms and managers act (descriptive), could act (instrumental) or should act (normative) in relation to those individuals or groups who can affect, are affected by or may be affected by, the achievement of the organisation's objectives (Freeman, 1984, 2010).

Freeman (1984) and Parmar et al, (2010) presented Stakeholder Theory as the foundation for a strategic and pragmatic framework for managing a firm's stakeholders and its relationships with them. Donaldson and Preston's (1995) view of stakeholder theory integrated aspects previously identified by Freeman and colleagues. Jones (1995) presented these aspects as a three-layered nested model shown Figure 2.8.

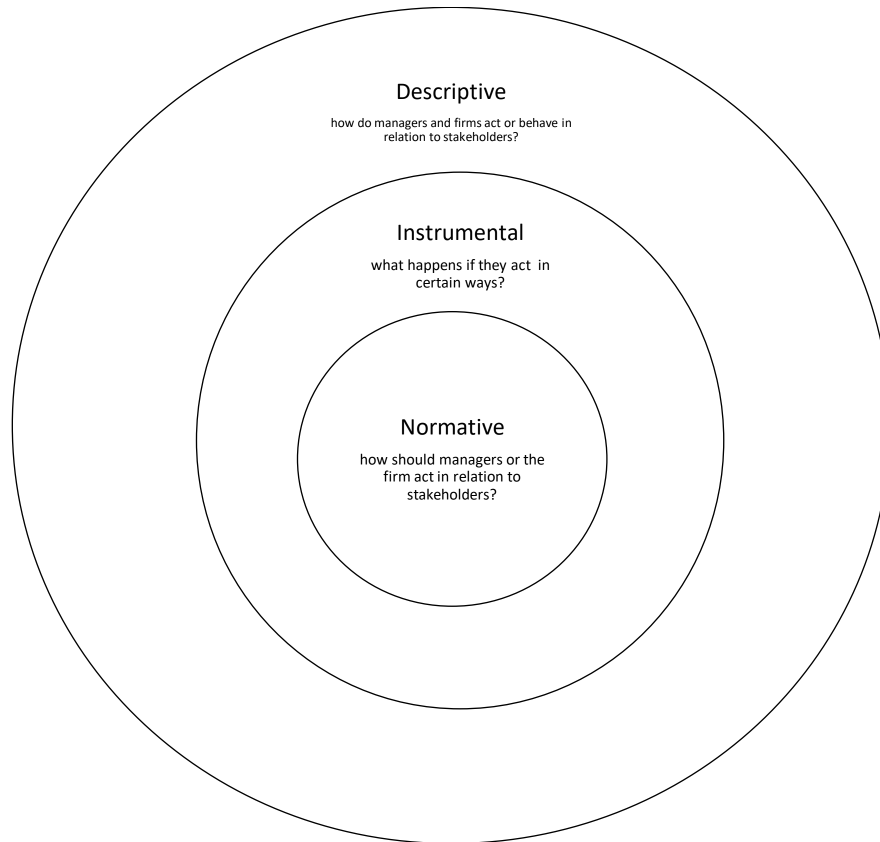


Figure 2.8 Three Aspects of Stakeholder Theory (adapted from Jones, 1995:406)

'The external shell of the theory is its descriptive aspect; the theory presents and explains relationships that are observed in the external world. The theory's descriptive accuracy is supported at the second level, by its instrumental and predictive value; if certain practices are carried out, then certain results will be obtained. The central core of the theory is, however, normative ... (and) presumes that managers and other agents act as if all stakeholders' interests have intrinsic value' (Donaldson and Preston, 1995:74 cited in Jones, 1995:406).

The descriptive outer layer seeks to identify and describe how the organisation operates and behaves in relation to its stakeholders. The middle instrumental layer is predictive, asking the organisation to evaluate the possible impacts of its actions on stakeholders and the normative core of Stakeholder Theory is essentially prescriptive (Freeman, 1984, 2010; Donaldson and Preston, 1995, Jones, 1995).
According to Parmar et al (2010), at its normative core Stakeholder Theory makes 'an explicit effort to answer two questions facing all corporations. First, what is the purpose of the firm? And second, to whom does management have an obligation?' (2010:409).

Ebrahim (2010), citing Edwards and Hulme (1996a), Kearns (1996), Lindenberg and Bryant (2001) and Najam (1996) noted the obligations of non-profit management to multiple stakeholders in three directions, 'upward to their funders or patrons, downward to clients, and internally to themselves and their missions'. This notion of accountability as a 'relational concept', suggests obligations vary 'according to the relationships among actors' and 'across different types of organizations' (Ebrahim, 2010 in Renz, 2010:103-104).

Parmar et al (2010) described Stakeholder Theory as a 'genre of management theory' (2010:406) with wide applicability across a variety of disciplines and as a 'living "Wiki" constantly evolving, as stakeholder theorists attempt to invent more useful ways to describe, re-describe, and relate our multiple conceptions of ourselves and our institutions such as business' (2010:433). Scherer and Patzer (2010) imagined Stakeholder Theory as 'an evolving, mutually informing network of methods with its respective discourses that address different aspects of actual problems in management practice' (2010:24).

Notwithstanding its wide applicability across disciplines and basic premise as a framework for management behaviour and action, applying stakeholder theory in other settings is seen by some (Donaldson and Preston, 1995; Schlierer et al, 2012) as contentious. Schlierer et al's (2012) study of European SME owner managers' views on stakeholder management revealed that although 'stakeholder theory cannot be scaled down to fit SMEs', relationships with what are known as primary stakeholders in the literature (Clarkson 1995), were recognised by SME owner-managers as essential for their survival and sustainability. SME owner-managers tended to intuitively 'apply the principles of the value creation stakeholder theory.' (Schlierer et al, 2012:49).

Donaldson and Preston (1995) believed non-corporate settings and situations to be 'fundamentally different' referring to 'critical stakeholder issues' 'unique to the corporate setting' such as ownership and the meaning of property rights, (Donaldson and Preston, 1995:69). This view was not shared by Brody (1995) who concluded that 'even in the absence of shareholders somebody still has to run the enterprise: to decide what objectives to pursue, and how; to manage its financial and human resources; and to span the boundaries of the organization in interacting with the key constituencies, other organizations, and the public' (1995:535).

Jegers (2008) agreed with Brody (1995) stating 'although there are no owners in the sense of shareholders, there are organizational stakeholders who have a stake in the organization and whose utilities are affected by the non-profit organization's activities or the lack thereof.' (Van Puvelde et al, 2012:432).

Speckbacher's (2008) observation that 'often, the connections between the non-profit organization and its stakeholders are informal or based on promises' (Speckbacher 2008 cited in Von Schnurbeim, 2014:367) would appear to reflect the experiences of the SME owner-managers in Schlierer et al's (2012) study. Although Brody (1995) maintained that 'a non-profit organization is a firm (albeit) by law, a firm without claimants to residual profits' (1995:535), few scholars have yet explored stakeholder theory in relation to non-profit or third sector organisations, where they are positioned in the centre as 'firms'. Exceptions include Wellens and Jegers (2014) who examined the relationship between key stakeholders and the effectiveness of non-profit governance and structures, revealing a need for stakeholder management by non-profit organizations (2014:223) and Knox and Gruar (2007) who linked stakeholder theory and relationship marketing strategy specifically within the non-profit sector.

2.6.3. Who are stakeholders?

The stakeholder concept was originally defined as "those groups without whose support the organization would cease to exist' (Freeman 1984, 2010), and by their contribution to value creation in the firm (Freeman et al. 2010). (Garriga Cots 2014:491). Freeman's stakeholder concept positioned the firm at the centre of reciprocal relationships with its stakeholders as represented in Figure 2.9.

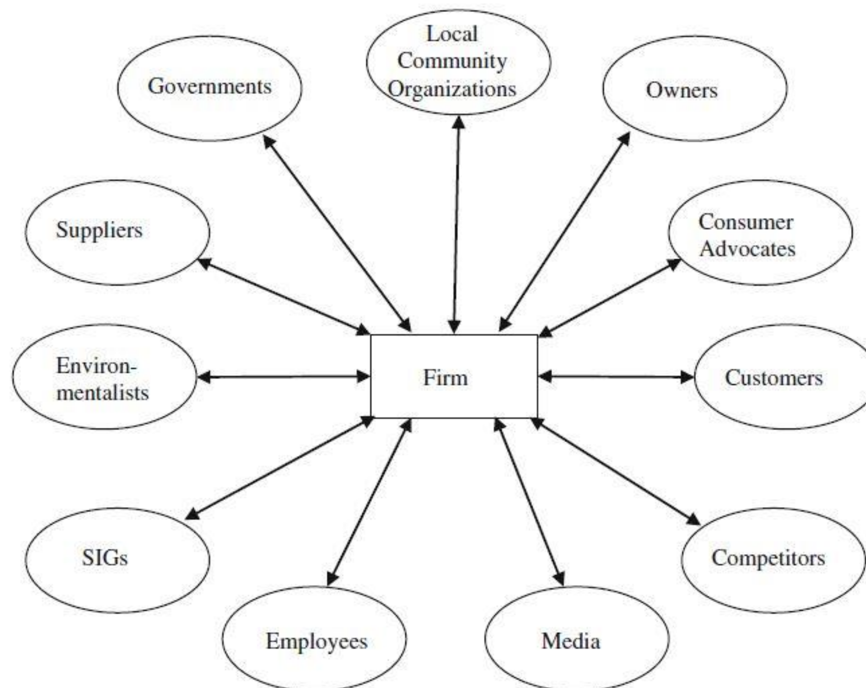


Figure 2.9 Freeman's Stakeholder View of the Firm (Freeman, 1984)

Freeman (1984) encouraged the use of environmental scans (PEST), to identify categories of stakeholders, in terms of their political, economic, social and technological influence and expectations. According to Crane and Ruebottom (2011), this was not widespread. 'Despite more than two decades of refinement and integration of stakeholder thinking into multiple disciplines, stakeholders are predominantly defined solely by their generic economic function - to consume, invest, supply, and so on' and 'ignore the social glue, the bonds of group cohesion, identity, and difference that typically form the basis for claim making in relation to the firm' (2011:77). Citing Feldman and Khademian (2002), Bryson (2010) expressed a similar view that 'thinking broadly about stakeholders is a way of opening people's eyes to the various webs of relationships within which the organization exists (Feldman and Khademian, 2002)'. (Bryson 2010 in Renz, 2010:235). Bryson (2010) suggests 'a stakeholder analysis is a way for the organization's decision makers and planning team to immerse themselves in the networks and politics surrounding the organization. An understanding of the relationships - actual or potential - that help define the organization's context can provide invaluable clues to identifying strategic issues and developing effective strategies (Bryson, 2004a; Patton, 2008)' (Bryson 2010 in Renz, 2010:235).

Listing a broad range of non-profit stakeholders including funders, customers, members, volunteers, the board, suppliers, other partners or collaborating organisations, Bryson (2010) emphasised the importance of attending to stakeholder concerns, identifying '*the satisfaction of key stakeholders' as 'the key to success in non-profit organizations and collaborations' (Light, 1998, 2002; Bryson, 2004a) (Bryson 2010 in* Renz, 2010:235 -236).

2.6.4 Stakeholder Salience

Since Freeman's (1984) seminal work on stakeholder theory and strategic management, a number of techniques and frameworks for identifying and analysing stakeholders have been developed (Mitchell et al. 1997; Bryson 1995, 2004; Frooman, 2010; Crane and Rubottom, 2011; Garrriga Cots, 2014). Beyond the concept of stakeholder salience, the literature also addresses questions of utility and value (Susniene and Vanagas, 2006; Sachs and Rühli, 2011; Harrison and Wicks, 2013), as well as stakeholder affiliation and networks (Nahapiet and Ghoshal, 1998; Freeman, Harrison & Wicks, 2007; Harrison & Wicks, 2013). Building on the work of Freeman (1984, 1994) and citing many other scholars in their detailed chronological review of the development of stakeholder theory, Mitchell et al (1997) developed a typology of stakeholders and a framework for analysing their salience. They explained their typology in terms of the presence, absence and combinations of three key variable and socially constructed attributes: power, legitimacy and urgency, adopting the previously articulated definition of 'stakeholders' as 'any group or individual who can affect or is affected by the achievement of the organization's objective' (Freeman,1984; Kreiner & Bhambri,1988; Jones, 1995). (1997: 869).

Power was defined as 'a relationship among social actors in which one social actor A, can get another social actor B, to do something that B would not have otherwise done' (Weber, 1947; Dahl,1957; Pfeffer, 1981). Legitimacy was defined as 'a generalized perception or assumption that the actions of an entity are desirable, proper or appropriate within some socially constructed system of norms, values, beliefs, definitions' (Weber, 1947; Suchman, 1995), (Mitchell et al 1997: 869). Urgency was defined as 'the degree to which stakeholder claims call for immediate attention' and was further described in terms of time sensitivity and criticality. Finally salience was defined as 'the degree to which managers give priority to competing stakeholder claims'. (Mitchell et al, 1997:869).

Mitchell et al's typology and framework represented here in Table 2.6 illustrates the dynamic nature of stakeholder relationships, serving as a tool for 'understanding how stakeholders can gain or lose salience' by gaining or losing an attribute (Mitchell et al 1997:868).

Bryson (2004) outlined a number of stakeholder identification and analysis techniques, including power versus interest grids and stakeholder influence diagrams previously described by Eden and Ackermann (1998). Power versus interest grids are used to identify which stakeholder interests should be addressed first as the most likely to influence a specific issue or an organisation's future. Stakeholders are placed on a two-by-two matrix where the axes are stakeholder interest in and power to affect.

The exercise results in four categories of stakeholders, which can be mapped against Mitchell et al's categories of Latent and Expectant stakeholders. Bryson's 'players' have both an interest and significant power (Expectant-Dominant); his 'subjects' have an interest but little power (Latent-Discretionary or perhaps Demanding); while 'context setters' have power but little direct interest (Latent-Dormant) and finally Bryson's 'crowd' consists of stakeholders with little interest or power (Latent-Dormant). (Eden and Ackermann, 1998:121-125, 344 - 346, cited by Bryson 2004:30 -31). Table 2.6 presents a model for analysing stakeholder salience based on Mitchell et al's (1997) typology. Once an organization's stakeholders are identified and analysed, a stakeholder influence diagram can be used to illustrate how they influence each other.

Table 2.6 Stakeholder Typology and Salience (based on Mitchell et al, 1997)

STAKEHOLDER Salience	LATENT (potential) 1 attribute			EXPECTANT 2 attributes			DEFINITIVE 3 attributes
A dynamic model							
	dormant	discretionary	demanding	dominant	dependant	dangerous	
POWER (to influence)	x			x		x	x
LEGITIMACY (of the relationship)		x		x	x		x
URGENCY (of the claim)			x		x	x	x

Stakeholders displaying the three attributes are classified as 'definitive' stakeholders or most salient. Those with two of the three attributes are classified as 'expectant' and stakeholders with only one of the three attributes are classified as 'latent' or 'potential' stakeholders. Possession of specific attributes further refine stakeholder types. Latent stakeholders with power to influence the organization are classified as dormant, latent stakeholders without power to influence but with a legitimate relationship with the organization are classified as discretionary while those with neither power nor legitimacy but with an urgent claim on the organization are classified as demanding. Expectant stakeholders are further classified as dominant when they possess both the power to influence the organisation and a legitimate relationship with it, dependant when they possess legitimacy and an urgent claim on the organisation, and dangerous when they have both power to influence the organisation and an urgent claim on it.

Stakeholders identified in this research include members of the participating HCOs, governments, celebrities, donors, medical practitioners, researchers other HCOs, suppliers and third party providers, and umbrella organisations such as the Consumer Health Forum.

Corporate sponsors from the healthcare industry such as pharmaceutical and medical devices companies, providers of other medical or diagnostic services and private services or care providers are considered separately to other sponsors as their stakes or claims are different. HCO stakeholders are discussed and analyses of the salience of respective stakeholders using Mitchell et al's (1997) framework are presented in Chapter 4.

Of particular interest to my research was Bastian's (1998) appraisal of the two-way nature of influence between different stakeholders, namely of '*people in the system wanting to conscript influential individual consumers (thus) being lobbied is one of the most common experiences of being a consumer advocate'* (1998:7). Recognition of the growing number of stakeholder relationships between HCOs and the pharmaceutical industry led to the development of 'Working Together: A guide to relationships between Health Consumer Organisations and Pharmaceutical Companies' by Medicines Australia in collaboration with the Consumer Health Forum of Australia in 2005.

2.6.5 Stakeholder Value and Utility

Harrison and Wicks (2013) define 'value' broadly as anything that has the potential to be of worth to stakeholders and 'utility' as value a stakeholder receives that actually has merit in the eyes of the stakeholder (2013:100-101). By further defining 'the total value created by the firm through its activities' as 'the sum of the utility created for each of a firm's legitimate stakeholders', Harrison and Wicks link the concepts of value and utility with stakeholder networks (2013:101-102). Citing Sachs and Rühli (2011), Harrison and Wicks (2013) assert that 'stakeholder interests are inseparably connected in a system of value creation, in which each stakeholder provides resources or influence, in exchange for some combination of tangible and/or intangible goods' (2013:102-3). Earlier research by Susniene & Vanagas, (2006) suggests that 'the quality of contributions of each stakeholder to the system influences the total value created in the system (Susniene & Vanagas, 2006)' (2013:102-3).

2.6.6. Stakeholder affiliation and networks

Although the early literature on Stakeholder Theory took the 'firm' or corporation as the focal point and defined stakeholders in terms of their relationship with the business, more recent literature has discussed stakeholders not only in terms of their relationship with 'the firm' but also in terms of their relationship to other stakeholders and to specific 'issues' (Roloff, 2008). Citing Rowley (1997) and Freeman et al (2007), and connecting Stakeholder Theory and Social Capital Theory, Harrison and Wicks (2013) noted that the treatment of one stakeholder can influence relationships with other stakeholders, 'the influence of the whole group of stakeholder relationships on the value created is greater than the sum of the influence of each relationship taken separately' (2013:105). Explaining 'utility through affiliation' as the ability to obtain benefits from membership in social networks (Lee, Lee & Pennings, 2001; Nahapiet & Ghoshal, 1998; Portes, 1998), Harrison and Wicks (2013) suggested that group affiliation motivates 'stakeholders to care about one another's interests and the success of the firm (Hartman, 2011; Putnam, 2000).' (2013:106)

Attempts have been made to modify Freeman's 'firm' centric model (Freeman, 1984), seen as problematic by some (Rowley 1997, Key 1999, Fassin 2008, Roloff 2008), by shifting the firm from the centre of the hub and wheel diagram and locating it within a multi-stakeholder network (Pajunen 2006; Rowley 1997), (Crane and Ruebottom, 2011:80). Other changes have been to substitute 'the firm' with 'the issue' at stake (Frooman, 2010). This suggests reframing the question from who is a 'firm's' stakeholder to who is a stakeholder of an issue, before then asking 'What do they want? How are they going to try to get it? Who do they know?' (Frooman, 2010:162). Bryson (2010) promoted stakeholder analysis as 'a way for the organization's decision makers and planning team to immerse themselves in the networks and politics surrounding the organization', suggesting that 'an understanding of the relationships—actual or potential—that help define the organization's context' can provide invaluable clues to identifying strategic issues and developing effective strategies' (Bryson, 2004a; Patton, 2008). (Bryson 2010 in Renz, 2010:235-236).

Noting only minor changes to Freeman's organization-focussed stakeholder definition (Freeman, 1984: 25), Roloff (2008) offered a different understanding of stakeholders within the context of multi-stakeholder networks, defining them as 'any group or individual who can affect or is affected by, the approach to the issue addressed by the network' (Roloff, 2008: 238).

Crane and Ruebottom (2011) developed a new framework for stakeholder identification, mapping social identities against traditional economic stakeholder categories, recognising the 'social 'glue' that binds stakeholders to shared values and goals (2011: 85).

2.6.7 Resource Dependence Theory (RDT)

The two key concepts in Resource Dependence Theory are resources and resource providers and 'the key to organizational survival is the ability to acquire and maintain resources' (Pfeffer and Salancik 1978 cited in Froelich, 1999:247). Since resources are not 'adequate, stable, or assured' (Froelich, 1999:247) 'organizations are never self-sufficient but are interdependent with other organizations in their environment (Helmig et al, 2014:1514-1515).

Hager (1996) positioned Resource Dependence Theory as a means to understand 'how well organizations maintain contacts with key funders, interlock with competitors, share information, and stay connected to developments in the community and with professional associations' (Hager, 1996:980).

Hillman et al (2009) drew attention to the similarities between resource dependence and stakeholder theories in their recognition of the importance of external stakeholder relationships, suggesting that 'combining recent RDT recognition of the multiplexity of dependencies' with insights from stakeholder salience research (Mitchell et al, 1997) might lead to insights on, and strategies for managing dependencies (Hillman et al, 2009:1417).

While resource dependence theory is useful in explaining the relationship between principals and agents in the non-profit context and in identifying economic stakeholders who affect the organization's survival and sustainability, stakeholder and social capital theories provided more insights in this research into Health Consumer Organisations.

2.6.8 Relationship Marketing Theory and Contemporary Marketing Practices

Relationship Marketing Theory is linked to stakeholder theory in that it views the business or organisation as a 'coalition of stakeholders' (Payne & Holt, 2001; Polonsky & Murphy, 2005).

According to Knox and Gruar (2007), ‘relationship marketing’ theory offers ‘a reformist agenda for stakeholder management since it places an emphasis on stakeholder collaboration beyond the immediacy of market transactions’ (2007:115). ‘Relationship marketing’ focuses on building closer customer relationships (Berry, 1983; Gro¨nroos, 1997) and refers to ‘strong stakeholder relationships’ (Kotler and Armstrong, 1999:50) (cited in Knox and Gruar, 2007:115).

The language of Relationship Marketing Theory suggests it also shares some concepts with Social Capital Theory as it involves ‘creating exchanges of mutually beneficial value across salient stakeholder groups (Christopher et al., 2002), interactions through direct relationships and within networks (Coviello et al., 1997; Gummesson, 1999), and building mutual commitment and trust (Morgan and Hunt, 1994)’, (Knox and Gruar, 2007:115).

Knox and Gruar (2007) offer several reasons why non-profit organisations are adopting ‘relationship marketing’ practices. These include recognition of the need by professional CEOs leading non-profits to engage stakeholders (Drucker, 1989), competition for ‘share of purse’, and experience in cause-related marketing partnerships with businesses arising from the CSR agenda (Porter and Kramer, 2002; Knox et al., 2005). Suggesting that there would be different expectations from business sponsors than traditional donors, Knox and Gruar (2007) argue for ‘rigorous’ identification and assessment, by non-profit organisations of their stakeholders and their salience, followed by an audit and assessment of current marketing practices deployed by them (2007:117).

Working with a major UK Health Consumer Organisation, undergoing a change in strategic direction, Knox and Gruar (2007) applied Mitchell et al’s (1984) framework to their identification and assessment of stakeholders. They then used Coviello et al’s Contemporary Marketing Practices (CMP) framework to the audit and assessment of marketing practices in use, developing a simple model to guide non-profit organisations through the process (2007:117). The CPC model presented in Chapter 6 builds on Knox and Gruar’s model, adding in features and considerations from Frooman’s (2010) INSPIRE model and elements from Al Tabbaa, Leach and March (2014).

2.6.9 Social Capital Theory

Kwon and Adler's (2014) suggest that the basic thesis of social capital, 'that social ties can be efficacious in providing information, influence, and solidarity, is no longer in dispute' (2014:419), is reinforced in the findings of this research. The HCOs participating in this research closely reflect Schneider's (2009) definition of organizational social capital as 'established, trust-based networks among organizations or communities supporting a particular non-profit, that an organization can use to further its goals'. (cited in Von Schnurbein, 2014: 360). Chapter 5 presents repeated evidence of the creation of bonding, bridging and linking social capital within the participating HCO's networks.

As Portes (1998) explained, 'to possess social capital, a person must be related to others' (1998:7). Relationships, as 'the basis for commitments, trust, information exchange, and resources (Brower, Schoorman, and Tan, 2000; Bourdieu, 1986)' create 'organizational value (Bouty, 2000; Tsai and Ghoshal, 1998)' (King, 2004:473). Key definitions of social capital are summarised in Table 2.7.

When created and stored within a group or 'dense' network, social capital is said to be bonding social capital (Putnam, 1993). Bonding social capital is characterised by high levels of trust between group members, strong horizontal ties, shared norms and values, and can be either a source of social control or a source of support within the group or network (Portes, 1998:9).

When social capital is created and stored through interaction between groups, it is known as bridging social capital (Putnam, 1993), and is essentially a source of benefits gained through networks (Portes,1998:9). The relationships that create bridging social capital are characterised by trust-based flexible networks with weak horizontal ties (Granovetter,1973). According to King (2004), Burt (2001) views this form of social capital which is closely aligned to his own 'spanning structural holes', as more productive than bonding social capital as it enabled access to new information and resources not presently possessed (Lin, 2001:27, cited in Glanville and Bienenstock, 2009:1512). Other concepts similar to 'bridging social capital' (Putnam, 1993), 'spanning structural holes' (Burt, 2001) and 'weak ties' (Granovetter, 1973) (Portes, 1998:6), include 'betweenness' (Tsai and Ghoshal,1998), 'flexible networks' (Gargiulo and Benassi, 2000) 'external social capital' (Adler and Kwon, 2002) (King, 2004:476).

Table 2.7 Defining social capital (adapted from King, 2004)

		What is Social Capital?	Type/Source
1973	Granovetter	cohesion and trust within a network, ability to bridge different and new networks, bringing new resources and ways of thinking	Strong ties = bonding/normative Weak ties = bridging/instrumental
1988:S98 1990:302	Coleman (Portes, 1998:5)	"a variety of entities with two elements in common: They all consist of some aspect of social structures, and they facilitate certain action of actors—whether persons or corporate actors—within the structure"	Reciprocity expectations and enforcement of norms
1986	Bourdieu and Wacquant	"the sum of the resources, actual or virtual, that accrue to an individual or group by virtue of possessing mutual acquaintance and recognition."	Relationships Bridging/instrumental
1990:619	Baker (Portes, 1998:6)	"a resource that actors derive from specific social structures and then use to pursue their interests; it is created by changes in the relationship among actors"	
1992:9	Burt (Portes, 1998:9)	"friends, colleagues, and more general contacts through whom you receive opportunities to use your financial and human capital"	Weak ties/instrumental
1993	Putnam	networks, norms, and trust that enable participants to act together more effectively to pursue shared objectives -horizontal networks have the capacity to bridge different groups of peers and use weak ties to nurture cooperation between groups for society's benefit.	Vertical networks = strong bonds + closure +solidarity Horizontal networks = weak ties
1998	Nahapiet and Ghoshal	the structural component refers to the ties within a social network	structural, cognitive, and relational
1998	Tsai and Ghoshal	networks of relationships, which enhance cooperation, trust, shared vision, and resource exchange in creating organizational value	Betweenness
1999	Leana and Van Buren	a resource reflecting the character of social relations within the organization, realized through members' levels of collective goal orientation and shared trust.	Bonding
2000	Burt	the competitive advantage gained by 'being able to bridge two groups, gaining access to new information and controlling the flow of information between groups	Spanning structural holes Bridging
2009	Schneider	established, trust-based networks among organizations or communities supporting a particular non-profit, that an organization can use to further its goals	Bridging
2014	Von Schnurbein	an individual or a collective asset that is stored in the relationships among individuals, groups, or organizations'	

The third type of social capital known as linking social capital is characterised by vertical ties between a single organisation, a network or an umbrella organisation, and their resource controllers or funders such as governments or sponsors/major donors. 'Linking social capital is embodied by ties between individuals and organizations occupying different levels of power or status, which are often mediated by institutions that help groups of people to communicate with those in positions of power and authority' (Passey and Lyons, 2006:482). The three types of social capital are represented in Figure 2.10.

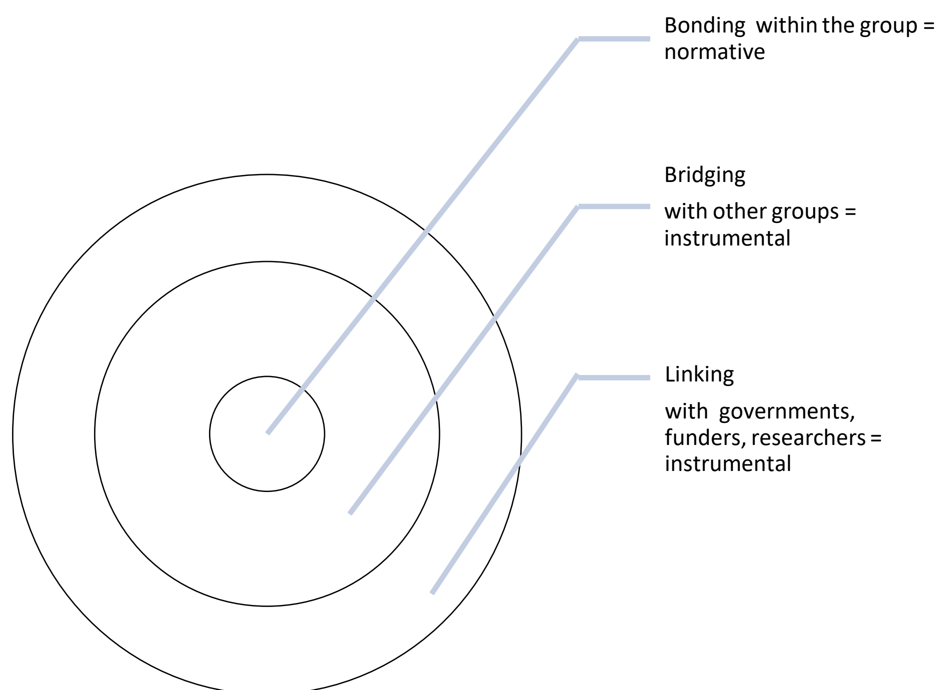


Figure 2.10 Model illustrating social capital within, between and across groups.

Ambiguity exists around the term 'social capital' partly because of its intangible nature and partly because it is both an input and an output in social relationships. According to Nahapiet and Ghosal (1998), three aspects of social capital: structural, relational and cognitive, 'work together to enhance information transmission and absorption among organisation members and thus enhance organisational performance' (cited in Leana and Pil, 2006:354).

Glanville and Bienenstock (2009) note that both Bourdieu (1986) and Coleman (1988) treat 'capital' in 'social capital' as an 'investment' in relationships, something of benefit that can be exchanged or reciprocated (2009:1509). Bourdieu, (1986:250) 'portrayed the accumulation of social capital as the result of conscious and unconscious long-term investment strategies designed to establish or maintain relationships of perceived obligations that can be accessed on some future occasion. (Glanville and Bienenstock, 2009:1513). This concept of reciprocity (Homans,1961; Blau, 1964) as a source of social capital (Schiff, 1992; Coleman, 1994) was previously described by Portes (1998) as 'primarily the accumulation of obligations, from others according to the norm of reciprocity' (1998:7).

Portes (1998) explains it in reference to more readily understood terms of economic and human capital. 'Whereas economic capital is in people's bank accounts and human capital is inside their heads, social capital inheres in the structure of their relationships (1998:7). Refuting the argument that the term 'social capital is counterproductive because social capital is not really capital at all (Fischer 2005)' Mouw (2006) maintains its popularity 'is likely due, at least in part, to the equivalence that it suggests with other forms of capital' (2006: 80).

2.6.10 Social Capital in Non-profit Organisations

The currency of social capital is used to explain the value non-profit organizations add to society (Bryce 2006) (cited in Von Schnurbein, 2014: 357). Onyx and Bullen (2000) maintain the conditions for generating social capital 'are most probable in the non-profit sector' (2000:39). 'Non-profit organisations are reputed to reproduce social capital' (Leonard and Onyx 2003; Wollebaek and Selle 2002) (Von Schnurbein, 2014: 358), and are said to play important roles in the reproduction of social capital (Dekker and van den Broek, 1998; Foley and Edwards, 1996; Stolle and Rochon, 2001; Torpe, 2003) ' (Passey and Lyons, 2006:482).

Adopting British descriptions of 'bonding social capital as "social glue" and bridging as "social oil", Passey and Lyons (2006) suggest that non-profit organisations 'might be viewed as social glue in that they themselves are networks of individuals who voluntarily associate in order to pursue shared interests in a public and collective space' (2006:482). The role of non-profits contributing 'to stocks of bridging social capital by linking networks of people together in the pursuit of supra-organizational aims' was described as 'social oil' (2006:482).

Glanville and Bienenstock's (2009) concept of a 'diversified social portfolio' which would 'allow an individual (or organisation) to draw on the appropriate segment of the social network, depending on need' suggests a link between stakeholder theory and social capital theory. Undertaking a stakeholder salience analysis in which stakeholder contribution to social capital is also evaluated, might help organisations in the development of successful strategies. Glanville and Bienenstock (2009) suggest that 'if an individual were to act strategically, her or his goal should be to accumulate different types of connections to be leveraged at different times for different situations because she or he might not be able to predict the type of social capital that would benefit her or him most in the future' (2009:1512)

2.6.11 Stakeholder social capital – a new theory?

Garriga Cots (2011) defines 'stakeholder social capital' the concept introduced by Maak (2007) 'as the goodwill that arises from the pattern of social relations (multiplex and dense) between the firm and its stakeholders realized through members' meta-purpose and shared trust that contributes to the common good of both the stakeholder network and the society'. (Garriga Cots, 2011:334). She states three intrinsic benefits of stakeholder social capital in addition to the traditional social capital benefits of 'information and knowledge influence, control and solidarity (Powell et al. 1996, Uzzi 1997, Podolny & Page 1998, Sandefur & Laumann 1998)'. (2011:334). Garriga Cots (2011) names these new benefits (1) solidarity weaver, (2) mechanism for collective action and (3) facilitator of intellectual capital among the firm and its stakeholders. (2011:334)

In proposing this new stakeholder social capital theory, Garriga Cots (2011) argues it would make a contribution to both 'stakeholder theory with a new normative core based on social capital', and 'social capital theory by introducing a specific social capital concept that comes from stakeholder theory' (2011:329). The main difference between the proposed stakeholder social capital theory and stakeholder theory is in the way it seeks to understand stakeholders not as individuals or groups but as a network, analysing the quality of entire network in terms of stakeholder social capital dimensions (structural, relational, cognitive and evaluative) (2011:335).

‘Stakeholder social capital requires that managers understand stakeholder networks. Managers must understand the structural interactions of multiple stakeholders within the stakeholder network as these stakeholders’ claims may be conflicting or cooperative. The framework of stakeholder social capital will assist managers in understanding and measuring the direction, strength and synergies between stakeholders within the complex stakeholder network.’ (Garriga Cots, 2011:336)

2.7 Success for non-profit organisations

The three categories of success (Performance, Profile and Purse) together with the seven enablers and inhibitors identified in this research are congruent with findings from earlier research. According to Lecy et al (2012), Price (1968), Bradshaw et al (1992) and Green et al (2001), cited in Callen (2010:105), described success in terms of obtaining and managing or controlling resources (Purse). Etzioni, (1964), Price (1968), Campbell (1977), Bradshaw et al (1992), Sheehan (1996), Green et al (2001) and Spare and Dail, (2002) described it as achieving goals (Performance). Georgopoulos and Mann (1962), Price (1971), Jobson and Schneck (1982) and Sharman (2007) described it as establishing and maintaining a positive reputation (Profile) (2012:439 – 440).

Forbes (1998) summarised these three approaches to effectiveness as (a) the goal-attainment approach; (b) the system resource approach, which emphasizes organizational resource procurement; or the (c) reputational approach, which associates effectiveness with the reported opinions of key persons, such as clients or service professionals’ effectiveness. (1998:184).

Lecy et al (2012) describe how they have been incorporated into different models of effectiveness including ‘multi-dimensional models (Connolly et al. 1980; Cameron and Whetten 1983; Zammuto 1984; Foster and Lock 1990), competing values models (Quinn and Rohrbaugh 1983), contingency models (Lewin and Minton 1986; Ebrahim and Rangan 2010), and a balanced scorecard approach (Kaplan and Norton 1996)’ (2012:440). They note that both Sowa et al’s (2004) ‘‘multidimensional and integrated model of not-for-profit organizational effectiveness’’ (MIMNOE), and Kaplan’s (2001) balanced scorecard approach, ‘incorporate goals, resources, and reputation’ (2012: 446).

Lecy et al's (2012) review of the literature identified 'four domains that can be used to better guide performance assessments: managerial, program, network, and legitimacy' noting that 'collectively, they suggest the range of variables associated regularly with organizational effectiveness. Each can be evaluated separately, allowing for the reduction of the complexity often associated with trying to gauge overall organizational effectiveness' (2012: 449). Citing Rojas (2000), Tucker (2015) agreed 'that performance in a NFP context is best conceptualised through a multidimensional framework rather than through a single construct' (2015:318 in Hoque and Parker)

Tucker (2015) also noted two opposing perspectives on non-profit performance aligned with contingency theory and 'new institutional sociology' (NIS) theory. Bradshaw's (2009) view, that 'what works in one setting or at one point in time, may not work in another and that efficiency is related to the ongoing alignment of various contingencies', differs from the views presented by Stone et al (1999), Herman and Renz (1999), Speckbacher (2003), Beck and Lengnick-Hall (2008) and Lindenberg, (2001). They suggest that 'the lines dividing for-profit and NFP organisations are becoming increasingly blurred' and that non-profits progressively look 'to private sector practices to improve efficiency and productivity' (Tucker, 2015: 314-315).

Helmig et al (2014) describe the complexity of defining success and failure for non-profit organisations, as partly due to two main characteristics of the sector. These are 'the nondistribution constraint' (Hansmann 1980,1986; Salamon and Anheier 1997), requiring surplus funds to be re-invested to ensure 'mission accomplishment' (Sandler and Hudson 1998) and the focus on social goals as part of their mission statement (Brown and Slivinski 2006; Oster 1995). Helmig et al (2014) also referred to 'the ambiguous nature of mission completion' seen by some to indicate success and others as failure in light of the organisation's demise (Fernandez 2008) (2014:1510-1511). Helmig et al (2014) also suggest that the different terms used to capture the concept of organizational success, including performance, sustainability, viability, and even efficiency and profit (Baruch and Ramalho 2006; Campbell 1977), have resulted in a fragmented literature (Cameron 1986, 2005). . (2014:1512).

2.7.1 The stakeholder view of success and effectiveness

According to Ospina et al (2002), non-profit managers 'must be involved in a continuous process that helps them identify the relevant stakeholders, determine each stakeholder's expectations, weigh the importance of these expectations against other demands from the organization's internal and external environments, decide what areas to focus energy on, and adopt a level of managerial activism based on these decisions' (2002:29). Murray (2010) citing Ospina et al (2002) maintained that 'there is now substantial consensus ... around the conclusion that there is no such thing as organizational effectiveness in any absolute sense nor is there any single indicator that will unambiguously reveal the degree of effectiveness at any one time. Instead, effectiveness is thought of as a "social construction", existing in the minds of the organization's diverse internal and external stakeholders. Insofar as they interact and need to make joint decisions based on an assessment of the effectiveness, the definition of it must be "negotiated" at that time and renegotiated as times change (Murray, 2010: 433 in Renz, 2010).

Lecy et al (2012) noted the development of 'more complex, multiple stakeholder approaches' to organisational effectiveness (Zammuto 1984; Herman and Renz 1999)' in recognition 'that organizations regularly deal with many constituencies and may have varied or conflicting reputations' (2012:440). Parmar et al (2010) acknowledged a number of proponents for a stakeholder approach to effectiveness including Cameron (1980, 1984) whose 'strategic constituencies approach' was 'based on at least minimally satisfying the demands and expectations of key stakeholders, Gregory and Keeney (1994), Kumar and Subramanian (1998) Hellriegel, Slocum, and Woodman (2001) and Dart, (2001),'. (2010:427- 428).

Multiple constituency models were explained by Balser and McClusky (2005) as 'multiple frames of reference and multiple criteria ... used when assessing NPOs' (Bies and Cowles, 2002; Herman and Renz, 2000, 2002; Miller and Faerman, 2002; Schmid, 2002), or as a portfolio of performance dimensions, assessed by a portfolio of evaluators (2005: 299). Harrison and Wicks (2013) ' affirmed Freeman's (1984) original claim that attending to stakeholders and their interests is a critical starting point for managers and provides a foundation that drives their ongoing success' (2013:117).

HCOs are important to a variety of stakeholders for different reasons. Firstly, they are important to their members, those who join them for personal support, information and advice. They are also of interest to their sponsors, governments and researchers.

Commercial businesses may identify opportunities to gain access to a particular market for their products via HCO endorsements such as the National Heart Foundation Tick or Cancer Council sunscreen endorsements and social entrepreneurs within the non-profit sector have embraced partnerships with corporations as a way of securing another revenue stream (Eikenberry and Kluver, 2004). According to Eikenberry (2009) 'cause marketing or consumption philanthropy' (2009:585) has grown in the past two decades as companies seek more 'strategic and profitable' philanthropic activities.

Companies within the health industry where 'direct to consumer' advertising is highly regulated seek to build relationships with HCOs as an avenue through which to indirectly promote their products or services. In developing advocates in specific therapeutic areas, they build consumer support in advance of applying for drug and device listings with the Therapeutic Goods Administration, the Pharmaceutical Benefits Scheme and Medicare Benefits Schedule. Relationships with HCOs serve pharmaceutical companies as a means of raising awareness of new drugs in pre-market clinical trials.

HCOs, in particular peak bodies, are important to government as sources of consumer input on policy. In addition, governments engage with HCOs as service providers when devolving direct service delivery. Balser and McClusky (2005) suggest 'that non-profits will be evaluated as effective when stakeholders interpret that they are serving the public interest, using behaviors that entail a consistent approach with them'. (2005:298)

Medical and other researchers value access to membership databases and registries when recruiting research participants. In addition, HCOs are important to healthcare providers targeting services to consumers. Each stakeholder has their own view of HCO success and each has an interest in measuring and/or developing HCO effectiveness in terms of these different definitions.

2.7.2 How was success defined in this research?

All but one of the HCOs, defined success in terms of having resources required for sustainability, named as Purse in this report. Only one HCO defined it in terms of mission completion, expressed as there no longer being a need for the HCO. Every HCO defined success as goal attainment or Performance. In addition, success was recognised as the ability of the HCO to transform or re-invent itself, and expanding its reach and influence through networks and alliances with other HCOs.

Sustainability and securing funds were reported as on-going challenges by all HCOs participating in this research. They receive funding through a number of channels including government grants for research and service provision or program delivery, at both state and national levels; membership fees and subscriptions; bequests and donations; fund-raising events, commercial sponsorships and income earned through fee for service activities, social enterprises and on investments.

The connection between profile, performance and purse in a type of symbiotic relationship emerged repeatedly from participant interviews, as did the importance of engaging with all stakeholders. The relationship between profile, purse and performance, where each constantly reinforces the others, is illustrated in Figure 2.11.

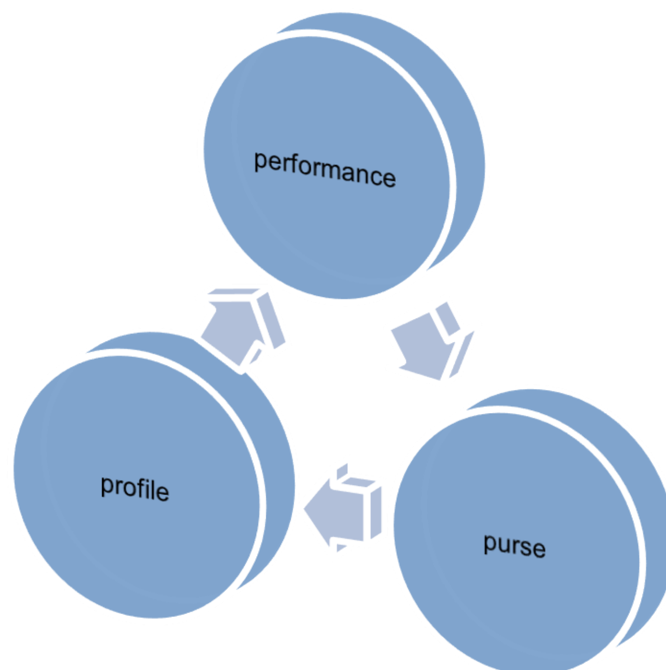


Figure 2.11 Success creating success

2.8 Summary

This review of the literature confirms a gap in research identified by Huyard (2009), regarding 'the inner structure, resources and functioning of formal [patient organisations]', illustrated earlier in Figure 1.1.

In attempting to answer questions on what success means for formally structured HCOs in a changing health environment, and why some HCOs appear to be more effective than others, this research contributes to narrowing the gap identified by Huyard (2009).

CHAPTER 3: RESEARCH METHODOLOGY AND DESIGN

3.1 Research Overview

The previous chapter presented the background to the study in the form of a literature review that confirmed (i) the importance of the topic thus motivating the research, (ii) a gap in the literature which the research addresses and (iii) the suitability of the research questions to establish the research direction. In this chapter the methodology of the research is presented and justified as appropriate for answering those questions

Section 3.1 outlines the purpose of this research, the questions it addresses and its value to Health Consumer Organisations and academia.

Section 3.2 presents the research design, based on the interpretive framework. Qualitative methods were identified as very appropriate for finding answers to 'how' and 'why' questions (Yin, 2009). Semi-structured interviews and content analyses of documents were selected as well suited to research into stakeholder views and practices. Section 3.2 also describes the data sources and provides justification for the interviewee selection and recruitment process.

Section 3.3 outlines the data collection and analysis process, illustrating how transcripts were coded and the use of memos, and Section 3.4 concludes the chapter with reflections on the research process.

3.1.1 Research Purpose

As stated in Chapter 1, Health Consumer Organisations (HCO), also known as Patient Support Groups, play an important role in supporting people facing a shared health condition. As portrayed in Chaper 2, it is difficult to ascertain how many such groups operate in Australia because there is no consistency in the way they are defined, nor any comprehensive registry of HCOs. However given that the Consumer Health Forum of Australia lists more than 100 HCOs as member organisations and the ACNC has 833 charities registered with 'Advancing Health' as their primary purpose and 'the general Australian public and people with chronic disease or terminal illness' as their beneficiaries, we might assume that the number lies somewhere in between.

As stated in the introduction, HCOs are important for a number of reasons, providing support and advice to individuals, a range of community services on behalf of the government, policy advice and research support. However little is known about how HCOs operate, how effective they are and what factors contribute to their success.

This research aims to identify and illustrate features contributing to the success of Australian HCOs. An understanding of what contributes to 'success' for HCOs will inform stakeholders seeking to work with them and enable benchmarking between HCOs and similar organisations. To my knowledge no studies have to date specifically investigated factors enabling or inhibiting HCO success, nor according to Huyard (2009) has there been interest in researching 'the inner structure, resources and functioning of (patient organisations)' (Huyard 2009:980).

3.1.2 Research Questions

My research set out to answer two main questions:

(i) What does success mean for formally structured HCOs in Australia in a changing health environment?

(ii) What factors moderate their success?

Guided by questions identified in Anheier and DiMaggio's "road map" for non-profit sector research, *"Why do non-profit organizations exist? How do they behave? What impact do they have and what difference do they make?"* (cited in Anheier, 2005 loc 2879 of 12375), this research sought to find out more about the type of work undertaken by HCOs in Australia, how they operate as organisations and who has an interest in what they do.

3.1.3 Research Value

This research has two primary practical outcomes. Firstly, it identifies and describes factors mediating success and secondly, it presents a framework for evaluating stakeholder relationships influencing success. In addition, by illustrating the application of recent work on stakeholder planning frameworks (Knox and Gruar 2007, Frooman 2010, Garriga Cots 2011 and Al Tabbaa et al. 2014) to HCOs in Australia, it makes a modest but new contribution to the extant literature on stakeholder theory.

3.2 Design

The research onion (Saunders et al. 2007) provides a clear framework to guide novice researchers through the process of writing about the methodological approach underpinning their research. Figure 3.1 presents an overview of my research methodology based on that model.

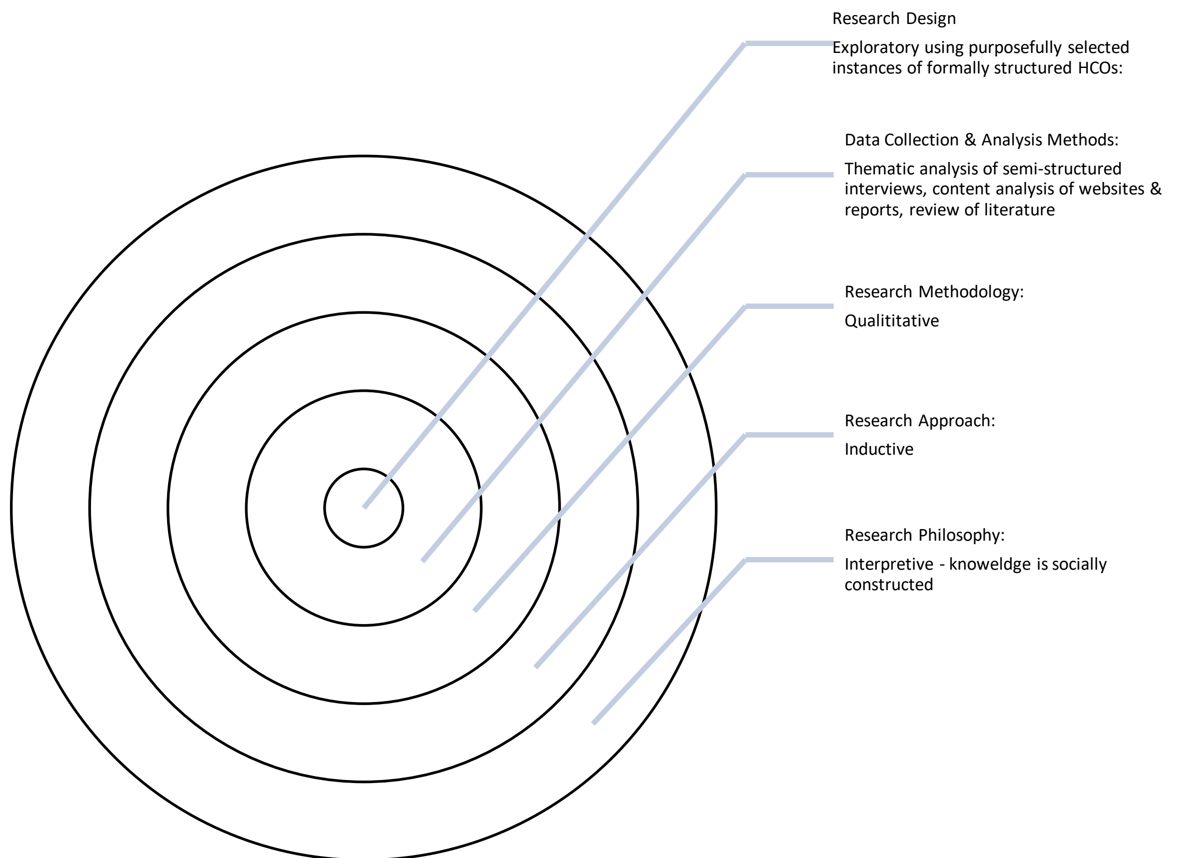


Figure 3.1 Research overview based on Research Onion concept Saunders, Lewis & Thornhill (2007)

3.2.1 Philosophical Approach underpinning research

The philosophical position adopted here arises from the belief that we are social in nature and learn from our experiences living in communities. Knowledge is created by people as they interact with others, and their beliefs can be inducted through analysing and interpreting what they say and write, and how they act. Qualitative research methods are best suited when seeking to understand what people think and when trying to identify concepts common to their experience.

3.2.2 Research strategies and methods

Qualitative research is appropriate when asking 'how' and 'why' in relation to contemporary issues. While the research design was not based on case studies, the selection of four organisations, chosen to illustrate some of the differences and similarities across formally structured HCOs in Australia, was guided by Yin's methodology for case study research (Yin 2009, 2011) and Eisenhardt's advice on the ideal number of cases (1989:545).

This purposeful selection of HCOs enabled insights from what could be considered as 'polar opposites' and short vignettes of each illustrated the broad range of HCOs operating in Australia from highly organised professional federated organisations to a network or alliance of small groups, and a small grassroots volunteer run organisation. Collection of additional data from state organisations was possible had it been necessary because two of the four participating HCOs were federated organisations.

Case vignettes (Figure 3.2) describing each organisation's history, structure, purpose and stakeholders, provide the backdrop to and context for data collection and analysis. Participating organisations were identified as HCOA, HCOB, HCOC and HCOD.

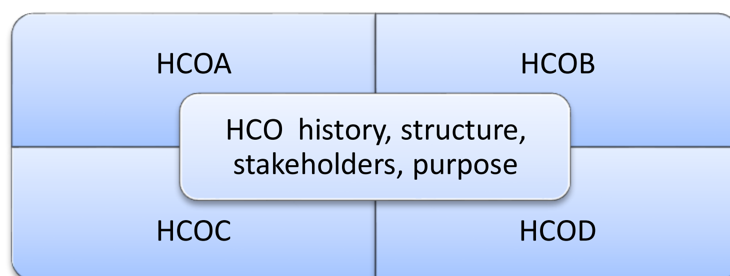


Figure 3.2 Descriptive Case Vignettes

The work of grounded theorists, Glaser (1999, 2007, 2012), Corbin (1998), Charmaz (2004, 2014), Bryant (2007, 2009), Denzin and Lincoln (1998, 2005), Denzin (2001, 2008, 2009) and Walsh et al (2015) and the debates surrounding their approaches, guided data collection and analysis through an iterative approach. Thematic analysis was undertaken on twenty-nine semi-structured interviews, and key documents including strategic plans, policies and reports were also analysed to identify key themes surrounding success.

The research outcomes, if not its design, to some extent reflect constructivist grounded theory as articulated by Charmaz (2004, 2005, 2014) with the three categories of success and the seven factors mediating success, identified through analysing the interview data, validated by members of one of the participating organisations

3.2.3 Primary and secondary data sources

Primary data included interviews and documents, website material, social media reports and annual reports Secondary data included histories of health and the development of the pharmaceutical industry, research on contemporary marketing practices and relationship marketing, and research studies on patient support groups and health social movements (HSM).

3.2.4 Participants

Selection of the four HCOs for this study was based on specific criteria. All four HCOs are registered with the Australian Charities Commission as non-profit organisations and are Voting Members of the Consumer Health Forum in Australia. Each HCO selected also has a national presence, cover or affiliation and all have been in existence for 10 years or more. While they share commonality in purpose, they also reflect some of the diversity among HCOs in Australia. This is evident, not only in size, scope, structure, services and the ways they sustain their activities, but also in how they define success for the organisation.

Two of the HCOs have federated structures and professional salaried management teams; one is a national network of affiliated organisations supported by a highly organised national office and salaried executive, and the fourth HCO is a small national group managed by ‘grassroots’ volunteers. The two federated HCOs provided the opportunity to enable multiple levels of analysis.

HCOs were contacted by email, inviting participation in the research, outlining its purpose and anticipated benefits, and detailing their potential involvement. A follow up telephone call was made one week later to the Executive to confirm the HCO's involvement. Potential interviewees were drawn from group leadership, advisory boards and members. They received background information about the proposed research together with an invitation to participate via email from the HCO Executive. On receipt of a signed consent to participate, the researcher made contact with the participant to set up suitable interview times. Interviews were conducted at the HCO office or at another location of the interviewee's choice. Times convenient to interviewees were negotiated.

While there was no pre-determined number of individuals per HCO to be interviewed, the researcher aimed to interview a minimum of five people from each participating HCO. However only one person in HCOD was available for interview. While this was disappointing, the lack of more HCOD participants did not compromise the research since the purpose of case vignettes was simply to illustrate the range of organisations. Rather the situation reflected HCOD's structure as a formal but loose network of smaller groups. Interviews were conducted with executives, managers or committee members of each organisation. With the exception of HCOA all interviewees were paid employees of their organisations. HCOA interviewees were all members of HCOA with experience in other HCOs.

Stakeholder organizations from industry, research and medical communities were contacted by email, inviting participation in the research, outlining its purpose and anticipated benefits, and detailing the potential involvement of key representatives. Potential stakeholder interviewees received background information about the proposed research together with an invitation to participate via email to their organisation's office. On receipt of a signed consent to participate contact was made with the participant to set up suitable interview times. Interviews were conducted with representatives of two stakeholder organisations.

All participants were fully briefed in advance of interviews and informed of their right to withdraw from the research at any time. All were offered a summary of the report in recognition of their involvement. All voluntarily chose to participate and signed consent forms circulated via the participating organisations.

Participants included their contact details on returned consent forms enabling the researcher to approach them directly to set up a suitable time for interview. Negotiating interview times and places most suitable for interviewees minimised the burden of participation.

3.3 Data Collection and Analysis

3.3.1 Process overview

Data was collected, analysed and integrated in three phases. In Phase 1, HCO data was collected in semi-structured interviews and via content analyses of collected documents.

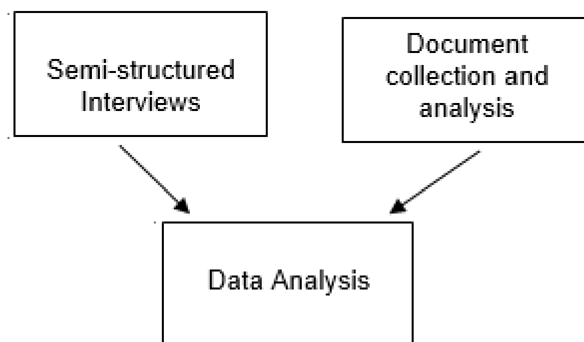
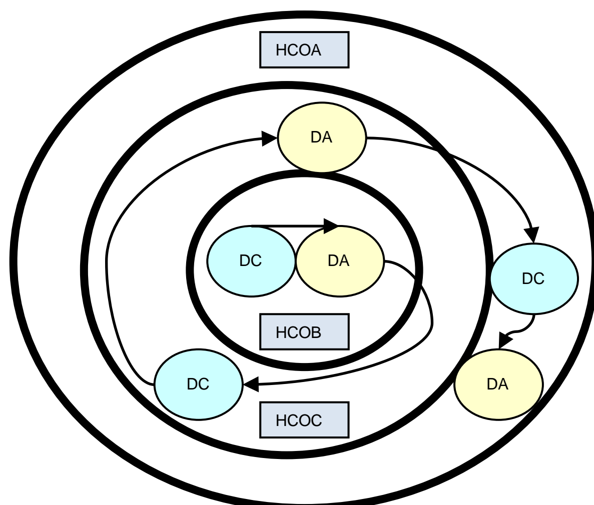


Figure 3.3 Data collection and analysis

Reflecting on data collected in one organisation informed what was collected in the next in an iterative process (Figure 3.4), enabling the grounding of concepts of success (Glaser and Strauss, 1967).



DC = Data Collection   DA = Data Analysis

Figure 3.4   An iterative approach

Phase 2 explored the views of external stakeholders primarily through analysis of secondary data in documents available in the public domain or via stakeholder websites or other online media. Umbrella organisations representing the interests of health and medical industries including Medicines Australia (MA), the Medical Technology Association of Australia (MTAA) and Pathology Awareness Australia (PAA) were identified as external stakeholders with all having published Consumer Engagement Policies. Other external stakeholders included research bodies such as the National Health and Medical Research Council (NHMRC) and Research Australia; government agencies such as the Department of Health and Aging (DOHA), the Therapeutic Goods Authority (TGA) and the Pharmaceutical Benefits Advisory Council (PBAC), and pharmaceutical and diagnostics companies. Interviews were conducted with participants from three stakeholder organisations.

In Phase 3 concepts of HCO success emerging in Phases 1 and 2 were re-examined in light of recent relevant literature as represented in Figure 3.5 below.

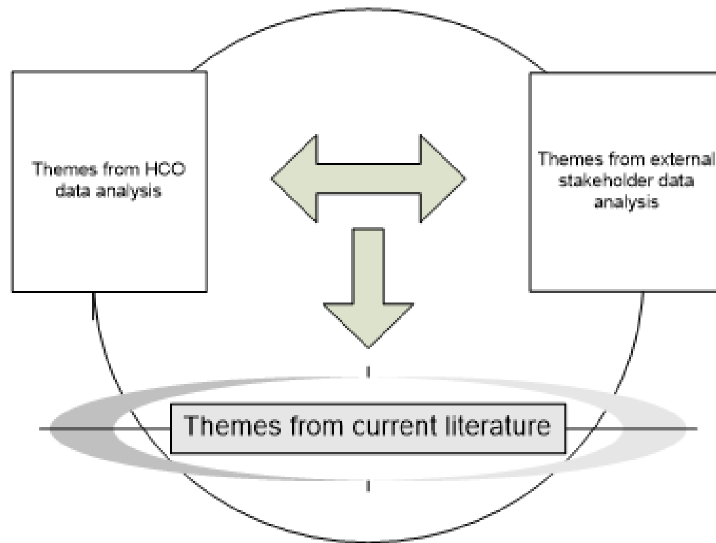


Figure 3.5 Integration of data collected from stakeholders and current literature

In addition to data from semi-structured interviews, observations and documents, my research drew on literature related to the governance and management of the broader classification of non-profit or not-for-profit organisations. Literature was constantly reviewed during Phases 1 and 2, and in Phase 3 a final review of the extant literature on Stakeholder Theory and Organisational Theory, research in the Not-for-Profit sector and changes in government policy was undertaken.

An initial review of literature was undertaken in order to help define the scope of my research question. Once the three categories of success (Performance, Profile and Purse or 3Ps) and the seven mediators (7Cs) had emerged from the interview data, another review of the literature revealed congruence between the three Ps and findings from earlier research (Lecy et al, 2012:439 - 440). The work of Forbes (1998) and Tucker (2015) informed the development of the strategic planning framework presented in Chapter 6.

3.3.2 Interviews

Semi-structured face-to-face interviews were conducted with participants in NSW, ACT, Victoria, South Australia, and Tasmania. Telephone interviews were conducted with participants from Queensland. There were no interviews with participants from the Northern Territory and Western Australia, and although this could be considered a limitation, I believe the experiences of interviewees in the smaller states of South Australia, Tasmania and the ACT reflected those of individuals in Western Australia and the Northern Territory. Standardised interview questions were prepared and used for all interviews ensuring reliability across instances. Interview protocols are included in Appendix 3.

Data was reviewed following each interview in order to 'fine tune' subsequent interviews. Interviews provided rich insights into individuals' motivations for being involved with the HCO, their experiences within the organisation, their views on current operations, factors contributing to or limiting its success and on changes they anticipated would be necessary for future success.

Table 3.1 shows the number of interviews planned and the number conducted. In total 29 people were interviewed from 4 HCOs and 2 stakeholder organisations. Three interstate interviews were conducted with 2 and 3 participants at the same time. Another two interviews were conducted by telephone. All interviews were recorded with participant permission. Although the quality of telephone recordings was not ideal, it did not impact the overall quality of data. Notes taken during these interviews assisted in the data analysis.

Table 3.1 Number of interviews

Interviews	Planned	Actual
Health Consumer Organisations (HCOs)	Min 4	4
Individuals (HCO leadership, advisory board, members, others)	Min 20	29
Stakeholder organisations		2

Table 3.2 presents a summary of interviewees.

Table 3.2 Interviewee Summary

Role in HCO	Primary Contribution	Professional background	HCO Scope	Code	Time in org'n
Management Committee Member, State Co-ordinator	Engagement	Administration Health	AUS	A1	6 yrs
Medical Advisor	Research	Genetic Research	AUS	A2	>5yrs
Vice President (National)	Program & Service Delivery	Nurse, Nurse Educator	SA	A3	27 yrs
President (National)	Strategy	Social Work Senior Manager, Public Service	AUS	A4	31 yrs
Secretary, National	AdministrationComms, Website & Social Media	Business Analysis, Public Service	AUS	A5	17 yrs
Member	Advice/Feedback	HCO/NGO management, NFP PhD	AUS	A6	11 yrs
GM, Operations (Federation/National)	Operations: Finance, Admin, IT, Programs	NFPs, HCOs	AUS	B1	3 yrs
CEO (Federation/National)	Policy & Strategy	Government; Health; NGOs	AUS	B2	15 yrs
Manager, Research (Federation/National)	Research	Public Service, own business	AUS	B3	3 yrs
CEO (State)	Policy & Strategy	State Government	NSW	B4	4.5 yrs
GM, Services (State)	Program & Service Delivery	HCOs, Public Health, NGOs	NSW	B5	3 yrs
GM, Marketing & Communications	Engagement	Health/Corporate Business	NSW	B6	4 yrs
Manager, Policy & Research (State)	Policy & Research	Government & NFP	NSW	B7	16 mths
CEO (State)	Strategy & Operations	Small business & tourism	TAS	B8	18 yrs
Business Manager	Administration, Operations & Finance	Accounting NFPs,	TAS	B9	3 mths
CEO	Strategy	NFP management	SA	B10	7 yrs
GM, Organisational Development	People:HR, Workforce planning, volunteers	NFP/Private commercial sector	SA	B11	3 yrs
CEO (Federation)	Strategy	Education, public & private sectors	AUS	C1	3.5 yrs
Manager, National Programs	Program & Service Delivery	Education	AUS	C2	7.5 yrs
Manager, Partnerships Manager	Engagement	Marketing	AUS	C3	<6mths
Manager, Community Support Programs	Program & Service Delivery	Corporate	AUS	C4	6 yrs
CEO (State)	Strategy & Operations	NFP management	SA	C5	5 yrs
Community Support Co-ordinator	Program & Service Delivery	Nursing	SA	C6	3 yrs
CEO (State)	Strategy	Nursing, Health Promotion	TAS	C7	13 yrs
CEO (State)	Strategy	HR/ER Government & Industry	VIC	C8	17 yrs
CEO (State) CEO (Federation/National)	Strategy	NFP Manager	AUS	C9	3.5 yrs
National Programs Manager	Program & Service Delivery	Consumer Engagement	AUS	D1	4 yrs
CEO Research Organisation	Strategy	Finance		E1	3yrs
CEO Diagnostics Company	Strategy	Scientist		E2	10 yrs

3.3.3 Data Analysis

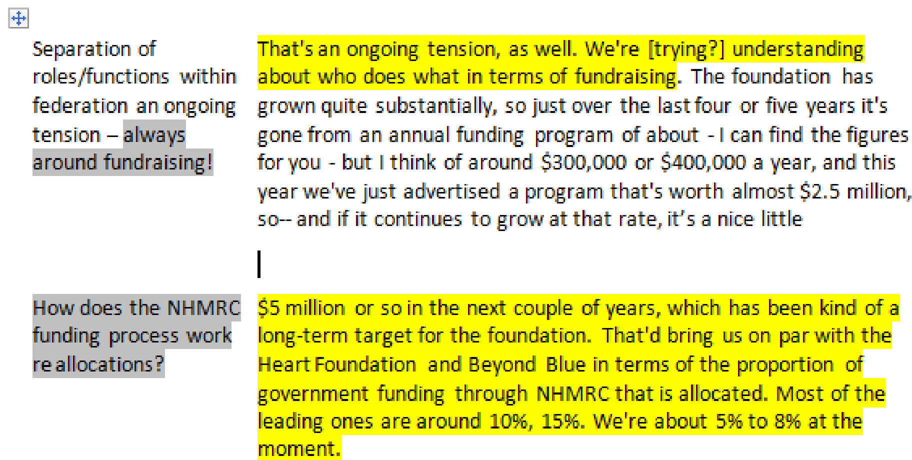
Analysis of semi-structured interviews generated a number of themes around concepts of success and factors mediating success. Content analysis of policy and position statements, annual reports and other external communications in printed publications and on-line media, informed an understanding of the purpose, structure, governance and operations of HCOs and the interests and positions of stakeholder organisations in relation to HCOs (Figure 3.3).

Maintaining detailed field notes during data collection and analysis enabled the synthesis of information between HCOs and the identification of gaps or questions for further exploration in subsequent interviews. Internal validity was supported by adopting the same approach in each instance, exploring and then comparing characteristics and features such as HCO purpose and governance structure, and finance and funding mechanisms. In addition, strategic plans and strategies for engaging members and external stakeholders including the community, government, healthcare providers and corporate businesses, were examined.

The concepts of success and mediating factors documented in Chapters 4 and 5 were 'distilled' from themes emerging from repeated listening to audio recordings of the interviews (often while driving to work), reading and re-reading transcripts, and reflecting carefully on what was said, what was meant and on my observations and notes made during the interviews. All interviews were transcribed verbatim and content analysis of transcripts and key documents was undertaken to reveal factors believed by stakeholders to influence success of HCOs in Australia.

Responses to the question, 'How would you define success for your organisation and other HCOs or patient support groups?' were coded and the codes were aggregated into overarching themes, with concepts of success emerging in three categories: profile, performance and purse. Similarly, responses to the question, 'What factors contribute to success for HCOs?' were coded and codes were aggregated and then distilled to reveal seven enablers: clarity, connectedness, credibility, contribution, capacity, capital and creativity. These are discussed in Chapter 5.

Figure 3.6 shows is an extract from one transcript with annotations in left side margin showing memos and codes (tension, separation of roles within federations).



Separation of roles/functions within federation an ongoing tension – always around fundraising!	That's an ongoing tension, as well. We're [trying?] understanding about who does what in terms of fundraising. The foundation has grown quite substantially, so just over the last four or five years it's gone from an annual funding program of about - I can find the figures for you - but I think of around $300,000 or $400,000 a year, and this year we've just advertised a program that's worth almost $2.5 million, so-- and if it continues to grow at that rate, it's a nice little
How does the NHMRC funding process work re allocations?	$5 million or so in the next couple of years, which has been kind of a long-term target for the foundation. That'd bring us on par with the Heart Foundation and Beyond Blue in terms of the proportion of government funding through NHMRC that is allocated. Most of the leading ones are around 10%, 15%. We're about 5% to 8% at the moment.

Figure 36 Example of transcript analysis

3.3.4 Data Integrity

NVivo 10 was used to maintain the “chain of evidence” (Yin 2008), serving as the database or repository holding interview audio files and transcripts, and pdf files of literature and documents. Memos, notes and observations were also stored in NVivo and interview transcripts were initially analysed using NVivo.

Having identified a number of nodes using NVivo I started line-by-line manual coding of transcripts at first highlighting and annotating hard copies of word documents. This helped me gain a deep understanding of emerging themes. Having completed line by line coding manually for a number of transcripts I returned to working online more efficiently.

The rigor of the research and its conclusions was supported by collecting data from multiple sources. External validity was further supported by investigating more than one organisation, exploring and describing characteristics of each HCO and by including data from a range of stakeholders external to HCOs.

Participant confidentiality was protected through keeping individuals’ details separated from their records of interview. In an attempt to minimise the attribution of data collected to specific participants or participating organisations, all information provided was treated confidentially and all interviewee data de-identified.

Identifier codes were applied to each interview transcripts, names of individuals were changed, organisations given acronyms and all conditions referred to as ‘the condition’ or as HCA, HCB, HCC or HCD (See Table 3.3).

Personal details were kept separately from responses and only de-identified data was used in reporting the outcomes of this research. The list matching names and code numbers has been stored separately from other records.

All electronic data files are password protected as are audio recordings of participant interviews. Participating Health Consumer Organisations have not been identified in the final report and are identified simply as HCOA, HCOB HCOC and HCOD.

All data have been securely stored at all times in a locked filing cabinet in the researcher’s home office. Password protected electronic files are also held on the researcher’s personal computer and password protected back-up files on a separate drive. On completion of the project, the data will be transferred to the University of Wollongong where it will be kept securely for 5 years, as per the University’s Code of Practice – Research and the Australian Code for Responsible Conduct of Research (NHMRC 2007).

3.4 Reflections on the research process

One of the challenges for this researcher has been reconciling unique contributions to the overall concepts emerging from this research with what had been identified in earlier research and literature. I have made every effort to acknowledge and reference the work of others where there appears to be strong alignment in the outcomes of my research and earlier studies.

Another challenge has centred on the literature review. I started out trying to locate literature using terms such as health consumer organisations and patient support groups before moving on to the much larger body of literature around the broader ‘not for profit’ sector and then finally discovering studies under health advocacy and activism. On reflection this reveals a bias on my part in assuming that terms familiar to me from my experience within the pharmaceutical industry, for example ‘patient support groups’ and ‘health consumer organisations’, would be more widely used.

Initially I approached this research from a business or organisational performance perspective but put this aside until after I had analysed the interview data. I have not attempted to explain my findings as relating to specific organisations because the research objective was to identify common concepts.

I have addressed potential concerns about a perceived lack of rigor in qualitative research, by following Eisenhardt's process for building theories (Eisenhardt 1989), 'showing the workings' (Holliday 2002) and applying replication logic (Yin 2009) through my descriptions of several HCOs

The next three chapters review the findings and present some practical tools for HCOs interested in applying a stakeholder approach to strategic planning.

Chapter 4 describes the organisations participating in the research before presenting an analysis of the findings, describing what success means for the research participants. Chapter 5 details the factors recognised as enabling or inhibiting its achievement.

The application of different theoretical lenses discussed in Chapter 2, helped with the analysis and interpretation of the concepts and mediators of success. Stakeholder literature contributed to understanding 'connectedness', 'contribution' and 'clarity'; social capital literature informed discussion of 'connectedness', 'creativity' and 'capital', and resource dependence literature 'connectedness', 'credibility' and 'capacity'.

Chapter 6 outlines a number of strategic planning frameworks before presenting a new model integrating the most relevant aspects of frameworks previously developed by Knox and Gruar (2007), Frooman (2010), Garriga Cots (2011) and Al Tabbaa, Leach and March (2014). It provides a number of practical tools for HCOs interested in applying a stakeholder approach to strategic planning.

In addition to this thesis, which provides a contribution to theory, a report is available for those participants who expressed interest in the outcomes and will be more widely available for other groups interested in adopting the framework to support their strategic planning process.

CHAPTER 4: RESEARCH FINDINGS PART 1

4.1 Health Consumer Organisations in Australia

4.1.1 Case Vignette HCOA

4.1.2 Case Vignette HCOB

4.1.3 Case Vignette HCOC

4.1.4 Case Vignette HCOD

4.2 Success for HCOs in Australia

4.2.1 Profile

4.2.2 Purse

4.2.3 Performance

This chapter presents the findings arising from an analysis of data collected from the four participating HCOs and relevant literature. Section 4.1 presents vignettes of each of the HCOs participating in this research, briefly outlining the history, purpose, structure, governance and funding arrangements of each organisation. Section 4.2 explores the three categories of success: Profile, Purse and Performance, identified in the research, and provides examples of the key factors mediating success in each category. Section 4.3 presents descriptions of each of the factors emerging from the data: Clarity, Contribution, Credibility, Creativity, Connectedness, Capital, Capacity, illustrating the descriptions with participant quotes. Together with the literature from Chapter 2, these findings form the foundation for frameworks presented in Chapter 5. Section 4.4illustrates some of the challenges identified by participating organisations.

4.1 Health Consumer Organisations in Australia

'I've never heard a term health consumer organisation. I've always heard them as support groups, patient support groups or patient support organisations. Health consumer organisations is probably a better term for the world we live in, and political correctness' (A2)

As introduced in Section 2.4.1, for the purposes of this research Health Consumer Organisations are defined as groups formed to support individuals with specific medical conditions, and/or their families and carers, through education, service delivery and advocacy.

In Australia, HCOs, also known as Patient Support Groups, play an important role in supporting people facing a shared health condition. HCOs across Australia vary in scope, size and structure. They range from very small groups active in local communities and include alliances established to represent, and advocate on behalf of individuals with rarer conditions. In addition to groups that focus on specific health conditions at state and national levels, there are also peak organisations established to represent the interests of all health consumers at either state or national levels and often set up by governments following major health reviews to get consumer input into and feedback on issues affecting the health system. Examples include state based Health Consumers NSW, Health Consumers Queensland, Health Consumers Alliance of SA, Health Care Consumers Association ACT, Health Consumers Council in WA and the national Consumer Health Forum of which the various state peak bodies are also members.

Members of these peak bodies include 'condition specific' groups, which in turn may be state based organisations, state based affiliates of federated organisations or national organisations.

The four HCOs participating in this research provide insights into 'condition specific' support groups operating at local, state and national levels. Each organisation has a national presence or affiliation, and each has been operating for a minimum of 10 years. All are registered with the Australian Charities and Not-for-profits Commission and are members of the Australian Health Consumer Forum. The participating HCOs are referred to here as HOCA, HOB, HCOC and HCOD, and the conditions they represent are referred to as HCA, HCB, HCC and HCD, to preserve anonymity as agreed with participants.

4.1.1 HCOA

HCOA is the peak organisation providing support for people with the most common genetic disorder in Australia. According to HCOA's website about 1 in 200 Australians of northern European origin have the genetic risk for the condition, referred to throughout this research, as HCA. If left undiagnosed and untreated, HCA can lead to chronic health problems as people reach early middle age.

Organisation, Structure and Operations

HCOA is a non-profit charity registered with the Australian Charities and Not-for-profits Commission (ACNC) as 'an institution whose principal activity is to promote the prevention or the control of diseases in human beings' (ACNC Register 01/01/14). With an annual revenue of less than $250,000, it is classified as a small charity on the ACNC register and has Deductible Git Recipient (DGR) status endorsed by the Australian Taxation Office. Established in Queensland in 1991 to provide support for people affected by the condition, HCOA is run entirely by volunteers. Until 2010 when a new national management committee assumed responsibility, the organisation had operated as a loose informal network of state groups.

'It just seemed to be a much more sensible thing to become part of a national movement, to be more powerful than simply to be a state body. And more powerful in terms of an overriding desire to not just support people's support, but to get the word out, so people can be diagnosed early - a timely diagnosis.' (A4)

'Yeah, well, in 2010, when the new people started, we switched it. It had been state groups. So there was the Tasmanian group and the South Australian group and the Queensland group, but we said, "Well, this really should be a national group." But because there wasn't, if you like, the manpower in those other states, it seemed the way to have a national umbrella was to make it a national group.' (A1)

Analysis of membership by state undertaken in February 2015, shows that HCOA has established wide if not complete national coverage. NSW and Queensland account for approximately 30% of national membership each and around 20% comes from Victoria. Around 8% of total membership is from Western Australia with another 6% each in South Australia and Tasmania. 2% is from the Australian Capital Territory with none recorded in Northern Territory. When the new committee took office in 2010 it adopted a different way of working together.

'Okay, so that's a point at which we sort of changed the way in which we operated…. So, the way we do operate is very largely by email. We have monthly voice meetings, which I do Skype, but my connection's so poor, we very often end up using the telephone - conference calls. There's a lot of email. We do use Huddle as a cloud program, so effectively we don't have a filing cabinet. We don't have an office. We don't like to tell people we exist in the cloud. It sound as though we're a bit more sophisticated than we are probably' (A4)

They meet face to face as a management committee once a year following the annual general meeting. Individual members also meet from time to time at information sessions. All other meetings are virtual via Skype or telephone.

We do most of our committee meetings on Skype. We used to do teleconferencing and it cost $100, $150, $200 a session. So I think that eight people on there was a couple of grand a year. (A5)

Members of the Management Committee bring direct personal experience to their mission as well as diverse professional and technical expertise. Apart from one, a rural GP who acts as the Medical Liaison Officer, all committee members have the condition. All are strongly committed to the vision, mission and strategic objectives of the organisation and each has assumed specific responsibilities drawing on their individual strengths and capabilities. The President, described by one of the medical advisors (A2) as '*the ultimate diplomat'*, has a long history in the public service and not for profit sector, training first as a social worker and working in administration and management of community services. The Vice President is a nurse/midwife, nurse educator and an experienced manager of Telephone Help Lines. The Treasurer has his own professional practice business and the social media/internal communications person running the 'virtual office' has a background in business analysis and a great willingness to learn.

'I have a fairly good grasp of technology and stuff. I didn't know any of this stuff before I started. I could learn and find out stuff really well, and that's a lucky skill. We didn't come in all equipped. We discovered all these things along the way.... I'm not a developer or a programmer [but] I understand how businesses work and how IT works and how they can go together'. (A5)

Other committee members have expertise in administration, advocacy, social media and medical research. Respect for each other's strengths and contributions was evident from interview transcripts and researcher observations made during two strategic planning meetings.

'We all respect each other, and we all bring to the table very, very different skill sets, and I think it's that combination of differences that actually has seen the group really progress and still exist after 20 years'. (A1)

'The powerhouse of operations is probably mainly Sam. He really operates like an executive officer. Sarah just carries that huge load of the 1300 number now, and Meg, Sam and I have come to operate as an executive group in effect. We've been delegated various things like who delegates the Awareness Week, and various other tasks. So, that's shaped up according to people's preferences, availability, attributes, commitments. That's it. That's fine then. It works well' (A2)

The Management Committee is guided by a panel of 5 Medical Advisors who are leading researchers in the field. One member of the Medical Advisory panel is also one of two patrons of the organisation. The other patron is the founder who was repeatedly acknowledged by the current management committee for her strong commitment to the original purpose of the group.

'And I think originally, it was Lou and a group of her friends at her kitchen table, literally. And they would fold 1,000 newsletters and put them in envelopes themselves and go and mail them. And they'd all come together on a regular basis and they'd do that. And you do need some level of commitment to be doing those sorts of things' (A1)

Vision, Mission, Strategic Objectives and Performance

In 2010 the Management Committee established a five year strategic plan, articulating a vision and mission for the 'new' national organisation and expanding its focus to increasing awareness of the condition among both the general community and the medical/research communities.

HCOA 's mission is 'to provide support and promote awareness, early diagnosis and research'. Its vision is simple: 'No Australian will suffer harm from HCA'.

HCOA's stated objectives clearly indicate what they do to achieve their vision.

- To provide support and information for people to assist them manage the condition
- To promote community awareness
- To raise awareness among medical health professionals, in order to improve the rate of early diagnosis and treatment.
- To influence and advocate for Health Policy Improvement
- To support, encourage and maintain a high interest in research.

Activities undertaken since 2010 have been closely aligned to these strategic objectives and the organisation can identify a number of successful performance outcomes. They collect and analyse data measuring the effectiveness of activities in relation to the achievement of objectives and the realisation of their vision. HCOA's revamped its website after the formation of the new committee in 2010. It launched a Facebook page to provide support for people with the condition. HCOA is active on Twitter. Information brochures are printed and distributed via general practices. National Awareness Weeks are held annually to promote community awareness, and (somewhat serendipitously) a successful awareness ad was run on regional television across Australia.

'We do dream about having a national TV ad. We've got one actually, but it's only on one particular network because they do it for free for us. That's been a big success actually. They said they'd play it around Tasmania and all of a sudden it starting popping up all over Australia on Southern Cross Austereo Network. We get an awful lot of phone calls from that. That's one of the things we'd like to do is get a TV ad more widely into the metro areas because that's where funding comes in' (A5)

A major milestone was achieved in 2014 when HCOA held its first bi-annual medical conference aimed at raising awareness among health professionals. They have also been successful introducing treatment pathways in a number of regions, and in developing close relationships with a number of research facilities nationally.

'*They perform very, very well. I compare it to some other groups, which I won't name, which do have funding, and their ability to deliver on such small amounts of money and entirely voluntary labour force is just fantastic. They clearly have had some level of influence in setting the agenda. The fact that there're discussions about the possibility of universal testing is just awesome, just great'. (A6)*

All of this has been accomplished on a very small financial base illustrated in Table 4.1.

Table 4.1 Financial Summary for HCOA for the period 2010 - 2014

HCOA Financial Summary	2014	2013	2012	2011	2010
Revenue	$80,248	$64,570	$75,255	$33,549	$29,455
Expenses	$69,448	$66,307	$47,608	$39,098	$24,420
Surplus/Deficit	$10,800	-$1,738	$27,647	-$5,549	$5,035

Funding

The activities of HCOA are funded principally through membership subscriptions, and individual donations usually made at the time of membership renewal. To date the organisation has received few grants. An internal analysis of HCOA's membership database revealed a potential challenge to on-going funding derived from membership subscriptions and donations with a 6% decline in overall membership over the past 2 years.

Analysis of the length of time individuals were members revealed about 45% of members have been members for five years or more and 75% have been members for more than one year. Individuals may join the organisation for a limited period, leaving (presumably) once their initial needs for information and support have been met.

'They'll drop off after a year or two, cancel their membership, and we never hear from them again.' (A5)

Others maintain membership for much longer periods indicating a commitment to the organisation's vision and recognition that the group is achieving their objectives. Figure 4.1 shows results of membership survey conducted in 2014.

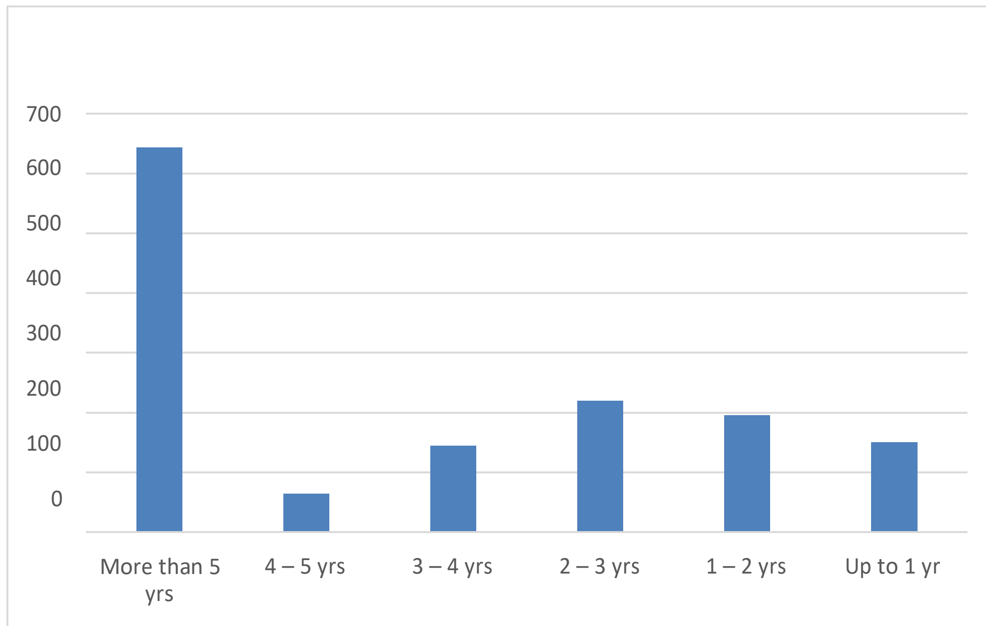


Figure 4.1 Length of time as member

The loyalty of longer-term members appears to be expressed as small donations at the time of membership renewals. This was thought to be a reflection of their satisfaction with the way HCOA communicates with them.

'Then we've got this bigger core of members who up to two, three, up to ten years, who are really loyal members. They sign up every year and they often give us a small donation with their membership. They don't give us donations at other times, but they often do at membership times. I think they're fiercely loyal to the organization and they're really happy now that they can actually see a lot of things happening. They were always loyal, but now they see all the media, and we're always having stories in the newsletter'. (A5)

As shown in Table 4.2 the donations are small. Nevertheless, they provide some indication that members are willing to support HCOA's work.

Table 4.2 Membership subscriptions, renewals and donations

Year	New members	Renewals	Average donation per new member	Average donation per renewal
2008	169	620	$1	$5
2009	176	638	$1	$4
2010	213	693	$1	$5
2011	298	788	$4	$8
2012	270	956	$6	$9
2013	212	853	$5	$10
2014	150	873	$6	$10

The number of new memberships could provide HCOA with a performance measure indicating the effectiveness of awareness raising activities designed to support the achievement of two of their strategic objectives, namely to provide support and information for people to assist them manage the condition, and to promote community awareness**.** Similarly membership renewals and donations could be an indicator of member satisfaction with the quality and quantity of information and services provided by HCOA, and/or a measure of their commitment and loyalty arising from the quality and quantity of media exposure and social networking//Facebook activity.

4.1.2 HCOB

HCOB is the peak organisation providing support services, advocacy, education and information for people affected by HCB the second leading cause of death in Australia, and a related condition known as HCZ. HCOB administers national government funded programs and services, and provides advocacy for the 1.5% of the Australian population living with HCB and HCZ.

Organisation, Structure and Operations

HCOB is a non-profit charity registered with the Australian Charities and Not-for-profit Commission (ACNC) as a Public Benevolent Institution, with an additional entry sub-type of 'Advancing Healthcare' (ACNC Register 01/0/14). With an annual revenue of $1 Million or more, it is classified as a large charity on the ACNC register and has Deductible Gift Recipient (DGR) Status endorsed by the Australian Taxation Office.

HCOB is a federation of state and territory member associations, representing more than 340,000 Australians living with HCB or HCZ and those involved in their care, providing advocacy, support services, education and information. Both conditions are well recognised in the community, with more than 1 million people involved in the care of someone with one or both conditions. Of the four organisations studied, HCOB has the highest profile within the community.

HCOB's national office is based in Canberra, the Federal capital a location which supports its advocacy and policy development role, and its role in administering national contracts with the Commonwealth Government. In addition to promoting awareness of HCB/HCZ, it provides research grants to emerging researchers through the Australia Research Foundation.

At the national level HCOB represents the interests of its federation of state and territory members on all matters relating to HCB/HCZ and carer issues. At the state and territory levels, HCOB provides support services, including community support groups, a national helpline, information, education and training. States and territories also undertake public awareness activities. Respective governments fund many of these programs.

'The growth of the organisation over the last ten years, and particularly over the last two or three years has been huge, and our profile with government has increased significantly, and our reputation.' (B1)

HCOB's agenda is inclusive of the diversity reflected in the broader Australia community with specific policies addressing the needs of Aboriginal and Torres Strait Islander people, younger people, people from culturally and linguistically diverse backgrounds, and lesbian, gay, bisexual, transgender and intersex (LGBTI) people. To inform its work and strengthen its role in representing its constituents, HCOB has established five national advisory groups, each with a different focus and/or membership.

The National Consumer Advisory Committee provides consumer representation to HCOB regarding issues of importance or concern to consumers and a voice for people with HCB/HCZ advocating for service provision, information, support and education. The Research Network has an active role advising on research and knowledge translation projects, and sometimes making decisions on project funding. The National Cross Cultural Network provides advice on raising awareness of HCB/HCZ, developing resources and delivering services for culturally and linguistically diverse communities. The National Aboriginal and Torres Strait Islander Advisory Group aims to improve equity and access to culturally safe services for Aboriginal and Torres Strait Islander people with HCB/HCZ and to their carers, families and communities.

The Board comprises the National president, elected by the members of the Association, the CEO and up to eight Directors nominated by each member organisation. It meets face-to-face three times a year and is responsible for the governance of the organisation. The Board establishes the results to be achieved and the task of achieving these results are delegated to the Chief Executive Officer.

The Chief Executive Officer is responsible for the management of the organisation and its operations. The current CEO is a career health consumer advocate with a high public profile. The previous CEO was a well connected ex public servant.
The Patron represents the face of the organisation in the community.

The current Patron is a highly respected and well recognised senior member of the Australian community with a long history in the public service. The previous Patron was also a well-recognised and respected high profile media personality.

Vision, Mission, Strategic Objectives and Performance

HCOB's Vision is to be 'a leader in the prevention of HCB and HCZ, while valuing and supporting people living with HCB or HCZ'. Success for HCOB was identified as:

- Being recognised by our stakeholders as the key leadership organisation for HCB and HCZ'
- Achieving outcomes that improve quality of life for people with HCB and HCZ
- Increasing the number and proportion of people with HCB and HCZ who we support
- Strengthening our National footprint in HCB and HCZ services and education
- Improving the extent to which we work as a partnership

HCOB has established six areas for strategic focus and identified 23 priorities in these areas. Strategic objectives have been identified for Policy and advocacy, Community awareness, understanding, attitudes and actions; Service innovation and expertise; Leadership in research (medical and non-medical); Organisational sustainability and growth; Governance and leadership.

Funding

The activities of HCOB are funded principally through government contracts and grants, donations and bequests, the sale of goods, fees for services and investment interest. Two separate pharmaceutical companies have supported HCOB with funding for an international conference and a research publication. The financial summary for the period 2010 – 2014 is shown in Table 4.3.

Table 4.3 Financial Summary for HCOB for the period 2010 - 2014

HCOB Financial Summary	2014	2013	2012	2011	2010
Revenue	19,629,990	18,352,236	12,900,770	12,508,665	11,470,731
Expenses	19,738,430	17,492,609	12,994,408	12,408,477	11,462,981
Surplus/Deficit	-108,440	859,627	-93,638	100,188	7,750

4.1.3 HCOC

HCOC is the peak organisation delivering 'evidence-based preventative health strategies' to over 200,000 people every year. HCOC 'offers support, training and resources to the primary health care sector, ensuring patients and their carers have the skills, information and power to be actively engaged in the decision making process' (downloaded from HCOC's website)

Organisation, Structure and Operations

HCOC is a non-profit charity registered with the Australian Charities and Not-for-profit Commission (ACNC) as a Public Benevolent Institution. A federation of state and territory member organisations, HCOC is committed to working collaboratively to seek a cure for HCC and to improve the quality of life of people with the condition by providing accessible, affordable and evidence-based services. Its vision is to be Australia's leading charity advocating for the broader therapeutic area in which HCC sits. HCC, recognised as a national health priority, a chronic disease affecting over 2 million Australians.

At the national level, HCOC provides leadership and support to the member organisations through its training and education framework and quality assurance program. It advocates on behalf of people with HCC on issues such as the cost of medications and investment in research, and issues influencing their quality of life. The State and Territory member organisations deliver training and related services to health professionals, community workers, teachers, staff and management teams, to ensure people with HCC receive appropriate medical assistance when they need it.

A National Scientific and Medical Advisory Committee and a National Research Council oversees medical research initiatives and advises on medical matters. Two mothers, whose children had HCC, initially established in NSW in 1962. Their foundation purpose was to raise money for research into finding a cure for the condition and this remains the primary purpose of HCOC today.

The board comprises eight members representing every state and territory, the national president and two independent board members. The Chief Executive Officer is responsible for the management of the organisation and its operations. The current CEO is a 'not-for-profit careerist 'with business qualifications and senior management experience within the broader not-for-profit sector.

Vision, Mission, Strategic Objectives and Performance

In 2013 a five year strategic plan was developed, articulating vision and goals for the newly consolidated national organisation. HCOC's goals fall under 6 strategic focus areas – Programs and Partnerships; Research, Evaluation and Innovation; Advocacy and Engagement; People and Performance; Profits and Sustainability, and Leadership and Governance.

Research support is a clear focus for HCOC, which is currently supporting a number of research projects with a contribution of just under $1 million in grants. It also promotes participation in clinical trials via its website. Annual reports from 2010 to 2014 report on Performance in terms of quantity, for example the number of programs delivered; the number of people trained.

Funding

The activities of HCOC are funded principally through the Department of Health and Aging and with support from a small number of national sponsors. Partnerships in a number of areas are listed in HCOC's annual reports. The 2014 -2015 report includes two pharmaceutical companies and a healthcare company as Program Partners, another four pharmaceutical companies were listed as Research Partners, with one of these sponsoring the group's conference. 19 Community Partnerships were listed and 10 Strategic and Business Partners. The financial summary for the period 2010 – 2014 is presented in Table 4.4.

Table 4.4 Financial Summary for HCOC for the period 2010- 2014

HCOC Financial Summary	2014	2013	2012	2011	2010
Revenue	4,019,247	3,033,213	2,703,866	2,577,154	1,204,147
Expenses	4,014,247	2,980,696	2,703,974	2,576,889	1,211,865
Profits/Deficits	5,000	52,517	-108	265	-7,718

4.1.4 HCOD

HCOD is the peak national organisation for Australians affected by HCD, and consists of a network of more than 110,000 members and 300 Member Groups. More than 90 per cent of our members have had a diagnosis of HCD, and the remaining members have had a personal experience with HCD through a family member or friend. HCD works to ensure that Australians affected by HCD receive the very best support, information, treatment and care appropriate to their individual needs.

Organisation, Structure and Operations

HCOD is a non-profit charity registered with the Australian Charities and Not-for-profits Commission (ACNC) as ‘an institution whose principal activity is to promote the prevention or the control of diseases in human beings’ and an additional entry sub-type of “Advancing Health’ (ACNC Register 01/01/14). With an annual revenue of more than $1 Million it is classified as a large charity on the ACNC register and has Deductible Git Recipient (DGR) status endorsed by the Australian Taxation Office . HCOD is the peak national organisation for Australians affected by HCD, and consists of a network of more than 100,000 members and 300 Member Groups. It was founded in Victoria in 1998 to provide Australians affected by HCD with ‘the very best support, information, treatment and care appropriate to their individual needs’ (downloaded from website, 23/7/15).

‘Advocacy was our main area, but then we ventured into information and support’ (D1)

‘Our advocacy campaigns are very considered, and the way we do that is to utilise the voices of (individuals) in telling the stories, linking with very key stakeholders in creative ways, having a media strategy. ... We're quite good at thinking about all of the stakeholders in our strateg, initiating discussions, whether a round-table discussion with key clinicians and other decision makers. So we've had a number of treatment-related advocacy strategies that have been really successful ‘(D1)

‘For us, we are a consumer organisation. We're not a service-providing organisation that needs to remember to engage with consumers. So we're different. We're the influencers who are trying to make that happen as a normal part of organisations' processes’ (D1)

The founder of HCOD and seven of the ten Board members at the time of this research have had direct personal experience of diagnosis with HCD. More than 90 per cent of members have had a diagnosis of HCD, and the remaining members have had a personal experience with HCD through a family member or friend. A Strategic Advisory Group of 14 leading health professionals was established in 2012 to inform and support the work of HCOD. The CEO leads a staff of 40 working across three main areas of activity categorised here as Supporter/partner engagement (including corporate relationships, partnerships, fundraising, online & events, media); Member Support (programs & resources, member services, community, diversity); Back/Head Office functions (technology, finance, policy, HR)

'Well, the way that it's structured here is we have a CEO and we have teams. My area is the programs area, and that encompasses the forums and the member groups and the community liaisons, our online engagement strategies, we've got an online community now, so we've got about 7,000 people who connect via the Internet. We have a sponsorship, communications, and marketing area, and that includes all of the relationships with our partners - our funding partners and our policy team a small team looking at what the issues are, what's the research saying? What's the latest in treatment and care? They have a lot of links with clinicians and researchers. They develop up all of our resources: fact sheets, position statements. They design our advocacy strategies. We have members of the senior leadership team that represent each of those three areas, our CEO and our Board. Our Board are very committed. Many of our Board Members have had HCD themselves or their family members have. So we're like an organisation of teams - that's how we work here.' (D1)

Member Groups are local community based support groups registered with HCOD, promoting the services and resources offered by HCOD. Approximately two-thirds of groups are located in regional and rural areas. (HCOD Annual Report 2013).
The relationship between HCOD and its member groups is one in which the central core group supports capacity building at a local level through its member group network.

'That gets back to what we are. We're a network that's what makes it successful.' (D1)

Vision, Mission, Strategic Objectives and Performance

HCOD 's stated mission is to support, informs represent and connect Australians affected by HCD. Its vision is that 'Australians affected by HCD receive the very best support, information, treatment and care appropriate to their individual needs' (website viewed 23/7/15).

HCOD's stated objectives clearly indicate what they do to achieve their vision.

- To support Australians affected by HCD through services, resources and programs.
- To develop and provide high quality information in a range of formats that helps empower people to make decisions about treatment and care.
- To advocate on behalf of Australians affected by HCD to ensure their voices are heard.
- To connect people who have experienced HCD to build support for individuals, groups and communities.

Information and resources are provided in a number of formats and through a variety of channels. In addition to Resource Kits which are distributed directly to individuals or through medical practitioners and community nurses, HCOD's website provides resource for people affected by HCD. It helps people find information about HCD, and learn about activities, support groups, programs and services.

'We have an online-engagement coordinator (watching) the traffic. And we also have online champions who have been brought on board to welcome new contributors.' (D1)

HCOD presents community information forums around the country to provide women and their supporters with the opportunity to learn about the latest in HCD treatment and research, hear about services available in their community and share stories and meet other local women diagnosed with HCD.

'In 2013, we presented 13 forums with 2,277 people attending. The forums focussed on reaching women living in rural and remote areas'. (D1)

Connecting people is supported through member groups, Community Liaisons, nurses and via individuals listed in the Review and Survey Group.

‘We offer the member groups an opportunity to have their own web page as well. So our support is to build their capacity to support more people in their community. Every few years, we hold a national summit and we bring together a representative from each of the member groups to one place, and run a three-day event where we design workshops, skills development, connection, sharing - that real opportunity for them to learn from one another and (to hear their) successes, what's worked, what hasn't, what have you. We get people in to run workshops on whatever they want topics on. We do a pre-survey with them to see what they want, what their needs are for that type of event.’ (D1)

Some of the performance measurements listed in annual reports include growth in memberships, social media followers, funds raised, services added to directory, resource kits distributed, blogs posted on social media and submissions to government departments/agencies. New memberships could provide HCOD with a performance measure indicating the effectiveness of awareness raising activities designed to support the achievement of two of their strategic objectives, namely to provide support & information for people to assist them manage the condition, and to promote community awareness. Similarly donations could be an indicator of member satisfaction with the quality and quantity of information and services provided by HCOD, and/or a measure of their commitment and loyalty arising from the quality and quantity of media exposure and social networking//Facebook activity.

Funding

The extensive support HCOD provides its network is underwritten by a strong financial position as seen in the financial summary for the period 2010 - 2014 presented in Table 4.5.

Table 4.5 Financial Summary for HCOD for the period 2010 - 2014

HCOD Financial Summary	2014	2013	2012	2011	2010
Revenue	6,994,635	6,871,620	4,848,062	4,957,000	6,217,000
Expenses	5,668,475	5,321,172	4,972,247	5,390,000	4,812,000
Surplus/Deficit	1,326,160	1,550,448	-124,185	-433,000	1,405,000
NET ASSETS	6,915,463	5,581,448	3,774,774		

While HCOD does not depend on member subscriptions, members (groups and individuals) impact the financial position by playing a key role in securing funding through advocacy and involvement in fundraising and awareness activities in their local communities. HCOD is funded by government at both national and state levels. The Australian Government is currently providing $2,382 million to support three programs for a 3 year period until June 2017. In 2013 HCOD implemented a new investment strategy allocating capital into different types of investments with the intent of supporting its long-term sustainability and generating income for programs offered by HCOD (Annual Financial Report 2013). That same year two major fundraising events raised $2.57 million.

HCOD's founding partner aimed to raise $1.5 million in 2016. 12 other corporate partnerships support key fundraising events throughout the year as well as funding specific programs and services.

'We get some funding through (a national research organisation) for particular projects. There's a very strict reporting and accounting process with that and I think part of the arrangements we have with our corporate sponsors is the ongoing connections and demonstrating what we're doing for the income'. (D1)

14 business partners support HCOD through probono work and discounted services. 19 product partners contribute a percentage of their sales revenue to HCOD through their 'cause marketing' activity. 15 companies facilitate workplace giving through regular payroll deductions

4.2 Success for HCOs: Profile, Purse, Performance

'That is why money flows our way - because people trust us, and know that we will deliver' (B7)

This section of the thesis presents what success means for HCOs as generated through an examination of the interview data, documents and literature reviewed in the course of the research. As stated in Chapter 1 there is no single definition of success because of its nature as a socially constructed concept. For this reason, the categories presented here are not definitive but are examples of how success is viewed at a point in time from the perspectives of those participating in this research. In order to uncover what HCOs understand as success, interviewees were asked to nominate other organizations they perceived to be successful and to identify how and why they thought this. Section 4.2 presents evidence from the research in support of the three categories of success identified here as Profile, Performance and Purse.

Successful HCOS

Organisations nominated as successful were recognised for success in terms of how well known and respected they appear to be in the community, their ability to raise funds and their performance. Table 4.6 lists the organisations nominated, providing reasons given.

Table 4.6 Successful HCOs as nominated by participants

HCO	Reasons
Cancer Council	very good at getting information out, advertising, getting attention (B1) (A5)
Arthritis Australia	very good at getting information out (A5)
Haemophilia Australia	marketing and website (A5)
MS Society	the way they share information on their web, the way that they do their co-ordinated research, the way they've set up their research fund (C8)
McGrath Foundation	leveraging its brand
Diabetes Australia	high profile across health, national program via pharmacy widely available, widely known very good support to people with diabetes, strong partnerships (B1)
HCOB	a really well oiled organization , really good for nursing as well for providing education (A3)
HCOA, HCOC, HCOD	
Vision Australia	the way they set up the national organisation (C8)
Life Without Barriers	How it found a solution for Government in an area that was particularly policy sensitive (C8)
Friedrichs	the huge contribution of parents (A2)
CHF	the way in which they are patient facing, and they genuinely engage with people so that they can represent those viewpoints (C8)
The Breast Cancer Foundation	
Beyond Blue	

4.2.1 Profile

'An organisation like this has to have a good public face. (B2)

Profile is often expressed in terms of public image or reputation (Forbes, 1998; Helmig et al, 2010; Drees & Heugens, 2013). Profile success depends on stakeholder evaluations and is supported by the reputational approach which 'measures effectiveness according to the self-reported opinions of some set of persons (Jobson & Schneck, 1982), usually clients, staff, or outside professionals who are familiar with the organizations at hand' (Forbes,1998:186). The main factors mediating profile success are identified here as Credibility, Connectedness and Clarity and illustrated in Figure 4.2.

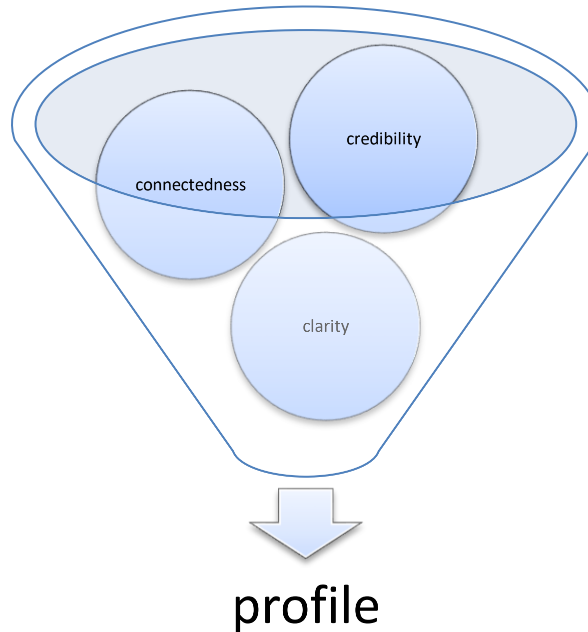


Figure 4.2 Factors mediating success for profile

Credibility

In this research, Credibility was associated with the credentials of its Board and those working within the HCO including celebrities, its reputation, the legitimacy of its claims and the evidence it presents, as well as its governance and financial management practices. Helmig et al's research (2010) identified 'reputation' and 'learning' 'as important value drivers' for potential employees (Helmig et al. 2010 cited in Von Schnurbein, 2014: 365), a view reflected by HCO interviewees.

I had known about this organisation for 12 years, and its reputation. It was an attractive proposition to work here' (B7)

Reputation or credibility is also very important to prospective partners and resource providers. Drees and Heugens (2013) suggested that 'resource providers prefer to liaise with organizations of impeccable social standing, because such linkages tend not to threaten their reputation for sound judgment (Baum & Oliver, 1991). Furthermore 'organizations that are seen as legitimate are also seen as understandable and reliable (Meyer & Rowan, 1977), such that resource providers tend to think of them as less prone to failure because of unanticipated risks' (Drees and Heugens, 2013:1674).

'If we're doing a media release, for instance, it's better off to get Professor So-and-so to do it than someone within the organisation such as myself who doesn't have that medical background. It's important that the board members be willing to use their networks to open doors for us' (C5).

'I think (celebrities) are incredibly valuable and have done a lot of work for these organisations. I know that Rob knows every celebrity with that condition'. (A2)

'In recent times, the profile has lifted dramatically with the arrival of Jan (national celebrity identity) as president. That has enabled us to reach audiences like Business Chic, conferences like Priceline, like Cosmetics, women's magazines, a whole range of settings where we wouldn't normally have got to, and invites from conferences that are now keen to have us because they can have Jan if she's free'. (B2)

'We're a sensible proposition, and we're a good organisation to deal with'. (B7)

Connectedness

The importance of strong relationships to building and sustaining a non-profit's positive reputation,was noted by Balser and McClusky (2005). Consistency in relationships across all its stakeholders leads to congruence in the information exchanged between stakeholders, further enhancing its reputation by supporting 'a generalized perception that the organization acts in a reliable, accountable way.' (2005: 311). Profile success also depends on good media coverage, described by Bonk (2010) as 'a prized commodity... built on a foundation of strong working relationships with key journalists and media gatekeepers' (Bonk, 2010 in Renz, 2010:329-330).

'We've been successful with the Government. We have good relationships with the Australian Nurses Federation. We're very close to the Australian Medical Association. We've worked very closely with Carers Australia. Those last three organisations are always a critical part of our communication strategy. They're always out there helping us. So partnership has formed an important part of our total strategy but it's probably an area where most NGOs could do a lot better.' (B2)

Partnerships with 'for profit' businesses can influence a non-profit's profile either positively or negatively. On the one hand, 'nonprofits can benefit from partnership with well-respected corporations as their reputation may enhance the credibility of the NPO (Nowak and Washburn, 2000)' (Hall et al, 2011:6). On the other hand, a HCO's image could be adversely affected if the corporate partner is perceived as acting in their own commercial interest.

'They have a commercial enterprise where a product manufacturer can buy the right to use a logo. We have enormous problems with it. We left their board, we tried to change it, and we couldn't. You couldn't sue them, they were very careful, but the average person thinks that means use that (and) I won't get HCC' (C1)

Clarity

According to Gainer (2010) branding has recently become a popular concept among non-profit organizations (cited in Renz, 2010:312). Gainer noted that successful brands required consistent delivery of integrated messages 'across all the different aspects of the organization with which clients interact' (in Renz, 2010:324). The need for non-profit organisations to spend time, energy and resources on impression management was identified by Dhanani and Connelly (2012), cited by Pawson and Joannidès in Hoque and Parker (2015: 212).

In this research, the role of a strong respected brand in ensuring a high profile was well recognised, and the lack of community awareness and brand recognition considered to constrain a HCO's ability to secure revenue. This research revealed mixed views among participants about branding and its challenges, particularly in federated organisations, as evident in comments from HCOC interviewees.

Three years ago there (were) eight individual logos (and) brands across the country, as though the condition was different depending on the State that you lived in. Now we've got one brand, one national brand and every State and Territory bar one have adopted that' (C5, national office)

We've not changed our name, and we're unlikely to because of the understanding of the brand' (C8, state office)

'Within the not-for-profit sector, the concept of a brand is not really well accepted but I think that we've certainly built a much larger profile. It's about being visible; it's about having a voice, a strong voice, having very clear foundations for what you stand for'. (B6)

Dimensions of brand strength, familiarity, attitude, and remarkability identified by Wymer et al (2016) were evident in this research. 'Non-profit brand familiarity refers to the level of knowledge the target audience has about the brand object. Non-profit brand attitude refers to the degree to which a brand object is perceived favourably by a target group. Non-profit brand remarkability refers to the degree to which a brand object is perceived by a target group to be extraordinary' (2016: 1454)

Summary

This research revealed a strong link between Profile and Purse noting the importance of celebrities especially those recognised as 'Australian of the Year', as did earlier research by Rossi (1978). 'In cases where popular personalities were afflicted by a particular disease, related charities grew faster than other charities. More broadly, the shifting of priorities to match somewhat faddish funding criteria, has been considered a key failure in the treatment and delivery of human services' (Rossi, 1978 cited by Froelich, 1999:251). A strong reputation or profile was reported to enhance an organisation's ability to secure funding (its purse) whether through government grants, corporate sponsorships, community fundraising events and private donations or bequests. This revenue enables the organisation to deliver programs and services which, if valued by stakeholders, in turn strengthen its profile further supporting its ability to raise funds.

The value of reputation and credibility in raising funds is striking in B2's comment noting that although 'fundraising is non-existent' in HCOB, '*this year, so far, (we've) got about 1.5 million that's just come through the door, without any direct mail of any kind. We even got one international donation of a million dollars, which I thought was an April fool's joke at first, but they (a Swiss foundation) decided we were a credible agency who needed support. When I first arrived, nothing came through the door. It's been exponential in the last couple of years, and I think with [the new celebrity president] this year, the sheer credibility of the organisation will do some of that. (B2)*

Section 4.2.2 describes the second category of success identified in this research by participating HCOs, referred to here as Purse, and discusses some of the factors that mediate the financial sustainability of HCOs.

4.2.2 Purse

Success in terms of Purse refers to the financial health of Health Consumer Organisations, their success in raising the financial and other resources required to achieve their mission.

Factors mediating Purse success identified in this research are expressed here as Capital, Capacity, Connectedness and Contribution, and illustrated in Figure 4.3.

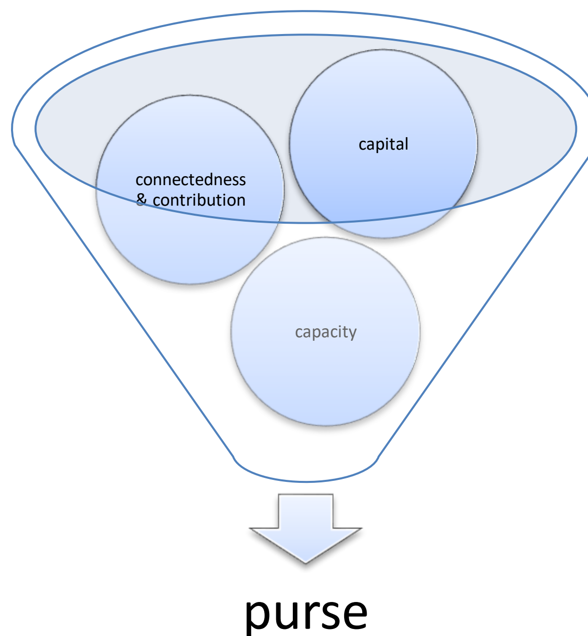


Figure 4.3 Factors mediating success for Purse

> *'It's about keeping the heart and a fat wallet too so that we can provide a bit of better service, provide more service to people, otherwise it's very hard'.* (C2)

According to Booth et al (2015,) ‘the literature has taken two paths in examining the factors which describe or predict a NFP entity’s financial health and/or viability. These approaches either model financial data (Tuckman & Chang, 1991; Greenlee & Trussel, 2000; Hager, 2001; Trussel, 2002), or take a qualitative approach, examining relationships within entities to explain financial performance, and in some cases financial vulnerability (Crittenden, 2000; Baber, Roberts & Visyanathan, 2001; Callen, Klein, & Tinkelman, 2003; Hodge, 2006; Tinkelman & Donabedian, 2007, 2009)’. (Booth et al, 2015 in Hoque and Parker, 2015: 114-115)

Capital

Tuckman and Chang’s (1991) four criteria: equity balances, revenue concentration, low administrative costs and low or negative operating margins have been accepted as primary indicators of non-profit viability (Booth et al, 2015 in Hoque and Parker (Eds) 2015: 114-115). According to Tuckman and Chang (1991) ‘financial flexibility is assumed to exist if an organization has access to equity balances, many revenue sources, high administrative costs, and high operating margins. Organizations that lack flexibility are assumed to be more vulnerable than organizations with flexibility’ (1991:450).

Booth et al (2015) argue however that these criteria which focus on an organisation’s short-term vulnerability or viability do not address the notion of sustainability, suggesting that an organisation’s reserves would be a useful addition to measurement criteria to for longer term survival. ‘There appears to be a core belief that some reserves should be kept as a hedge against uncertainty and to enhance financial sustainability, while at the same time continuing to expend resources on mission activities. On the other hand, there is evidence that some NFP organisations operate with very low levels of reserves in both the U.S. and Australia, indicating their ability to operate under conditions of limited resources and high uncertainty’ (Booth et al, 2015 in Hoque and Parker (Eds) 2015: 130-131).

Research by Froelich, (1999), Lyons (2001), Zappala and Lyons (2006), Renz et al (2010) supported the importance of diversity of income sources, revealing that fewer income sources means financial vulnerability for non-profit organisations, a view shared with other researchers.

‘The revenue concentration index, for instance, posits that the more an organisation relies on one or two sources for revenue, the greater the risk of financial failure’ (Buckmaster et al 1994; Greenlee and Trussel 2000, 2002; Tuckman and Chang 1991 cited in Zappala and Lyons, 2006:401).

This research revealed that a variety of sources contribute to the revenue of Health Consumer Organisations and reflect the diversity within the broader non-profit sector previously reported by Froelich, (1999), Lyons (2001), Zappala and Lyons (2006), Renz et al (2010).

Governments pay HCOs for contracted services and provide grants for special projects and research. Contracts were thought to offer ‘value for money from a public purse perspective’ and grants were thought to be less prescriptive offering greater flexibility to design and deliver what was required, a view supported by research into the government-not-for-profit relationship in Australia undertaken by Sidoti et al (2009). One interviewee suggested that grants tended to be more suitable for seeding projects whereas tender-based contracts suited large, national, service-delivery programs’ (2009:13). According to Sidoti et al (2009) ‘the bigger issue for most small organisations, is the burden of preparing submissions and, if successful, the costs of meeting the reporting and compliance requirements’ (2009:14).

In addition to government funding for programs and service delivery, other sources of revenue reported by HCOs participating in this research include memberships and subscriptions, donations and sponsorships, and interest and income earned on investments and assets. Individual donors make ad hoc donations and bequests, and corporate sponsor provide a range of support including direct financial support, support for fundraising activities, marketing advice and administrative support, workplace giving programs and employee volunteers.

Some of the different sources of revenue for each HCO are shown in Table 4.7.

Table 4.7 Sources of revenue of participating HCOs

Sources of revenue	HCOA	HCOB	HCOC	HCOD
Memberships	✓			✓
Donations	✓	✓	✓	✓
Sponsorships		✓		✓
Government Funding & Grants		✓	✓	
Fees for services		✓	✓	
Bequests		✓	✓	✓
Fundraising Events		✓	✓	✓
Employee Giving Programs		✓	✓	✓

Connectedness and Contribution

How connected an organisation is to funding bodies, sponsors, donors and members impacts its success. While revenue diversification is generally seen positively in order to counter dependence on a single source of income (Chang and Tuckman, 1991; Gronbjerg, 1993; Kramer, 1981; Powell & Friedkin, 1986), cited in Froelich (1999:262), it also raises issues of how best to manage the different expectations of different stakeholders resourcing the HCOs.

Each revenue source imposes 'its own expectations for operations, management performance, and organizational accountability' (Renz, 2010: 801) and 'satisfying the criteria of one provider may preclude satisfying another' (DiMaggio, 1986b cited in Froelich, 1999:262). The need for HCOs to be 'adept at multiple stakeholder management' (Weerawardena, 2010:348) is brought into sharp focus when considering revenue sources. Zappala and Lyons (2006) reported on different views of the relationship between government funding and contributions from donations or fundraising, citing Salamon (1987).

They argued ‘that government funding can act as a seal of approval and can therefore assist non-profits to raise additional funds through fundraising from the public’, and referring to studies by Abrams & Schmitz (1986), Steinberg (2003) and Weisbrod (1988) which suggested that organisations already supported by government are less likely to receive support via donations or fundraising activities. (Zappala and Lyons, 2006:404).

Warning against the risks of commercialisation for non-profit organisations, Eikenberry (2009) noted the time and effort to start entrepreneurial ventures for ‘perhaps not much income’ (Foster and Bradach, 2005), arguing instead for greater investment in cultivating relationships with individual donors. ‘The important goal here is to build social relationships and social networks, in line with Grace and Wendroff’s (2001) suggestion that fundraisers shift from a transactional to transformational giving model that engages individuals more regularly and more deeply in the work of the organization’ (Eikenberry, 2009:591), a view reflected in this research.

*‘One thing we've learnt is that you can't take any of your donors for granted at all. You've just got to recognise that they make a difference and thank them, so we consciously work on this program towards be-questing. If they start off as a caller to Mel's information line, and we can engage with them and support them, then they might become a member, then they can become a regular donor, and then they might end up be-questing’ (*C5)

Although recent literature on non-profit effectiveness has promoted administrative efficiencies as the way to the pockets of donors and funders, and increasing requirements for reporting of funds acquittals would suggest that efficiencies influence success in sourcing grants, there is evidence that strategic marketing of the non-profits’ mission and values is a better path to donor hearts and purse strings.

Frumkin and Kim’s (2001) research supports Tuckman & Chang’s (1991) view that ‘donations are contingent on the good will of contributors ... and are not directly based on the work that the recipient organization does, but rather on the satisfaction that donors receive from contributing to an organization (Tuckman, 1991:447). Noting that donors’ preferences may change from year to year, depending on what is ‘fashionable’ at the time of donating, for example, ‘AIDS research one year and cerebral palsy the next year’, he cautioned that ‘non-profits working in these areas [would] experience considerable fluctuations in their revenue base’ (Tuckman & Chang, 1991:447).

Frumkin and Kim (2001) found that clarity and positioning of Mission was 'a critical part of the giving process since it determines what information reaches donors as they make their decisions on where to direct their funds' (2001:276). Citing Nielsen (1985) and Ostrower (1995), Ashley and Faulk (2010) cautioned against grouping 'different types of donors-individuals, foundations, and corporations into one category' and adding that when non-profits fail to differentiate between funder types, they may 'overemphasize financial ratios in contexts where they may be less important than other measures' (2010:43).

Reciprocity, responsibility, reporting and relationship nurturing were four strategies proposed by Kelly (2001) for use by non-profit organisations in developing successful funding relationships with stakeholders. Reciprocity refers to an expression of gratitude on the part of the organisation via a thank-you and/or a receipt acknowledging their tax-deductible donation. Responsibility refers to the involvement of donors in decision-making about disbursement of donations so that they have confidence is how the money is being spent. Reporting refers to the accuracy and transparency of financial information provided to donors and *relationship nurturing* refers to the ongoing engagement of donors through a variety of events and activities. (Van Puyvelde, et al, 2012:438-439).

'If you're putting out a major call, if you like, for funding, I think it's even then more important that you can show what you're doing with the money' (A1)

Harrison and Wicks's (2013) argument that organisations 'that provide more utility to their stakeholders are better able to retain their participation and support' and that 'creating processes for engaging stakeholders and understanding value creation from their perspective is critical' to success and sustainability (2013:116-117), was also supported in this research.

'We're working now on a project to look at ways that we can ensure that that helpline works effectively and (is) cost effective for the Department, as well as meeting our requirements'. (B1)

'It doesn't hurt to explain to them [the members], our projects. You can put it in the newsletter and on the website - this is a major project we want to do to try and increase an awareness for people who haven't been diagnosed and it's going to cost this amount of dollars and we need to raise money for it' (A3)

According to Brody (1996) 'a non-profit organization dependent on a concentrated or organized donor base might be forced to make poor choice (and) because donors often do not consume the services they donate, donor control can lead to inefficient overproduction of what particular donors want to support' (1996:470). Some donors seek involvement with the organisations they support, particularly those who make large contributions. 'Although many small contributions are made on a wish and a prayer, donors of large contributions regularly seek more information before making any commitments and then demand greater involvement and engagement with the organizations they support (Miller 1997)' Frumkin and Kim, 2001:269).

*'One thing we've learnt is that you can't take any of your donors for granted at all. You've just got to recognise that they make a difference and thank them, so we consciously work on this program towards be-questing. If they start off as a caller to Mel's information line, and we can engage with them and support them, then they might become a member, then they can become a regular donor, and then they might end up be-questing' (*C5)

Contribution, a key enabler of success in terms of Purse, relates to the HCO's achievement of stakeholder value. In addition to services delivered on behalf of government agencies, HCOs deliver training and provide other paid services for other agencies and organisation. The idea of doing fee for service and more entrepreneurial work to fund goal achievement was expressed frequently, especially by the two federated organisations which offer service delivery at the state level. Research by Tuckman (1998), Helmig et al, (2004), Amendola et al. (2011) and Helmig et al (2014) found commercialisation within the non-profit sector likely to influence HCO revenue raising practices as they adopt more entrepreneurial practices to create revenue and become 'more business like' in their operations.

'When I came in, I said to the board, "If you continue down this track, there's no government funding for policy and advocacy, you have to do something different or you value-add." So then they agreed with me to promote more service delivery. That's really how that evolved into the revenue that we're bringing in now and the increase in staff'. (B10)

Capacity

Capacity and sustainability are constant concerns of HCOs as they balance the immediate needs and obligations against future viability.

'How much of your investments do you pull down for programs? How far do you cut back on what you're delivering, before the service is affected to the point that we can't do anything well? That's sort of a cultural mindset as well with the board is, when I first started … investments…But I'd say pretty much now, we've got a board that is good at that sort of balance, of realising, well that's what your investments are. You don't sit with a million in the bank and yet you're struggling to - not that we've got a million in the bank but you know - you're struggling on the ground'. (C7)

Weerawardena et al (2010) link capacity and non-profit sustainability, describing it as the ability of the organisation 'to fulfil its commitments to its clients, its patrons, and the community in which it operates'. (2010: 347). Booth et al (2015) citing earlier research by the Productivity Commission (2010) and others, reported on the influence of perceptions of an organisation's capacity to fulfil its obligations in terms of service delivery now and into the future, on its ability to secure funding. 'Funders, especially governments, are interested in knowing the appropriate level of reserves to facilitate the ongoing sustainability of organisations and the sector, particularly when organisations provide essential public goods and services'. (Booth et al in Hoque and Parker (eds) 2015: 109).

According to Pink and Leatt (1991) 'research suggests that younger organisations have greater difficulty in raising funds compared to longer established organisations as the former have not yet "earned sufficient trust capital to induce donors to give" (1991, 318). Zappala and Lyons (2006) suggested that 'recently established organisations may not have had sufficient time to build a reputation with government and this would increase the tendency of young organisations to be more reliant on fundraising revenue' (2006:403). They identified a number of factors influencing reliance on and success in fundraising for Australian non-profit organisations. These include the field of activity or industry in which the organisation is engaged (Leiter 2005; Lyons 2001), its age, or the length of time the organisation has been established (Lyons 2001), its size, geographical scope, geographical location and tax status, for example whether or not it is recognised as a Deductible Gift Recipient (DGR). (Zappala and Lyons, 2006:403).

Summary

'Fundraising becomes very important to you in terms of enabling you to do what you want to do' (B7).

Securing funding was considered essential to ensuring capacity for on-going operations. The strong links between Purse and Performance, articulated in the system resource approach, which assumes 'that organizations achieving their goals are also likely to receive continued financial support (Georgopoulos and Tannenbaum 1957; Yuchtman and Seashore 1967)' (cited in Lecy et al, 2012:439), are further illustrated in the next section.

Section 4.2.3 discusses Performance, the third category of success identified by HCOs in this research.

4.2.3 Performance

'We've delivered everything they've asked us to deliver on time'. (B1)

In this research performance was defined both in terms of mission accomplishment or goal achievement and as social capital or contribution. At state and local levels performance was reported as direct delivery of information, support services and programs, while at the national level it was reported as raising awareness, supporting research and advocating for policy and practice changes. Successful performance was also described in terms of growth and innovation.

Purse and Performance impact the success of the other. ' If an organization cannot effectively meet its stakeholders' performance criteria at a reasonable cost, then regardless of its "inherent" worth, the stakeholders are likely to withdraw their support.' (Bryson, 2010 in Renz, 2010:240).

Factors mediating performance are expressed here as Contribution, Creativity and Capita and illustrated in Figure 44.

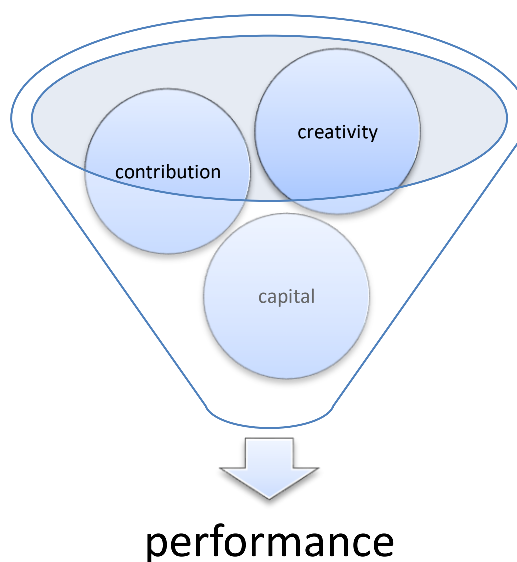


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Figure 4.4 Factors mediating success for Performance

According to Forbes (1998) ‘early researchers of effectiveness adopted one of two approaches, either the goal-attainment approach (Barnard,1938; Price, 1972) or the system resource approach (Georgopolous & Tannenbaum, 1957; Yuchtman & Seashore, 1967)’. (1998:185). The goal-attainment approach, based on the assumption that organizations' goals are identifiable and unambiguous defined effectiveness as ‘ the extent to which organizations succeeded in meeting their goals’ (1998:186), in other words how well they performed or achieved expected outcomes.

‘For this organisation, success is when we have in place a system, so that really everybody is diagnosed in a timely fashion. So, if we were to convince the system somehow that age-based health checks included [tests for the condition], that would be across the board, it'd fabulous. If the day comes when there is genetic screening that would be success. So, success is about the number of people who are diagnosed in a timely way, and at that point, it may be that as an organisation we can fade away’. (A4)

Progress towards goal achievement was also viewed as success, as was being able to measure and quantify this.

‘To say we're not where we want to be is a fair call, but to say that we're well and truly where we should be from where we started from, I think, is important to recognise that too’ (C2)

‘For us [success] is progress towards achieving long-term objectives’. (B3)

There was also an understanding of the relevance of connectedness in achieving the HCO’s mission.

‘You achieve [success] by all sorts of means of support: community awareness, professional awareness. In the end, I don't care whether the medics know about us or not. I only care that they know about the condition, and we raise their level of suspicion. So, if this is all achieved by other means, it doesn't matter’. (A4)

Performance success was reported by HCOs in terms of advocacy, the ability to influence policy and practice changes, and in increased public and professional awareness of the condition.

We've been much more successful in having our voice heard on national committees, and [on] government advisory groups, implementation planning groups and all the rest of it'. (B3)

'Well, for this organisation, success is when we have in place a system, so that everybody is diagnosed in a timely fashion. If the day comes when there is genetic screening that would be success. So, success is about the number of people who are diagnosed in a timely way. And at that point, it may be that as an organisation we can fade away. So, success isn't in growth in the organisation'. (A4)

'Better community understanding of what [it] is and its impact. Better understanding and application by people with the condition and their carers, of self-management guidelines. Better adherence by health practitioners to the clinical management guidelines'. (C1)

'The people with mental illness groups, some of those have been highly successful. Nothing About Us Without Us, which has been enshrined in the principle of mental health policy making and service provision is reflected at every level of the mental health system from the policy frameworks to the delivery of services, at least in the non-government sector. (A6)

Mediators of performance success were identified as Contribution, in terms of service delivery, support and information, research; Capital (human, social and intellectual); and Creativity.

Contribution

Contribution, a key enabler of success in terms of Performance relates to the HCO's achievement of stakeholder expectations.

'We've delivered everything they've asked us to deliver on time. We've created more awareness by doing research, and then having the evidence to demonstrate the growing numbers of people with the condition and highlighting for the government how they need to be prepared'. (B1)

The concept of Contribution also reflects the notion of social capital 'not only as a resource but also an outcome of nonprofit activity' (Leonard and Bellamy (2010), cited in (Von Schnurbein, 2014: 360).

'You go home with a sense of purpose. You go home with knowing what you've achieved is something more than a shareholder increase'. (B11)

HCOs deliver information, services and programs to individual consumers, carers, medical practitioners and healthcare providers, through a variety of channels including telephone help-lines, websites, training courses, care and personal carers. In the two federated organisations (HCOB and HCOC), services and programs are usually delivered at the state level by the state organisations.

'Under delivering services there's a range of things, information, a helpline. We do counselling, we do a lot of education. We do an increasing amount of consultancy work and we do some - not a lot of - direct service delivery to people with HCB' (B4)

'That is essentially what we do - delivering information and education to people'. (C4)

'We've done some wonderful work with health professionals, with training and courses, again because of the expertise and passion of our health services manager who works those areas, and the passion of our networks who join' (C5)

Providing support to individual members and their families was recognised as a key contribution of all HCOs involved in this study. Support offered by HCOs ranges across many different forms from informal get-togethers to formal meetings, forums, educational events and information lines. However, contributions are constrained by HCO capacity, especially when it is a completely volunteer organization.

‘There's only a limited amount of things that we can do. We actually don't know where people get their [treatments]. And a lot of people have trouble getting access to [treatments] and they ring us and say, "I live in this particular town. Where can I go?" As the peak body for this condition, we can't answer that because there is no data. A couple of times we've put out a call to membership: contact us, tell us, where do you have your [treatments]? Has this been convenient?’ (A1).

Unfortunately, success in performance can also have a negative impact on a HCO’s ability to keep members (and importantly their membership fees).

‘There's a pretty high turn-over of people coming in, joining up, getting information. They find out about the condition, they get treated, and then in three months they'll drop off and after a year or two, cancel their membership, and we never hear from them again.’ (A5)

HCOs contribute to research in a number of ways. Some raise money or organise conferences, others provide seed funding for research, while others provide access to individuals as potential research participants.

‘I think as a researcher we've been incredibly fortunate to have had hundreds and hundreds of thousands of dollars in funding from these groups that has allowed us to do our research’. (A2)

‘We have a lot of researchers contact us wanting to conduct research with members. We've got about 1,300 (members) and we can filter them according to their demographics’. (D1)

‘We have a different attitude to research in this state compared to some of my other colleagues. We only fund small amounts to kick-start careers. We're not about funding $200,000 worth, that's somebody else's business. But if we could give Di $20,000 that enabled her to do something that showed how good she was, and that parlayed in to $2 million, that's our job. Not to find the $2 million, but to kick-start your career. That's a bit different’. (C8)

Capital

Capital whether human, social (as input) or intellectual, enables HCO success in Performance, supporting contributions to research and in service delivery, and creating social value. 'Social capital, generally defined as the actual and potential resources embedded in relationships among actors, is increasingly seen as an important predictor of group and organizational performance (Adler and Kwon 2002, Leana and Van Buren 1999, Nahapiet and Ghoshal 1998, Bourdieu 1986)' (Leana and Pil, 2006:353). This is powerfully illustrated in the comment below.

'They perform very, very well. I compare it to some other groups, which I won't name, which do have funding, and their ability to deliver on such small amounts of money and entirely voluntary labour force is just fantastic. They clearly have had some level of influence in setting the agenda. The fact that there's discussion about the possibility of universal testing is just awesome. It's in part about the declining cost in testing, but just great' (A6)

Human capital was considered a key to HCO success in performance.

'The right people in the right jobs [means success]'. (B10)

'You need well-trained people… You do need someone that knows their way round the health system. I think the group needs not only to be passionate about the condition. They'll benefit from a reasonable level of health literacy and an understanding of the system'. (A1)

'We're doing it better all the time because of the expertise, and the professionalism, and the background of our staff. They really do have the goods when it comes to knowing about HCB, and there's no one else that's filling that role' (B4)

'Each of those managers have come with wonderful experience and they talk knowledgeably whenever we're in government meetings, and people trust them' (B1)

For the participating HCOs success isn't just about 'individuals with the rights skills and knowledge but is also reported to result from the generosity of people working together on a common goal, recognising and valuing each individual's contribution.

‘The team works well together. It's a good team. We share information, support each other’ (B1)

‘As an organization, we work well together, considering we’re so far apart. I believe, because we do work well together, we are slowly getting the word out there’ (A3)

‘We've got a team of very committed and knowledgeable, passionate staff who deliver the information’ (C5)

‘It's a culture of getting in and doing what you need to do. it would be nice to have the extra hands to do it. Kate and I are always here beyond 6pm. I'm not sure that Jill (the CEO) ever goes home, but she does say she does’ (C2)

‘I don't see it as a chore to take the Information Line as much as I do because I feel that, as a nurse, it's something I can give the organization better than probably some of the others, and they've got other skills that are better suited to some of the other things that we're trying to do’. (A3)

Each of the HCOs in this research benefitted from the contributions of volunteers including academics and other professionals doing Pro Bono work; trainees, cadets and young people starting out in their career, help in a wide variety of activities.

‘A lot of the graphics that you'll see built around us. I had two Year 12 students in January who had nothing to do - they're waiting to go to uni - so they came in and did a lot of work for us. One of them was my son, and one of his mates. But they're very quick and they're very clever. You go and buy a photo from iStock and you can pay anything from $10 to $300. What they were able to do for us was to get a whole lot of free photos and manipulate them into the color scheme. In-house we do that’ (C8).

‘His area of expertise is health-consumer organisations, and he sits on the board of two other groups … He wasn't prepared to go on the national committee because he's already involved and he works full time. But he's been very helpful. He's sort of acted as an informal, unpaid consultant to advise us about broadening our reach and different strategies’ (A1)

'One of our successes has actually been to get work done pro bono by academics and clinicians and others, and to successfully outsource the management of many projects. So, 18 staff is what we have now, is 18 times more than we had in 2000, which is when I arrived and was by myself and a lot of that is possible, because we have been successful in getting pro bono stuff done for us'. (B2)

Some volunteers report working with a HCO is the job they wished they had when working for wages, indicating the social value or capital of 'working' with other like-minded people. Their generosity is exceptional and often they have more than one volunteer commitment.

'*How much time do I spend? An awful lot. I do something every day, whether it's only looking at my emails. I read about something peripherally related every day because I find it interesting. I'm genuinely interested in the whole thing. Around the AGM time [I probably spend] 30 hours a week. Or I'll be organising information sessions so around the time of each of those, it'll be fairly busy - probably ten hours a week because I've started doing stuff plus extra reading'. (A1)*

'*We are all still volunteers, and that's a fairly big limiting factor not in regard to our time because I think some people in the group put in huge amounts of time - more time than they would if they were working'* (A1)

They're two lovely ladies (the volunteers). One - the retired nurse has about a 90 minute trip in and out each time she comes, three times a week, and she looks after our resources, and our brochures and our stock. That's Suzy's job and, to some extent, she sees it as that' (C8).

'There's a movie producer in Melbourne who had a liver transplant as a result of the condition, and so he's indicated that he's willing to provide services in helping to put together something for us There are going to be still costs, but there's not going to be the exorbitant costs, because he's going to not charge us for some of it. We will have an educational video, another advert, and a longer one' (A3)

'I started doing this just before I retired. I retired early and I don't know what I'd do if I wasn't doing this. This is the job I would have liked to be paid to do for the last 40 years. Now I've got it, I can just do my own hours, make the rules, and I'm the boss. And I've learned so much'. (A5)

Creativity

Creativity or the ability to learn and do things differently was reported as another factor influencing success. Creativity was said to be supported in environments offering opportunities to put forward new ideas and to act on them.

You've got minimal red tape and you actually can see the result of what you do. I think that's why I've stayed on for so long because things are forever changing, good and bad, but never a dull moment kind of thing. You have an idea and initiative, and you can put it out to the board. And we're not stopped. We haven't got too many obstacles that actually stop something being implemented if it's a good idea. (C7)

'I have a fairly good grasp of technology and stuff. I didn't know any of this stuff before I started. I could learn and find out stuff really well, and that's a lucky skill. We didn't come in all equipped. We discovered all these things along the way' (A5)

Summary

This chapter has described the first part of research findings. It presents vignettes of each of the participating HCOs, outlining their history, purpose, structure, governance and funding arrangements. It then identifies and explores what success means for these organisations. Chapter 6 describes the seven factors mediating success in three categories identified in this research: Profile, Purse, Performance

CHAPTER 5: RESEARCH FINDINGS PART 2

5.1 Factors mediating success

5.1.1 Clarity

5.1.2 Contribution

5.1.3 Connectedness

5.1.4 Credibility

5.1.5 Capital

5.1.6 Capacity

5.1.7 Creativity

5.2 Challenges

Section 5.1 presents descriptions of each of the factors emerging from the data: Clarity, Contribution, Credibility, Creativity, Connectedness, Capital, Capacity, illustrating the descriptions with participant quotes. Together with the literature from Chapter 2 and the findings described in Chapter 4 they form the foundation for frameworks presented in Chapter 6.

Section 5.2 illustrates some of the challenges identified by participating organisations.

5.1 Factors mediating success

Factors mediating success identified in this research emerged from interviews and from literature reviewed during the course of this research. While specific factors influencing success in one or more of the three categories are outlined in Section 4.2, this section now describes Clarity, Contribution, Credibility, Connectedness, Capital, Capacity and Creativity, providing evidence of their pervasiveness and connections between them. A6's description of the creation of social capital also encapsulates the momentum created by mediating factors driving success.

'The spiral metaphor is actually the appropriate one because it does actually everything. They're building to each other, and off each other. A single causation, multi-factorial causation, plus - what's the statistical term where things build on each other? Mediating, but it's more catalytic or continuous. How I've described it in my own work is momentum (A6)'

Figure 5.1 illustrates the factors identified in this research as those mediating HCO success. A limitation of my exploratory research is that it did not identify how or to what extent these factors influenced success, and this presents an opportunity for future study.

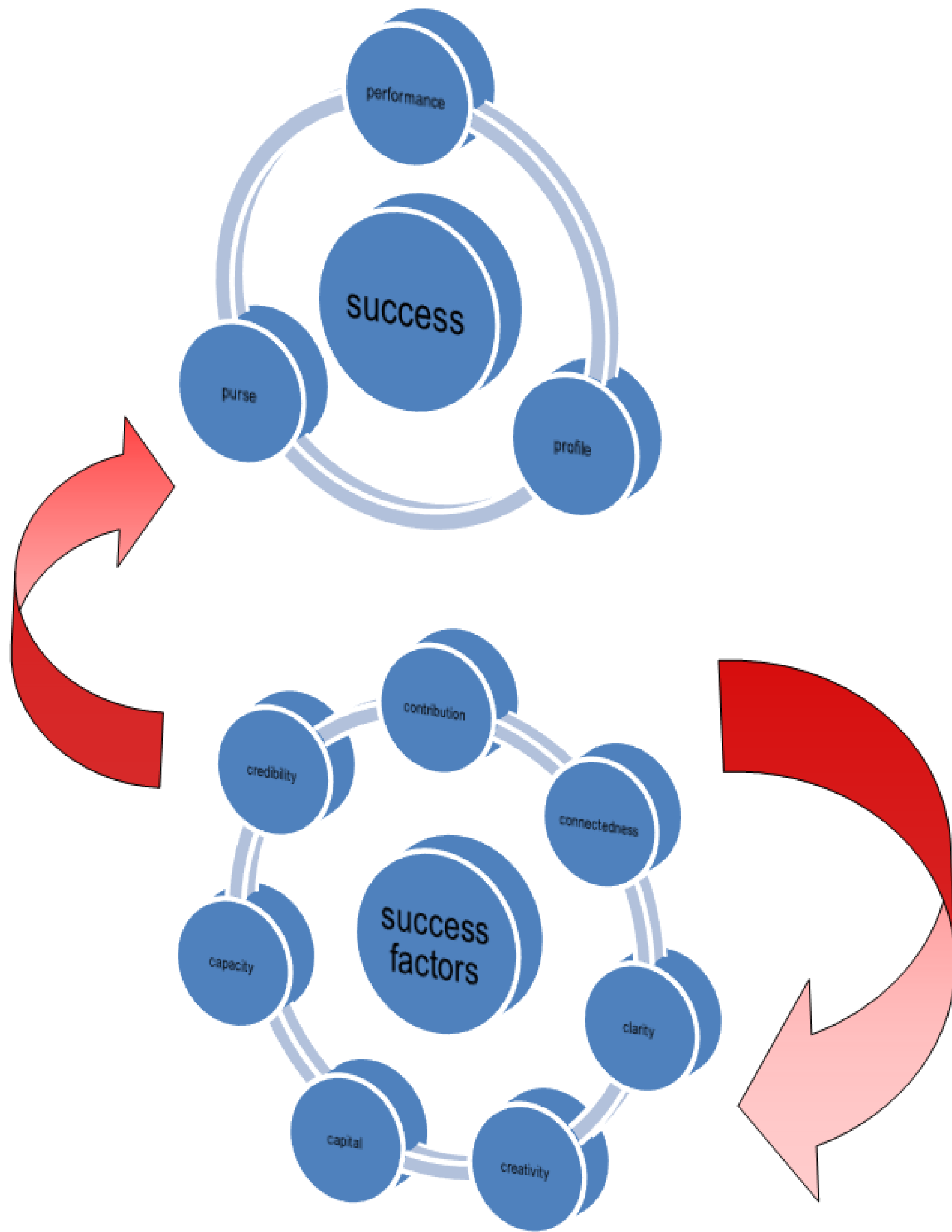


Figure 5.1. Driving success: factors creating momentum

The notion of identifying a single list of definitive factors influencing success is problematic given the range of Health Consumer Organisations operating in Australia, and their different purposes. Nor are the mediators identified in this research unique, as shown in Table 5.1 which aligns them with the results of other studies on not for profit organisations, including Sidoti et al (2009), Crutchfield and McLeod Grant (2012), Judd, Robinson and Errington (2012) and Raine and Ellis (2014).

Crutchfield and McLeod Grant (2012) identified and described six key practices contributing to success for non-profit organisations in the USA. Advocate and Serve, Make Markets Work, Inspire Evangelists, Nurture Non-profit Networks, Master the Art of Adaption, Share Leadership all match the seven enablers identified in this research. In their case study of Australian charities Judd, Robinson and Errington (2012) described key contributing factors for success as purpose-driven strategy; the purpose-driven board; purpose-driven leadership, succession planning and leadership development; an engaged workforce; remuneration; recruiting and managing performance; living with charity law; harnessing the finances; engaging the community.

Raine and Ellis (2014) identified seven principles of effective citizen advocacy, also closely aligned to those uncovered in my research. The first principle Content, refers to establishing 'credibility as a valued external partner by taking the time to gather and analyse data from a wide range of sources and bring useful knowledge to the table' (2014:25) 'Character' also relates to the concept of Credibility. 'Clearly defined goals' and 'communicate' both relate to Clarity while collaboration and coalition building, consensus, consult and compromise are all linked to the concept of 'connectedness' (Raine and Ellis, 2014:25).

Table 5.1 Factors mediating success discovered in this thesis compared to other key research

Prince 2016 (this thesis)	Sidoti et al, 2009	Judd et al, 2012	Crutchfield & McLeod Grant 2012	Raine & Ellis, 2014
CLARITY		Purpose driven strategy	Share Leadership	Clearly defined goals Communicate
CONTRIBUTION	Diversifying the service offering	Engaging the community Recruiting and managing performance	Advocate and serve	
CREDIBILITY	Actively participating in the relevant ‘peaks’ and other strong organisations	Purpose driven board Purpose driven leadership	Inspire Evangelists	Content Character
CREATIVITY	Quarantining creative and innovative sub-projects	An engaged workforce	Master the Art of Adaption	
CONNECTEDNESS	Collaborative relationships with other service providers Strong external links to enhance organisational security	Engaging the community	Nurture Nonprofit Networks	Collaboration Coalition building Consensus Consult Compromise
CAPITAL	Diversified funding bases Building financial insurance Introducing fee-for-service options	Succession Planning and leadership development Recruiting and managing performance Remuneration	Make markets work	
CAPACITY	Adapting organisational structures and expanding staff development	Living with charity law	Make markets work	

The following sections describe different factors identified in this research through the application of stakeholder theory, social capital theory and resource dependence theory. Figure 5.2 illustrates the application of theoretical lenses applied in the discussion of success mediators.

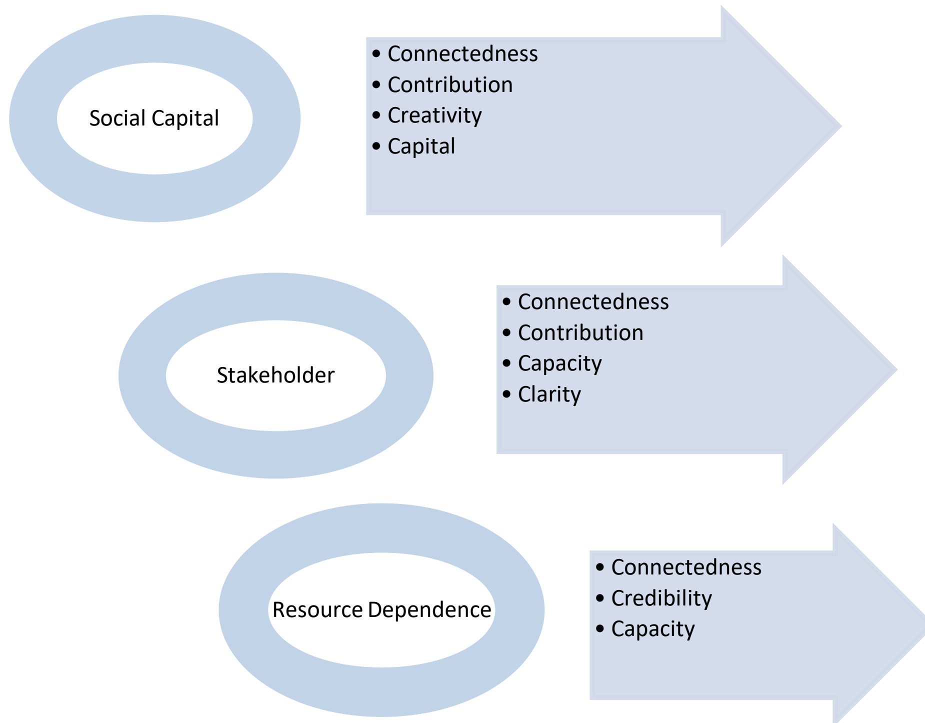


Figure 5.2 Theoretical lenses and mediators

5.1.1 Clarity

Clarity, as expressed in relation to its vision, mission, priorities, plan, brand and messages, is illustrated in Figure 5.3.

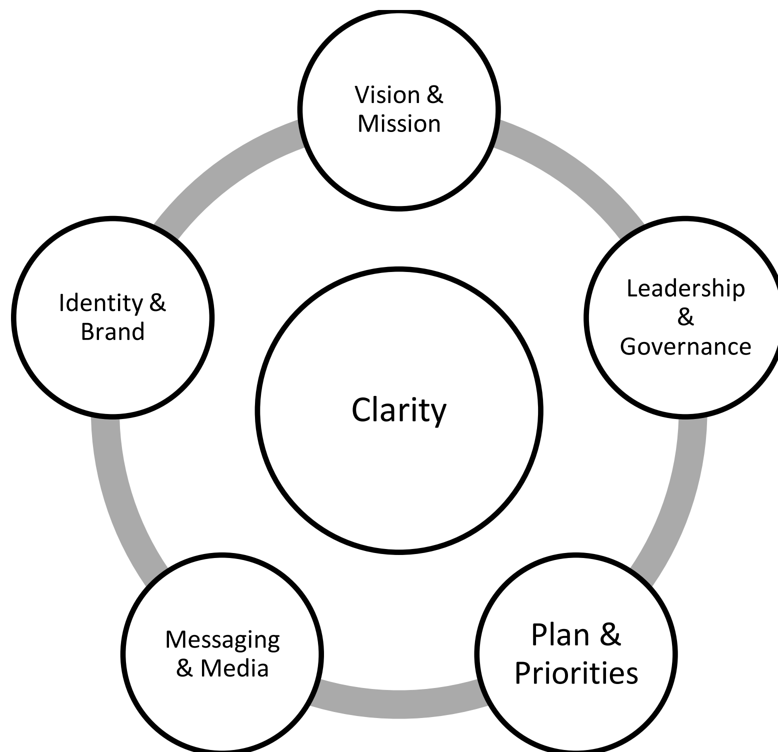


Figure 5.3 Clarity – a key mediator of success

Vision and Mission

A clear mission is essential as it 'defines the value that the organization intends to produce for its stakeholders and for society' (Moore 2000, p. 190, cited in Al-Tabbaa et al., 2014:670). Furthermore 'a mission that is well articulated and appreciated by society is expected to enhance stakeholder trust' (Frumkin and Andre-Clark, 2000 cited in Al-Tabbaa, 2014:670).

‘There’s got to be a really clear vision of what it is you want to do and that's got to be an active live vision in the organization, making sure you don't end up with displaced goals’. (A4)

Of the three primary purposes identified in Section 1.4 (Care, Connect, Cure) ‘Care’ was most frequently expressed as the purpose and identified in mission statements for each of the HCOs participating in this research.

‘Our prime reason for being is to help people with HCC and related conditions and their carers, whether they're at home or community carers’ (C8)

For other HCOs, raising money to support research and ultimately find a ‘Cure’ was the primary purpose.

‘I overheard one of the hierarchy (of another HCO) say to the other, "They want to have bloody patient support. We don't do bloody patient support! We raise money. And we're not having coffee mornings." So not only did that individual see patient support as not part of their (purpose), but clearly was quite uncomfortable about the whole thing. Maybe it's hard to do all things. (A2)

HCOB interviewees across the federated organisation agreed on the clarity of its vision and mission.

‘*We've got a very clear vision of what we want to do’* (B4)

“We're clear about our priorities’ (B1)

Leadership and Governance

In addition to having clearly articulated Vision and Mission statements, Clarity was expressed in terms of strong leadership and governance.

‘We have great leadership from our CEO. We all have our own sort of particular interests, so sometimes we can get diverted, or states and territories have got a great idea and then I get diverted but the CEO will say, "No, these are our priorities," so we keep getting realigned’ (B1)

'*You've got to have the ability to follow your strategic direction, follow what your priorities are. And get the staff and the rest of the team, say, "Okay well, that's the path we're going down"   to say, "We're on a path here and we've got limited resources." What we do we want to do really well, and it's much better to say, "No, we'll just do this bit really well'* (C7)

Priorities and plans

Raines and Ellis (2014) identified clearly defined goals as integral to success the success of advocacy efforts (2014:27) and consistency between vision, strategy and operation was listed by the Dutch international education provider EP-NUFFIC as one of five capabilities in organisational capacity development. (EP-NUFFIC The Five Capabilities Approach in Capacity Building of Organisations, viewed 4th November, 2015 https://www.nuffic.nl/en/library/the-five-capabilities-approach-in-capacity-building-of-organisations.pdf.

'I'm about to sit down with all my staff and do a three year strategic direction. So these are our key directions, these are our objectives within those, these are the actions within these, and that's how we're going to measure them' (C9)

Messaging and media

The importance of getting the message right is supported by recent research (Kreutzer 2009, Reid and Turbide 2012, Waters 2014, Shea and Hamilton, 2015) suggesting the way messages are framed and delivered, and the modes and means of communicating information are important, especially during challenging times including growth and transitions.

'It's been just wonderfully managed by the national CEO who is just so careful about the way she communicates, the tone of the way she communicates is always respectful. It always uses the language that says, "We are one." Over time, if you say things often enough to people, they start to believe it, don't they? I think it's been managed really well in that regard. She works with the national board and that's all the national presidents, and bit by bit that language is permeating and the idea is permeating'. (C2)

You have to be able to define what it is you stand for, you have to be able to have a very clear simple message, and you have to be able articulate that very clearly, concisely'. (B6)

Communicating with stakeholders clearly and regularly on progress towards goals was considered critical to stakeholder engagement. Clear and transparent communication of results and financial reporting was recognised as important to government funders and commercial sponsors for future resourcing.

'*As a policy person, I learned back in 1985 when I was first allowed out on the streets to do things that you have to control language and the message to get the decision you want'* (B2)

The need to confirm what was understood and the importance of follow up was also noted.

'*People will always take away their own message from that as well. So we can be as consistent and very, very clear, but one person is going to hear something completely different. You just have to make sure that you're following up.* (B10)

Each of the participating HCOs acknowledged the importance of simple clear print media and an engaging website. Some interviewees actively benchmarked their resources against that of other organizations.

'*What I've noticed is if I'm looking at other health-based not-for-profits I see a lot of jargon, I see a lot of text, I don't see a lot of pictures, I don't see a good design. I think we're close to doing it as well as we can with the resources we've got, and if we could employ someone to do our website full-time, it would be a whole different world'* (C2)

'*Another thing we do well is the website, the videos, is very strong, very informative. People always comment, "Your website's good because it gave us all that information." The way it steps through things, it's fairly straight-forward. It only contains the right stuff*. (A5)

Identity and brand

Liu et al (2015) cited a number of studies (Ewing and Napoli, 2005;, Hankinson 2001, 2002; and Sargeant et al 2008), investigating branding and identity in non-profit organisations. These studies recognised non-profit brands as one of their most important assets in attracting donation income and volunteers (2015, 319-320).

While each HCO in this study considered a clear brand and identity important to a successful profile each admitted some difficulty in building one that satisfied its internal stakeholders. In spite of the value of a clear brand there are considerable challenges associated with branding non-profit organisations.

'Branding can absorb considerable financial resources because of the advertising required to develop and sustain the brand' and creating a successful brand requires the support of every part of the organisation for the ideas that the brand is trying to communicate' (Gainer, 2010 in Renz, 2010:312). These challenges were very real to the HCOs participating in this research and Gainer's second challenge was particularly relevant to the two federated organisations, each of which had struggled with establishing a new 'national' brand or aligning with international counterparts.

'Internationally, HCB is always the number one disease and the organisation tends to be known as HCOB. It used to be 'HCB and related [conditions]' but that's a mouthful, so it was shortened to HCOB. Should it be HCOZ? No [although] internationally all the organisations have gone that way' (B6).

HCOC adopted a new logo and associated branding initially rejected by one of the member states, which had only recently invested in a new state brand. The national office perceived this rejection of the national brand as a sign of deeper resistance to organisational change.

'Because we didn't take on the branding, there was a perception that we weren't taking on the national agenda, which wasn't the case' (C7).

'*As a consumer based organisation, we can have our differences and discussions behind the scenes, but as a face for the community, you've got to present one unified face*. (C5)

Recognising the importance of the media in raising brand awareness but constrained by the associated costs, HCOB had some success through harnessing less conventional methods of engaging the media. With the benefit of a dedicated experienced corporate marketer, HCOB was able to engage the media without investing in traditional marketing activities, working instead on achieving 'media mentions', a successful strategy as indicated by its brand awareness survey results.

'It looks at how much an organisation has spent in media plus it adds in what sort of free publicity value you've got. So the value of the media mentions which you don't have to pay for, and then It adds that together and gives you a total ad equivalent. So a larger organisation that's more well established and has got bigger budgets will always rate well, but you don't have to spend those dollars if you can get the media pumping for you, so then that balances up your ledger' (B6).

'Media mentions' rely on newsworthy publicity and HCOB was fortunate to have a very well known celebrity as its Champion. These more recent developments were reported to be very different to the strategies used a decade earlier.

'In 2003, which is when we put out our first major report by Access Economics, we really used conventional media, media releases, media conferences. Ten years later, we're sophisticated in the use of branding, marketing, and social media in a way that I don't think we would have thought was possible back in 2000'. (B2)

5.1.2 Contribution

'Our constituents and stakeholders want us to succeed, and the reason they will maintain or even increase their support is because they see the value in what we seek to accomplish' Renz, 201: 799).

Contribution, recognised here as value created for HCO stakeholders, is a key mediator of success in terms of Performance. Contribution also refers to how a HCO achieves its purpose whether Care, Connect or Cure.

Figure 5.4 illustrates some of the different manifestations of Contribution.

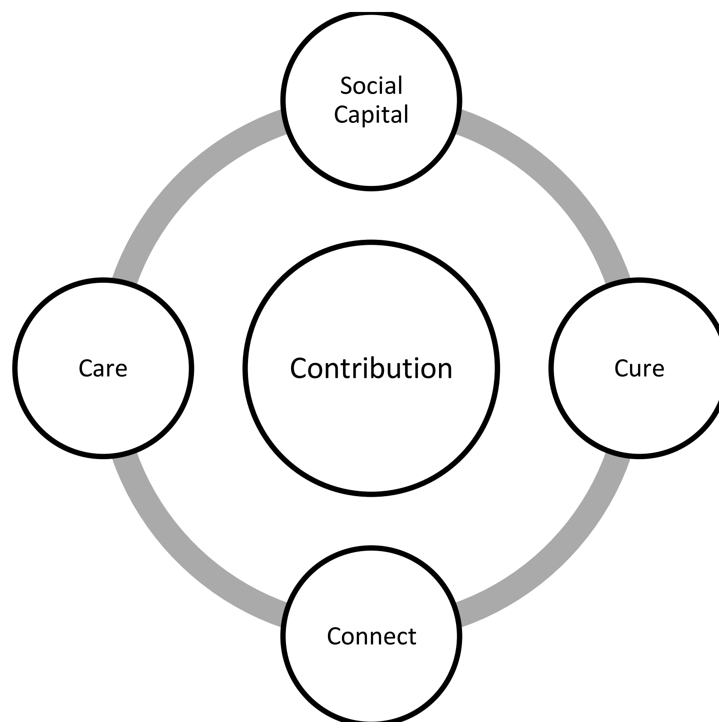


Figure 5.4 Contribution – a key mediator of success in Performance

Social capital theory, in particular the concepts of bonding and bridging social capital, supports the understanding of Contribution presented in this section. Contribution here reflects the notion of social capital 'not only as a resource but also an outcome of nonprofit activity' (Leonard and Bellamy, 2010 cited in Von Schnurbein, 2014: 360).

Different stakeholders benefit from their involvement with the HCO in different ways. For members contribution represents 'bonding' social capital. For alliance partners it represents 'bridging' social capital created through collaboration. For corporate industry sponsors contribution represents 'linking' social capital created through the introductions to individual members. By clearly articulating their value to stakeholders, HCOs enable them to measure the benefit from their relationship.

Contribution as Bonding Social Capital

Every interviewee valued the experience of working in the sector and … with others who shared their interest.

'It keeps you challenged, keeps you motivated, keeps you interested working with like-minded people - because the majority of people here are. It gives you an enormous sense of satisfaction that you know what you're doing is making a difference' (B11)

'Working well together is really good, and we all came together wanting to do something and not see it fold, so we were all rather enthusiastic in what we're doing. That enthusiasm is really what is helping us… We've all got our skills which complement each other and I think that's what's really good in that respect.' (A3)

This year we're running 14 forums around the country, and we will have about 250 people attend each one. Anyone's invited to come along, and we encourage them to bring a partner or support person' (D1)

'*In our community support program where something like 30,000 people have been assisted over the past four years, primarily in a group setting… they go out to where people are - and that's how we do a lot of our work.'* (C1)

'Lots and lots of problems come our way, but the way that we work together and collaborate as a team amongst ourselves make that all quite easy' (C2)

'We want to link them (people with the condition) together' (D1)

Contribution as Bridging Social Capital

Passey and Lyons (2006) note that 'bridging social capital is proxied by "horizontal" organizational links with other non-profits. There are tools used by associations in joint undertake activities of common interest to their members. Examples will include jointly delivering services to members and other people in the community, collective fundraising, or sharing facilities such as buildings and other equipment. Associations will choose whether or not, to work jointly with other non-profits, although in essence, of course, they may do so for the purpose of surviving as an organization, and so in important ways their "choice" is forced on them. That said, these links do constitute "bridges" between different groups of people.' (2006:484-485).

Citing research by Renz (2006), Conforth et al (2015) note 'although organizations and groups may deliver services individually, they are often coordinated and resourced through a wider network of relationships' and suggest that the focus of future research 'might usefully shift from the single organization to encompass the inter-organizational level and the collaborations and alliances in which non-profit organizations engage'. (2015:792-793).

'Coalitions that can foster communication among their members might be in a better position to have member organizations act in concert toward the coalition's goals. As such, communication represents an aspect of social capital in that coalition organization members are building connections with each other, developing a common language and vision about advocacy, sharing knowledge with each other, and finding ways to collaborate' (Honeycutt and Strong , 2011:235-236). Many examples of 'bridging' social capital where value was created for medical practitioners, alliance partners and other organisations within the HCO network were provided in this research.

'We also support existing support groups. We offer them an opportunity to come under our umbrella if they want to, to become one of our member groups. So currently, there are about 315 member groups, who we promote through our avenues. We like to promote the member groups on our website, so that (people) can go in, punch in their postcode, and see where the member groups are. We rely on member groups … to do things like populate our local services directory, which is a directory online… that details all of those services (for individuals with the condition) that are local that … friends tell each other about. So all of that practical support we like to capture, but we need our member groups to actually populate that'. (D1)

'*We're happy to share information. We see that as our role as well. We know that we can't deliver everything here, that we can only do so much. So we don't work on the basis that we're in competition with anyone' (B8)*

'No matter what partnership you're involved in, if you can make the person you're dealing with's job easier, then that's going to be a success as well. So whether that's a bureaucrat in Canberra, or someone in a marketing department in a corporate, they're all in it for, "What's in it for me?" '(C2)

The importance of well -networked people in facilitating bridging social capital is clear in the comments of participants. A1 described how she co-ordinated a meeting for a number of academics with an interest in HCA. During the meeting she raised the issue of difficulties in the referral process in NSW. One of the academics visiting from Western Australia was surprised to hear of the problem since process time in that state was quick.

'He'd never heard of this being a problem. What we didn't know was that (he) was on a sub-committee or something or other so he said he would raise it. He came up with the idea. He said, "Well, why is this happening? Why is there not an online referral system?" He said, "Let me look into it."' (A1, volunteer committee member HCOA)

'We also support existing support groups. We offer them an opportunity to come under our umbrella if they want to, to become one of our member groups. So currently, there are about 315 member groups, who we promote through our avenues. We like to promote the member groups on our website, so that (people) can go in, punch in their postcode, and see where the member groups are. We rely on member groups … to do things like populate our local services directory, which is a directory online… that details all of those services (for individuals with the condition) that are local that … friends tell each other about. So all of that practical support we like to capture, but we need our member groups to actually populate that'. (D1)

'The Genetic Support Network of Victoria has been very positive in bringing various organisations together. When your disease is 1 in 100,000, you have very little clout. But if you have 100 organisations that are 1 in 100,000 that thing comes 1 in 1000, and that becomes a much more important and stronger' (A2)

Contribution as Linking Social Capital

According to Andrews and Edwards (2004), 'Linking social capital is measured through membership of "vertical" networks of higher levels of association. Membership of a vertical network will typically comprise being part of a peak body or a wider network that provides information, training, and voice and representative functions for associations. Although most interactions will not be face to face, these networks do "build significant connections among the organizations involved' (Passey and Lyons, 2006:485)

'I certainly knew a consultant working in the area and suggested they get in contact with her. This particular consultant … had been very successful in establishing connections with the Commonwealth Department and I knew that she would be great in giving them advice on how to write the submission, things like that. The fact that they've had that funding, they had the conference which has flowed from it, was really awesome and that, of course, just leads on to other things.' (A6, HCOA member)

'*We will foster opportunities through our links with, say, research entities and that's where a lot of the treatment guidelines are developed and a lot of the national committees occur. A lot of it emanates through the relationships that we've formed with key stakeholders. Clinicians are involved in, say, clinical trials groups, and we'll make sure they know about those opportunities. So requests come in. We then look at our database of (members) and look at what their areas of interest and perhaps expertise or what have you are.'* (D1)

'*The most successful person that I've seen in this is the Head of the HCOQ in America. He has raised tens of millions of dollars for research. He's brought the research world together and he's an incredible person'.* (A2, medical advisor to HCOA)

'One of the things we identified was actually connecting to the Divisions of General Practice. One of the Divisions of General Practice was a former client of mine. I rang the former President and she was kind enough to give us advice on how to access the general practice area and the specialist's area. I had that initial meeting, but then it's taken on a life of its own' (A6)

Contribution as Care

A primary purpose for HCOs especially in their foundation stage is to care for others experiencing the same condition.

'We tend to mainly work with carers. We do some work with people in the earlier stage of HCB through some of our programs, and through counselling but mostly we stay with the carerr as the condition progresses' (B5)

Research cited by Lydon (2009) revealed that 'cancer support and self-help groups were first mentioned in the early 1970s as a means of enabling those affected by cancer to gain emotional support from others going through similar experiences and to use those experiences to help 'cushion' their own journey (Miyashita 2005). Support groups aim to foster such emotional support and deliver practical advice for participants through the sharing of mutual experiences (Gray et al 1999, Docherty 2004)'. (2009:12). The value of belonging to support groups was also reported across the HCOs participating in this research.

'*Any new person who's diagnosed (who) wants to come along and have a chat, they're quite welcome. It's quite a good little group. We're not formalizing it. A lot of people don't want to come to formal meetings. We just want to make it like a social thing and we talk about anything and everything, and the condition. They were very good last year when we were preparing for our big information sessions here, and they all helped, which was really great, and they're willing to do it again this year'*. (A3)

While most participants 'were satisfied that joining the group had allowed them to make new friends, find out more about cancer and meet others facing similar difficulties ... they were less satisfied in terms of learning how to cope better with cancer, share problems with others or support others.' (Lydon, 2009:13-14).

Earlier research by Kyrouz et al (2002) found that people supported by CHOs 'showed improvements in knowledge, mastery, coping, control and psychosocial wellbeing'. (Boyle et al, 2007:554) and other more recent research (Beesley et al, 2009; Boyle et al., 2009; Sav et al, 2014) also suggests 'high levels of satisfaction and emotional, informational and practical support benefits' (Boyle et al, 2016:394).

HCOD attempts to provide members with the information they want by consulting with their members on the development of support materials. These resources are freely available on their website and through their extensive network of local support groups.

‘O*ur flagship product is the comprehensive package of information that's available free and it was put together through extensive consultations with [people diagnosed] …it's very much a resource which is shaped and guided by [personal] experiences. There are a lot of quotes from [individuals]. There are a lot of pictures. They've told us what they think needs to be in it as something that's going to be helpful for them when they're newly diagnosed’* (D1).

In addition to providing support for individual members. HCOs work with the medical community to increase awareness and support offered to people experiencing the condition. A number of studies of Australian support groups undertaken by Boyle et al (2003, 2007, 2009 and 2016) explored collaboration between general practices and support groups, reasons for contacting them and types of support offered. ‘Most commonly, SHOs reported working with GPs by providing informational resources for both patients and GPs. GPs most often reported working with SHOs through patient referrals, assisting with educational programs and by displaying SHO brochures and posters in their practices.

Other less common, but reportedly successful, collaborative activities involved joint case management and research’. (2003:76). ‘Overall, GPs saw SHOs as meeting a variety of patient needs; in particular, information and education; psychosocial support to help people adapt to health problems and cope better; and a greater sense of control or self-reliance’. (Boyle et al, 2003:77).

Boyle et al (2009) identified a number of specific benefits reported by members of CHOs including useful information about health, learning to manage health problems better and gaining information about treatments, medication and latest medical research. In addition they reported valuing getting information about available health professionals and services, access to services like counselling, exercise classes or seminars, connecting with and helping others with similar health problems, and gaining more confidence in talking to doctors and other health professionals. (2009: 632). Boyle et al (2016) propose a stronger role for HCOs in the primary health environment in Australia. ‘CHOs are well placed to meet the varied support needs and preferences of patients through a range of support options including printed information, newsletters, links to other resources, telephone and online support and information, and educational activities’ (2016:394).

Contribution as Cure: Advocacy, Research, Policy and Practice Change

The contribution of HCOs in terms of advocacy is well researched (Rabeharisoa 2003, 2006; Jones, Baggott and Allsop, 2004; Zimmerman et al. 2005; Baggott and Forster 2007; FitzSimons 2008; Sharp et al. 2008; Nahuis and Boon 2011; Baggott and Jones 2011; Sav et al, 2012; Rabeharisoa et al 2014; Rabeharisoa and O'Donovan, 2014). Each of the HCOs participating in this research referred to their role in advocacy in their mission statements. The way in which they achieved their advocacy goals differed from HCO to HCO depending on their structure and available resources. HCOD reported a sophisticated advocacy program incorporating the voice of their members.

'Our advocacy campaigns are very considered, and the way we do that is to utilise the voices of (individuals) in telling the stories, linking with very key stakeholders in creative ways, having a media strategy. We're quite good at thinking about all of the stakeholders in our strategy, initiating discussions, whether a round-table discussion with key clinicians and other decision makers so we've had a number of treatment-related advocacy strategies that have been really successful' (D1)

In contrast to HCOD, HCOA relies on personal connections of committee members and a small group of volunteer advocates to achieve its advocacy goals.

'They have done well, seeking political sponsorship, or advocacy in a way, engaging with the politicians and administrators, actually realizing the benefits of that relationship, building that connection with the medical community' (A6)

The much larger and well-resourced HCOD has implemented a clearly defined strategy for developing member skills to act as consumer advocates, and their program is recognised in the sector as 'a flagship model for consumer organisations with regard to advocacy' (D1)

'They act as consumer representatives on committees, places where decisions are made around the condition. They have a seat at the table where any discussions and decisions are made. That program has grown over time… Last year we had (people) involved in about 70 activities across the country. They will range from national committees where guidelines are being developed on treatment and support. They might be on specific committees around, say, genetics and the condition. They might be presenting at national conferences representing others with the condition' (D1)

In addition to their contribution advocating for change to policy and practice, HCOs in this study consider supporting research as another key aspect of their mission, providing essential evidence required for changes to policy and practice.

An increasing body of work (Crompton 2007; Entwistle et al 2008, Ward et al 2009; Savory 2010; Saunders and Girgis 2010, 2011; Nierse et al 2011; Read and Maslin-Prothero 2011; Saunders and Crossing 2012; Brett et al 2012; Rabeharisoa et al 2012 and Lawn 2016) details the research contribution of HCOs and their impact in this area.

Rabearisoa et al (2011 and 2012) undertook a major study of European patient organizations, known as the EPOKS study (European Patient Organizations in Knowledge Society). Their research examined the growth of patient organisation interest in research activities and the production of knowledge around specific conditions, as well as their impact on health policy and the governance of health issues across conditions across Europe. Before the EPOKS Study, Cromptom (2007) reported on collaborations between the biotechnology industry and patient groups in which 'the biotechnology industry is working with patient groups at the policy level and also in clinical trials planning, where patients sit on steering committees and help in the recruitment of patients' (2007:205).

According to Cromptom (2007) patient contributions 'to the production of knowledge about rare diseases and orphan drugs' are many and varied including family histories, videos and photographs of disease progression, as well as 'blood, skin and muscle tissues and post-mortem organs for medical and genetic research' (2007:208). They raise money for research and 'collaborate with industry in the lobbying of government and regulatory bodies' (2007:208).

More recently Lawn (2016) noted that in the current climate of ever decreasing research resources there is 'increasing pressure to conduct research that has genuine translational value (i.e. research that clearly benefits the community)' (2016:1). Citing Saunders and Girgis (2010), Ennis and Wykes (2013), and Snape *et al* (2014), Lawn (2016) suggests that despite the need for 'greater consumer involvement in all aspects of the research process and its translation', their inclusion 'continues to be challenged in some sectors of the health research community (2016:1).

Hewlett *et al* (2006), maintain 'the research partnership challenges [the] traditional clinician–patient relationship because now they meet as colleagues, collaborating, arguing, challenging, and then socializing' (Lawn, 2006:677).

Citing Brett *et al(* 2014*a),* Buck *et al (*2014) and Kenny *et al (*2014), Lawn (2016) identified other barriers to research partnerships. The desire of researchers to maintain authority over the research design and ensure scientific rigor creates tension. Concerns about 'representativeness of consumer voices, and the needs of more disadvantaged consumers and groups; maintenance of confidentiality; consumers' low or inconsistent attendance rates at project reference meetings; and professionalisation of the consumer researcher role, which then hinders representativeness and freedom from bias of the consumer voice' also present barriers. (2016:5-6).

5.1.3 Connectedness

Connectedness to the broader community, to members, to other similar organisations, to the medical community, to researchers, to government, to industry and to other stakeholders was seen to mediate success in each of the three categories identified. Figure 5.5 illustrates some of the many HCO stakeholders.

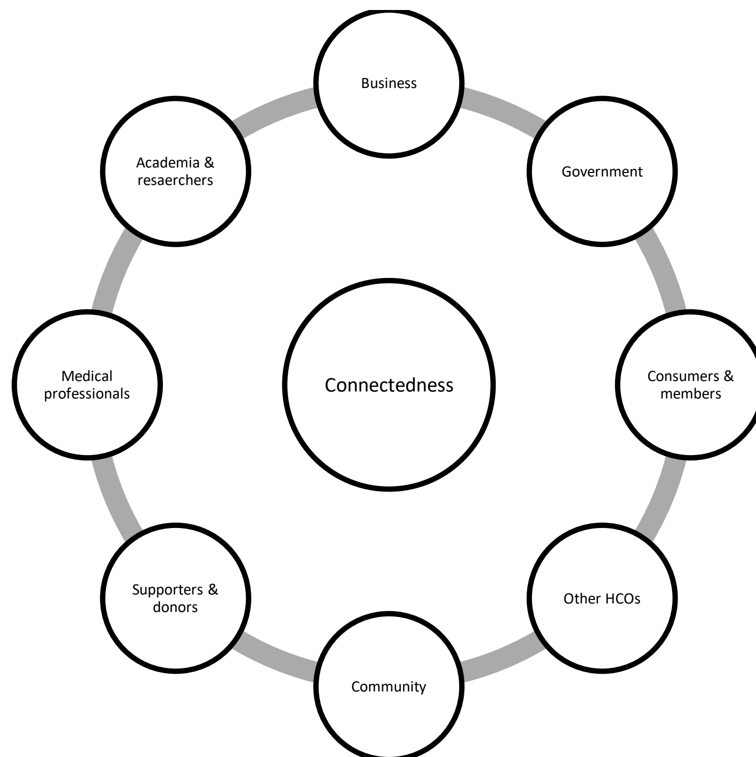


Figure 5.5 Connectedness - a key mediator of success in every category.

Connectedness can be examined through several theoretical lenses. Stakeholder Theory is used to identify and evaluate which stakeholders are important to HCOs and resource dependence theory is helpful when considering which stakeholder benefit to HCOs.

Social Capital Theory also shines light on the importance of the HCO network in relation to building social value and community. In this research, connectedness was referred to as networking, collaborating and engaging. Connectedness also refers to 'the relational aspect of social capital (Nahapiet and Ghoshal 1998)' .(Leana and Pil, 2006:354), and 'thinking broadly, at least initially, about who the stakeholders are is a way of opening people's eyes to the various webs of relationships within which the organization exists (Feldman and Khademian, 2002)' (Bryson 2010 in Renz, 2010:235 -236).

Salient stakeholders - the right connections

In their comprehensive review of the literature on segmentation of non-profit stakeholders and relationship marketing, Rupp, Kern and Helmig (2014) conclude that non-profit stakeholders are generally categorised as belonging to either the supply side, e.g. resource providers, or the demand side, e.g. beneficiaries, members of the non-profit's network. (2014:77). Identifying who stakeholders are, their respective salience and the value of their networks is a first step to developing relationships which contribute to success for HCOs. Managing those relationships over time is critical to their sustainability. The diversity of these partnerships and their relative importance to participating HCOs is reflected in the interview data. The different relationships with business, governments, researchers, members and other organisations are discussed separately in this section.

'Engaging with the politicians and administrators, actually realizing the benefits of that relationship, building that connection with the medical community, it all becomes almost a virtual spiral - one thing leads on to the next, on to the next' (A6)

'We have a lot of partners, external partners, which are universities, other non-government organisations, government departments. We partner with them on research and service development projects. Those partners are either non-government organisations in both the health and the community sector. Some of them are providers. (B5)

We're quite good at thinking about all of the stakeholders in our strategy, initiating discussions, whether it be a round-table discussion with key clinicians and other decision makers, so we've had a number of treatment-related advocacy strategies that have been really successful' (D1)

'Good relationships with key organisations within the sector, private and other not-for-profit organisations. We've had very good relationships with a number of big. providers, with trusts and foundations, with pharmaceutical companies even' (B3)

'We have very broad partnerships. In fact, that's really core to our work' (B5)

'We have an advisory group consisting of some of these organisations. The state government's a stakeholder … more for the state-based organisations, but we need to be aware of those relationships and of course, suppliers. We've got a lot of people that provide services to us. So contractors, they're stakeholders, our consumers. When we say consumers, they're clients … they're other people with HCB or their family members … carers' (B1)

'*We're positioned well for people to come to us and say, "You're a good organisation to partner with" We've got wide networks, I think that's what we do well. We have wide networks with consumers, with the general public, with health providers, with community providers, (and) growing as some of our programs grow, in terms of corporate sponsors'* (B5)

'The other reason why we succeed as an organisation is we've got a commitment to partnering with other organisations. I think the staff are sick of me saying (it) but we do nothing in this life alone, and if we're going to be successful we have to increasingly work with other parties' ' (B4)

Connectedness with business

Sustainability is a critical issue for non-profit organisations and is recognised as a key challenge by HCOs participating in this research. Al-Tabbaa et al. (2014) citing Andreasen (1996) and den Hond et al (2012) contend that non-profit/business collaborations (NBCs) can support sustainability through 'generating new income streams, knowledge and skills transfers, and publicity (2014:659).

Research undertaken by Hall, Jones and Iverson (2011) cites a number of ways in which NPOs benefit from corporate sponsors or partners.

'Involvement with a corporate organization often brings needed support, including financial and other resources, such as personnel who may act as volunteers. Partnerships may also lend legitimacy or substantiate the cause, as well as increase opportunities for publicity (Polonsky and Wood, 2001). Further, non-profits can benefit from partnership with well-respected corporations as their reputation may enhance the credibility of the NPO (Nowak and Washburn, 2000)' (2011:6)

Citing earlier research, Al-Tabbaa et al (2014) suggest that in non-profit/business collaborations 'each partner should be able to deliver value to the other (Austin, 200b), {and} common objective(s) should underpin the collaboration (Bies et al. 2007)' (2014:658). Kwon and Adler (2014) note that 'connections between organisations are often forged with a specific goal in mind' citing the example of 'selling and distributing a new medicine' (Powell, White, Koput, & Owen-Smith, 2005: 1138) (2014:416). However Al-Tabbaa, et al. (2014) citing Harris (2012,) maintain that there has been little attention on examining these collaborations 'from the non-profit sector perspective' nor on 'how NPOs can maximize their benefits from collaboration with businesses'. (Al-Tabbaa, et al. 2014:659), and in some cases there is no perceived benefit from collaborations. This view is supported by research undertaken by Hall et al (2011) which suggests that NPO sponsored disease awareness advertising is more effective without the co-sponsorship of a pharmaceutical company' (2011:15-16).

Businesses benefit from relationships with non-profit organisations in a number of ways. 'NPOs enjoy legitimacy in the eye of society and have dense networks of stakeholders that businesses can access, such as donors, regulators, and public lobbyists (Yaziji 2004). Businesses might also be interested in other benefits such as the geographic location in which the NPO operates. If the NPO is geographically spread, a business can tap into this advantage to increase its reach and hence better engage with the communities at the grassroots level. Businesses might also be interested in a well-established and widely recognized NPO brand, such as in the case of cause-related marketing (transactional collaboration). Such features would put an NPO in an appealing position in regard to maximizing the return that businesses can achieve from their social investments (Cantrell et al. 2008)' (Al-Tabbaa et al 2014: 666). In addition, certification and labelling agreements which endorse products (Murphy and Bendell 1999), (Baur and Schmitz, 2012:13) are beneficial to business.

From the non-profits perspective, branding alliances are beneficial according to Dickinson and Barker (2007). 'Attracting a partner with matched values and brand meanings leads to long-term partnerships and access to important funding sources in the long term, which are vital given increased government withdrawal from the non-profit sector' (2007:77). Eikenberry (2009) identifies cause-related marketing or consumption philanthropy as another area for partnerships between non-profit organisations and businesses.

Providing examples such as the pink-ribbon campaign and the Product (RED) campaign, and citing Grau and Folse (2007, p19), Eikenberry (2009) suggests that "cause-related marketing involves profit-motivated giving [enabling] firms to contribute to non-profit organizations while also increasing their bottom line by tying those contributions to sales'. (Eikenberry, 2009:585). Citing Peloza and Falkenberg (2009) and Simpson et al (2011), Al-Tabbaa et al. (2014) maintain that collaborations with business offer non-profit organisations 'various tangible and intangible benefits that foster their organizational sustainability' (2014::671). They present a framework to assist non-profit organisations developing 'a collaboration strategy to attract prospective business partners' so that they might become more pro-active rather than re-active to what businesses might offer. (Al-Tabbaa et al, 2014::671).

Connectedness with Government

Salamon and Toepler (2015) describe a number of conditions they believe are key to successful relationships between governments and non-profit organisations.
Noting that the strengths of the non-profit sector as service provider, and the strengths of governments as generators of revenue and rights to benefit are both complementary and counterbalanced by their respective limitations in each area, they report government/non-profit co-operation or partnerships are 'a highly effective way to organize a wide assortment of publicly financed services'. (2015: 2174). They suggest a number of strategies, which governments and other sponsors could use to support the work of non-profit groups, which would enable non-profit agencies to preserve an element of independence and flexibility. These include 'payment schedules on grants and contracts that avoid costly cash-flow problems for non-profit organizations, avoidance of undue interference with the non-service functions of the organizations … challenge grants or other funding devices that reward agencies for the use of volunteers … the generation of private-sector funds to supplement public resources, and continued encouragement of private giving' (2015: 2172).

Cornforth et al. (2015) examine the dynamics of non-profit/public collaborations, studying how they are formed, how they develop and how they fail. Noting that such 'collaborations or networks are unlikely to constitute partnerships of equals (Entwistle, et al 2007; Lowndes & Skelcher, 1998)' they identified the need for non-profit organizations to recognize that their public partners 'exist within a complex and changing national policy and economic environment' (2015:790-791).

Referring to Takahashi and Smutny's (2002) model, Cornforth et al. (2015) propose that although it is not easy, initial governance structures can be changed when the commitment of different partners to the collaboration is more important to its long-term future than are difficulties encountered in changing how it is governed. They note the importance of managing 'important tensions' for collaborations to be successful as internal tensions around 'efficiency and inclusiveness (Provan and Kenis, 2008)' and 'goals and ways of working' may lead to changes in governance structure or a reduction in commitment of some partners or even withdrawal from the collaboration. (2015: 791). They present their model, an extension of Takahashi and Smutny's (2002) model, as a tool to assist 'researchers gain additional insight into the formation, development, and effectiveness of public/non-profit collaborations, and how the tensions and challenges they face can be overcome'. (2015:792-793)

Salamon and Toepler's (2015) advice is timely for HCOs in Australia in light of recent changes to funding arrangements for service provision (with the implementation of the National Disability Insurance Scheme (NDIS) and My Aged Care initiative. Similarly Cornforth et al's (2015) model be helpful for organisations seeking to collaborate on health and medical research in light of the current National Health and Medical Research Council's (NHMRC) grant program review.

Sawer and Jupp (1996), citing Baldry (1992) and Dugdale (1992), referred to the creation and funding of the Consumer Health Forum (CHF) in 1986. Moves from within the Australian 'consumer movement for a more specialised health consumer peak coincided with the aims of the then Minister for Health, Neal Blewett, to open up the decision-making processes of his department still dominated by the medical model of health'. The CHF 'was intended to be a counterbalance to the power of the doctors and to increase the policy autonomy of state actors in relation to powerful non-state interests' (Sawer and Jupp, 1996:86).

Although peak bodies such as the CHF have a key role in providing policy advice to the government, Dugdale (1992) observed that increasing their capacity to participate in the policy community reduces the effectiveness of community-based organisations as channels of information regarding emerging needs in the community. (Dugdale, 1992:157, cited in Sawer and Jupp, 1996:87). HCOB participants report that it maintains its independence in relation to advocacy at the same time as influencing policy.

'Those other organisations might argue that "we like being free of government, so we can say what we like". Well, we say what we like. The (national advocacy) campaign is out there in the face of the government, but we still have a partnership where we manage to work together. And in areas like primary care and hospitals now, we've got an agenda agreed with the department, which is quite extraordinary' (B2).

Citing Bass et al. (2014) and Grant and Crutchfield (2007), Salamon and Toepler (2015) note 'a growing consensus among experts that committing to both service and advocacy is a key to high performance by non-profits (Bass et al. 2014)' and that 'all high-impact organizations bridge the divide between service and advocacy'' (Grant and Crutchfield 2007, p. 35).' (2015: 2171-2172). Nevertheless, reliance on government grants leaves groups such as the CHF and other peak HCOs at risk of financial unsustainability as the extract from CHF's Annual Report 2014-2015 indicates.
'During the year CHF had to take stock of its future viability as a consequence of reduced income streams in the challenging national funding environment. The Board noted at the beginning of 2015 that there was no surety of this trend being reversed for some time, which included uncertainty over future arrangements for the critical base funding for national peaks from the Department of Health and Ageing to support the organisation'. (CHF Annual Report 2014-2015:5)

According to Furneaux and Ryan (2014,) the 'purchaser/provider model of relationships' with its 'emphasis on competitive tendering and contracting-out' ' has shifted to a 'focus on more relational forms of contracting' (Osborne 2006). These varying contracting arrangements result in different types of relationships between government departments and NPOs (Brown and Ryan 2003)' (2014:1114).

Comments from HCOC and HCOB participants reflect these relationships. HCOC expressed the view that they had a higher level of connection with government and were better at partnering with government than other chronic disease organizations, and that they could work with governments in a different (more effective) way than their network partners.

'You get arm's length independence, advocacy, trust, and you hook in all our networks: corporates and clinicians and researchers all work with us, but they won't work the same way with Government, they can't'. (C1)

HCOB's relationship with governments was said to be the result of the previous experience of their National CEO as a senior public servant in Health and a state CEO's experience as state political leader.

'If you compare us with most other NGOs, we probably have a partnership style with government that's unique, and that's partly because I used to be a deputy secretary in health ... we've got almost a unique relationship with the department, where they regard us as policy advisors and take us into their confidence' (B2)

'I met yesterday with somebody from the (health) department who'd met (similar) organisations from Japan and the Netherlands and one other country, while he was in Tokyo, and he said we're unique. They were astonished about the government funding relationship with us. I think we work well in the space of government-- partnering, collaboration and government relations. (B5)

'We've got a very strong relationship with the New South Wales Department of Ageing, Disability and Home Care. They just contracted us to do some education across their home and community care workforce. They've also contracted us to do a carer coaching project, to build capacity within carers to care at home and to support longer term caring in the home. We're also doing an Aboriginal engagement project with them as well, which is really aimed at looking at how do you engage around risk reduction and support and better access to services up in those communities? And we're doing a multicultural project with them as well, so actually we do lots of projects.' (B5)

The recent introduction of the Federal Government's National Disability Insurance Scheme (NDIS) and My Aged Care will undoubtedly influence Health Consumer Organisations in Australia involved in the delivery of services to these target groups as they compete with other non-profit and for-profit service providers. Those HCOs providing services and programs are now accessing NDIS or My Aged Care funding rather than government grants for services.

Reassessment and evaluation of stakeholders and their respective salience is critical with governments assuming quality assurance oversight while consumers 'hold the purse strings' make choices on which services they will access. As Salamon and Toepler (2015) note 'generally speaking, producer-side subsidies such as grants or contracts are much preferred to consumer side subsidies such as vouchers and tax expenditures, because the former deliver their benefits directly to the organizations whereas the latter put the resources in the hands of consumers, who can "shop" among providers'. (2015:2172). B7 believes enabling consumers to 'shop' for providers is a change for the better.

'I think one of the really exciting developments for aged care and disability is a move to consumer directed care, and the model that the NDIS - the National Disability Insurance Scheme - is putting forward of individualised funding models, because that puts the power in the hands of the consumer. So if you're not doing a good enough job, they'll go elsewhere. You can no longer skate on your laurels. You can no longer just assume that you've got this bloc funded grant from the Government, and that's safe as houses, and you can go on doing that forevermore, and the money will never be taken off you. So it completely flips the power away from service providers and also, if you like, gets the bureaucracy off the hook because they don't have to ask those questions - they can leave it in the hands of the clients. They'll take the money where the good services are. So yeah, I think it's an exciting development in that sense, but as I keep telling a lot of my former colleagues who still work for aged care providers or disability providers, it's a good time to be working in a peak advocacy organisation because that headache is in front of them. They're going to have to deal with it, otherwise-- the certainties of their business model, these bloc funded grants with no end dates on contracts - there is going to be an end date fairly soon on those, and they're going to be in a competitive market driven environment. It's going to change their business models, and they're going to have to think very differently to ensure that their income levels are sustained at current levels. They're going to have to be doing some things very differently. (B7)

From a resource dependence perspective, 'consumers' are now added to the mix alongside government and donors as salient stakeholders. Brody's (1996) observation is just as relevant two decades later, 'issues of effectiveness and accountability are likely to become even more complex as non-profits straddle a more 'commercialised' business environment without a 'clear category of principals' (1996:465). As Salamon and Toepler (2015) note, 'This puts non-profit organizations at a disadvantage because they generally lack marketing skills and access to capital due to the constraint on their distribution of profits to potential shareholders. Lacking access to investment capital, they find it difficult to expand to meet the new demands often triggered by new government voucher programs'. (2015:2172).

From an advocacy perspective, having someone on the inside of politics with direct experience of the condition is seen to be beneficial to enhancing the credibility of the HCO and raising its profile in government.

'You have this hope that-- it's not a nice one, but it's a hope that someone influential in Federal or State politics knows someone who has HCB and (who) becomes your champion on the inside. It's not nice to wish that upon someone, obviously, but we believe that would make a tremendous difference to the claims that we make' (B7)

Connectedness with consumers and members

Wellens and Jegers (2016), citing Hyndman and McDonnell (2009), Smith (2010) and Wellens and Jegers (2011), maintain that 'beneficiaries undoubtedly are a crucial stakeholder group' and 'that NPOs that are not paying attention to accountability toward their beneficiaries possibly undermine organizational performance' (2016:295).

A number of studies reveal why people contact health consumer organisations. Boyle et al (2009) found that 'people contacted CHOs primarily to obtain further information about their condition or to access services or products. Most believed CHOs offered useful information relevant to their health and better ways to manage health problems' (2009:628). Research by Klemm et al (2003), found that 'internet support groups may be more acceptable (to males), because men focus on obtaining information and education, rather than on kinship and mutual aid, and online groups make this easier to accomplish. Studies by Cella and Yellen (1993) and Grande et al (2006) revealed women use face-to-face support and self-help groups more often than men do. (Lydon, 2009:14).

Van Puyvelde et al (2012) note the importance for non-profit organisations to understand the motivations of their members 'since member entry, participation and retention are critical to the survival of the organization' .(Van Puyvelde et al, 2012:441). This research shows that there are however different views on the value of consumer input, even within the same organisation.

'There's a different school (of thought) on (the value of consumer groups), a view that they are archaic and past their time, and there's better ways of researching issues with consumers. They work for us and … contribute to our reputation. Having a consumer group is incredibly powerful.' (B7)

Consumer engagement was most obvious in HCOB and HCOD. Both have extensive networks and conduct regular regional forums.

'We've got eight consumer groups across the State, and our members sign up to be part of those groups, about 2,500 members. They're invited to join those groups across the State. They meet in person, so that obviously does disadvantage some people when they meet in only eight locations, at the same locations, twice a year. We go out with issues that we want to talk to them about, and they … raise issues at those meetings that they want to have communicated to us, and taken on board or done something with, or brought back to them later. Across the three hours … we'll … be guided and advised by them about future topics for research that we should be doing, or service initiatives, or media or marketing, or something like that. They'll have an opportunity to communicate back to us about what's going on in the whole organisation and things that we could consider and do' (B7)

'Probably the key thing which perhaps differentiates us from some of the other organisations is our real focus on being guided by consumers. Something (the CEO) has done from the outset really, is to have strong networks of consumers, and to be guided by what they see as their priorities, as their key priorities'. (B3)

'*Having active consumer involvement is critical, because you can think yourself what your consumers may or may not want or need, but unless you're regularly talking to them, then you might be out of touch. And you may also miss things, that without having that engagement, you wouldn't be aware of.'* (B1)

'*As far as consumers go, it's the ability to keep listening to them. To keep reviewing what the issues are. Our forums give us that great opportunity just to hear about what some of the issues are (and we) make sure we spend time in that forum program for questions'*. (D1)

D1 described the value of having consumers involved at the beginning of developing support materials rather than reviewing at the end and saying, "Look, we don't understand the language you're using here". *'Ensuring that they're involved at the grassroots level and at the beginning of undertakings, rather than at the end' (D1).*

'We are a consumer organisation. We're not a service-providing organisation that needs to remember to engage with consumers. So we're different' (D1)

In this research, each HCO reported the benefits of consumer involvement, planning and participating in HCO activities.

'All the professional conferences always had a major lay conference that happened alongside and together and I think that worked incredibly well' (A2)

'I don't know if it is unique but I think one of the things that we do very well is because we have people who work every day with people with the condition that is a really good method of hearing what their issues are, from real people with the condition.' (C4)

'We're fairly grounded too. Most staff here, in each office, actually get to see someone with the condition every day and that's really, really important because you stay focused in your area. No matter if you're in reception, or business manager, or my role, we always get to see the people with the condition and that keeps everybody grounded as to why we're here' (B8)

'We're about supporting people with the condition, people live in communities, they want to see and know people in communities. The closer we can get our identity to those people and for them to get to know us and trust us, and therefore inform our work, and benefit from it'. (C1)

'Not-for-profits can be very inward focused, the DNA of this organisation is carer support groups, so every day we meet and speak to carers and that's really critical to being really relevant and focused on what you do about trying to help them get through their diagnosis'. (B6)

'We're a network. And (in) the forums, we make sure, as much as we can, that we invite local presenters, local medical oncologists and psycho-social health professionals. And we get the local nurses involved, and we draw on our local champions to help us plan it. What are the key things that happen? The night before, we have a dinner with some of the key (members). Tell us about your community. What are the issues you're dealing with? What are some of the challenges? And then we can feed that back into our policy team, and see if there are ways that we can support that, it's all very interlinked. You can see there are many layers and I think that's what makes it successful'. (D1)

Walker and McCarthy (2010) note the role of network affiliations in supporting organisations, 'especially given that networks share best practices for raising funds (and) further, legitimate organizations in general tend to be rewarded with resources (Aldrich and Auster 1986; Pfeffer and Salancik 1978).' (2010:333)

'We had almost nothing two years ago, and by gradually building that up we've developed quite strong collaborations with a number of different research organisations. We've got ourselves involved as a funding partner in the NHMRC Partnership Centre. It's a $25 million program, public-private kind of partnership mostly funded by either the NHMRC or the Department of Health and Ageing, but with three service providers, and ourselves, as additional funding partners' (B3)

'The sector does things so much more cheaply than others. Our secretariat gets $160,000 a year - that's it from Government. And everything I just described to you - where would you get that for that investment? Plus you get arm's length independence, advocacy, trust, and you hook in all our networks: corporates and clinicians and researchers all work with us, but they won't work the same way with Government, they can't. It's a fabulous sector but all the reasons that make it good, make it hard'. (C1)

Connectedness with other HCOs

Partnerships and relationships. That's really been important and certainly something that is intrinsic' (D1)

In their analysis of three European patient organizations (EPOs) Rabeharisoa and O'Donovan (2014) concluded that they no longer represent aggregated health issues from the perspective of individual member countries within the European community. Rather, by 'associating European institutions, national patients' organizations, and European and national stakeholders in their condition area', they promote 'the idea of a confluence of interests of the 'partners' acting collectively to shape 'European' health policy (2014:727-728). Since each of the EPOs studied also had members in countries beyond Europe, the authors contended that they were constituents of 'International Patients United' (in their words), contributing to the 'globallization of patient advocacy' (2014:734).

Zimmerman et al (2005) reported on the evolution of international advocacy groups from national support groups. Interestingly their study on groups in the USA, UK and Italy actively supporting people with psoriatic arthritis and psoriasis and Ankylosing Spondilitis. was published in the Annals of Rheumatic Diseases, the official journal of EULAR (European League Against Rheumatism). EULAR is sponsored by global pharmaceutical companies as are other international alliances such as IAPO (International Alliance of Patient Organizations. According to its own website, EULAR 'is set up of four types of institutional members: scientific societies, national organisations of people with arthritis/rheumatism and health professionals as well as corporate members. With 45 scientific member societies, 36 PARE organisations and 22 health professionals associations, EULAR underscores the importance of combating rheumatic diseases not only by medical means, but also through a wider context of care for rheumatic patients and a thorough understanding of their social and other needs. 23 corporate members support EULAR financially with their membership fees' (downloaded from http://www.eular.org/eular_members.cfm 29/4/16).

While the HCOs participating in this research were in favour of collaborating with other groups, they recognised significant challenges in establishing connections.

‘I think there's a lot of benefit for us in being involved with other consumer health organisation and … alliance type arrangements. We are members (of) the Consumers' Health Forum and Research Australia. It has a different kind of angle but we're a member there’ (B3)

‘Our organisation can probably benefit from a closer relationship and joint messaging simply because of the crossovers in the diseases. We've had a lot of difficulty trying to do so. Some of those organisations have seen the fairly substantial growth (of HCOB) and think that our organization is probably a bit of a threat, that HCOB's is trying to take over the world, that kind of thing’ (B3)

‘I think that's a real challenge for us, is who should we be partnering with and how do we respond to everyone else who wants to be associated with us? As the external environment changes and we move to more of a situation where people would be able to choose their own providers and pay for their own services, everyone wants to have (our) tick of approval ‘(B5)

‘I’ve made approaches to (other HCOs) nationally and locally… I sometimes feel that people think we're in competition with one another, competition for resources, competition for the public space…, I'm wanting a strategic alliance’ (A4)

Having established connections with other organisations, HCOs recognised the challenges associated with developing and maintaining relationships. According to HoneyCutt and Strong (2012), frequency of informal communication between organisations within an advocacy coalition enhanced connectedness between them, which lasted beyond a particular project and its funding. They suggested that ‘communication represents an aspect of social capital in that coalition organization members are building connections with each other, developing a common language and vision about advocacy, sharing knowledge with each other, and finding ways to collaborate.’ (2012: 236).

‘I think they finally realize that we probably do mean business. And they're going away now and looking at ways that maybe we could work together in some projects, because they can attract funding from other areas, and if we work together in some of those projects, it might be a way we can get some side funding as well’.(A3)

‘That's a question I've been asking myself for some time, for six months. I chaired one of their meetings yesterday and still walked away and went, "What exactly are we here for?" The organisation is still in its infancy, it's less than 12 months old. But what is clear is that it's almost like a forced marriage, or a strategic alliance of convenience. … There is goodwill and intent, but that's not enough." But having said that, though, there's a bit of fear in me that if we're not there (?).’ (C9)

According to Prusak and Cohen (2001), networks ‘are incubators of collaboration’, providing ‘the structure and the means for people to interact’ (King, 2004:473) and as B11 notes, *‘One of the things that not-for-profit does particularly well is network’.*

“They make the most of opportunities when they're out in the community, and come back and say, " that person might be able to be a consumer rep for this." or they might be able to do that schools program and his wife happens to be the leader of some business that's looking for a partnership.’ (C7)

‘I'd love to have a network here where I live, where I could go once every month or once every couple of months and have a chat to ten other groups of a similar size or purpose just to hear about what they're doing and share information and knowledge. There's so many things that we stumble across. How to do such and such, or do you know you can buy these things from here and do something with them. But if you only just stumble across it, it takes us a long time to find it out and maybe it's a year too late sometimes. If you could just share information with other people on their successes and their problems and what they're doing - it would have to be with a health or community type focus because if it was too broad - although you could include environmental groups as well. I just think you'd want to be facing similar issues, challenges. Although I probably wouldn't exclude people, similar groups would probably work better I think’ (A5)

‘Certainly there have been times where we've shared information or shared the basis for a policy, or asked ‘how did you handle that situation?’ so I'm not having to reinvent the wheel doing something. One thing I've found in the not-for-profit is, we're actually quite generous with our knowledge and our skills with each other, more so than I found in the corporate sector’. (B11)

‘We share information because whilst we are both in the same field, if you like, of seeking donations, we're also both in the same arena of providing support, so it's not necessarily competitive’. (C5)

‘They're more informal coffee meetings, if you like. We'll set them up in the diary and talk about issues that our organisations are facing, whether they're HR issues, or-- and it's really helpful to get opinions that are valuable, independent’ (C5)

‘There's a few organizations around like Connecting Up. They're brilliant. . Connecting Up , amongst other things co-ordinates all software donations for not-for-profit charities in Australia. They also run training in technology and marketing and that sort of stuff. Once a year they have a big conference. I've been to two of their conferences and learnt so much from that. That's what got HCOA started on Facebook. That's what got us started on Office 365. Through that as well, I have more interactions with other charities (and) people who want to talk to not-for-profits about stuff’. (A5)

‘I think it's also individuals, because if they know you, they will come. Recently, we had the guy from Disability Services on the north-west ring me, because in a previous life he knew me. It was that previous contact, that brought it together’ (B9).

‘I mix a lot. I network a lot with other organizations. Some of these organisations are quite small and Arthritis New South Wales, which is quite a small organisation also quite nice work in some self-management programs and online stuff. (B5)

‘I went to a social media workshop. It was a networking thing. They were (mostly) all community organizations, a really good mix of groups, all out there trying to do things for people in their own different ways. It was networking in that you got some ideas on what they were doing although it was basically to learn how to manage social media. We handed out business cards and I've been contacted by someone as well since, and I found someone there who had HCA so I gave her a little booklet’ (A3)

‘I think my particular background might have helped. I've been in and around social policy in various forms for 25 years or so in Australia. I've got huge networks into research and policy, and I think that's helped’. (B2)

‘We have arranged for like-minded people within the organisations to get (together) so the education managers will share information, and fundraising managers will have informal conversations from time to time. But that's driven from the CEO level’ (C5)

'I think also what we do very well is connect with people from every demographic and across the key target groups that we are aiming at' (C2)

'[One of the committee members] is very well connected with the medical scientific community'. (A6)

'I don't seek out like-organisations, we find ourselves in places together like Government consultations. But remarkably I don't think we have a lot in common. I watch what they do and I learn from them and I've got some good friends, but you won't see them in our strategic plans as much as you'll see the community partners'(C1)

Connectedness with community

'We're obviously very much a grassroots community organisation that is interested in being the first point of contact for people with the condition; their families, their carers. We don't claim to be a research centre. We don't claim to be an emergency service. But we want to be in front of people's mind when they think HCC and their management. So we want to be very contactable, reachable, accessible to the community' (C7)

'I have a view that we need to broaden our remit, and audience, and interest, so that's why we do that stuff. What pushes us is how can we make this issue real for the wider population? Because if we get that, we attack the issue of stigma, we potentially get more fundraisers, we get more government action, all of that, so we need to speak to the wider community.' (B4).

'One area which we've just embarked on is the cultural-diversity area. We hadn't ventured into that area in a strategic way in the past. We undertook a research phase. We employed a coordinator to look at what [members] from diverse cultures need, what exists, what the research says. That's shaping a raft of strategies that we'll implement over the next couple of years. That's been a challenge because we've never had the ability to get to that [and we realize] that you can't do it in a token way. You've got to do it properly.' (D1).

'We're about supporting people with the condition). People live in communities, they want to see and know people in communities. The closer we can get our identity to those people and therefore for them to get to know us and trust us, and therefore inform our work, and benefit from it'. (C1)

'What we have found that it's the nurses who are doing the (treatments) that understand the real need because they're the ones that are getting the questions from the patients. (they) say they're being asked questions by patients that they can't answer. They don't know. And they're over the moon when we say there's something like this. So there's a real need, but we haven't yet translated that need; it's not fully acknowledged by the system ye't (A1)

'There are also the outside partnerships. I can go to (a number of community organizations) and get feedback through all states and territories. There're those sorts of connections. We have a national advisory group for the funded programs that we bring together every 12 months in regard to keeping those partnerships alive and well. We don't work in isolation - there's all that connectivity.' (C2)

'We have strategic and formal partnerships in the following ways: in community, for example one of our community partners is COTA, so why would we be trying to talk to older people, we talk to COTA, and they talk to older people, so community partnerships; clinical (partnerships) throughout our medical and scientific advisory committee and networks. Research (partnerships) though our national research program. And corporate (partnerships) - we've been through the excruciating process of working out, with whom you partner, and how you mission align, and how you never give a consumer a missed message for a cheap financial benefit in how do you do that, how do you do that? (C1)

'Where we get our greatest systematic feedback with the community is [through] those relationships with organisations that have another purview that's not HCC' (C1)

'Our interest in that has been to position consumers front and centre in that whole big centre undertaking. We had a consumer who (was) sitting on their executive group, and we've got a network of 25 consumers who are involved in each of the activities that the NHMRC's going to undertake' (B3).

“As part of the policy we have a consumer advisory committee. We take their feedback on what consumers need and look at how we refine our services’ (B10)

‘We've got a policy team that develops high quality material. One of the reasons why that's really good is that we also have a consumer committee structure. We've got eight or nine committees across New South Wales. No other HCOB group has that, interstate, and I don't think there's many other in the not-for-profit health sector that have the same well developed structure that we have. (B4)

‘Why we work well is because of our commitment to people with HCB, and the fact that we fold them into our operation, whether it's in education, or whether it's in awareness raising and so forth’ (B4)

‘South Australia's got an interesting model where they have a central advisory committee but then they bring bureaucrats into it. I'm not sure I agree with that. They do roadshows, and don't go to the same place, to the same people all the time. They'll go to different towns, but they do it all the time, so it's not a flash in the pan kind of thing’ (B7).

‘The AGM had always been in Brisbane (as) it was a Brisbane-centred group. When we expanded we said to show that we're really are a national group, we should move the AGM around." That involves money in terms of flyers, travel. Because most of us are retired and we're volunteers, (it) was a bit contentious, but I think it's been a very good move. The first non-Brisbane one was Melbourne, Sydney last year, in Parramatta and the next one will be Adelaide.’ (A1)

‘We listen to what consumers have to say. We don't just try to say, "This is good for you. We know what you need." We really try to address individual needs and community needs, and work towards cultural competency …that’s really important’ (C5)

‘I think people have appreciated that (this) was an issue that wasn't talked about, wasn't addressed, wasn't planned for, was neglected by government and others, yet most people have some family connection or connection of some kind with it. So there's a degree of sympathy and support.’ (B2)

‘You just need somebody. If there was a deputy secretary in health who was aware of it, it'd take off. I just haven't managed to crack it. We will’ (A4)

'We have some key, really strong partnerships. (A major retailer) is another corporate partner … we encourage all of our (members) to go into (those shops) and thank their staff, and (our members) present to their big get-togethers. So they'll do some fundraising through their stores, and also information dissemination through their stores' (D1)

Connectedness with supporters and donors

HCOs recognise different sponsors and donors require different levels of engagement. These differences were highlighted by Miller (1997) who referred to the great information demands and involvement of donors of large contributions (cited in Frumkin and Kim, 2001:269), and Ashley and Faulk (2010) who cautioned against grouping 'different types of donors- individuals, foundations, and corporations into one category' (2010:43). Citing considerable variation across these groups in motivation and orientation (Nielsen, 1985; Ostrower, 1995), Ashley and Faulk (2010) noted that when non-profits fail to differentiate between funder types they may 'overemphasize financial ratios in contexts where they may be less important than other measures'. (2010:44).

'*Member groups, stakeholders, supporters and sponsors, that's another area where I think we have really succeeded. Our very first major supporter was (a well-known food franchise). This is a really nice story. (It) is a franchise-based company, and it's headed by a husband-and-wife CEO team, who met up with (the founder of HCOD) way back at a time when she was probably herself and one staff member, speaking at some sort of public event. They just said, "Let us know if we can help you out." and they did help us out. In fact, they gave her some office space, which has become this whole bottom floor -this is their office building. We've grown from two staff to about 35 staff since then, and the partnership and the culture of (HCOD) that's entrenched throughout their (franchises) is quite unique… The key to success (is) a very strong commitment to nurturing partnerships. They (the sponsor) have not only supported us in this way, but they also do fundraising for us all of the (franchises) get on board with a campaign that runs once a year, and last year raised a million dollars for us. That is a big venture, and they've been running it for a number of years'.* (D1)

‘I gave them advice on how they might fundraise with their own membership as well as foundations, and they did their first appeal and they got a good response. I sent (the appeal) out to my family, it's a family issue, and my mum made her biggest private donation she's ever made - not a huge amount - but it's lovely that it was for their video and she sent a cheque off to them and it was the largest single donation for that campaign. What was really nice was that they looked after her well, in that when the video was produced, they sent her a copy of the video’. (A6)

‘Having somebody who will actually ring up these people (on their database), check up how they're going, call in have a cup of tea with them building the relationship, which it's time consuming but it's what needs to be done’ (C7)

Connectedness with medical professionals and advisors

Research by Boyle et al (2009, 2016) recognised the value of developing referral pathways from primary care to HCOs, suggesting ‘structured practice-based approaches [including] social prescribing, patient navigator or linking schemes (Mossabir et al., 2015) and lower-intensity interventions, such as printed referral materials (Boyle et al., 2011)’. (2016:401). Citing the case of Diabetes Australia they noted that ‘health system-driven approaches that facilitate the development of formal linkages ... are clearly beneficial for improving referral pathways’. They recommended ‘promoting greater understanding of the role and contributions of CHOs ... through greater prominence in clinical practice guidelines and professional training’, noting ‘CHOs also need to ensure their messages are conveyed clearly to health professionals and the public to avoid misperceptions ‘ (Boyle et al, 2016:401)

‘So what do we most need? Acknowledgment that we're a critical part of the health system, and the resources to do that, and I don't mean a billion dollars but I do mean a few million’ (C1)

‘We now have a GP liaison officer, a GP working with us. She's been a very good conduit into that side of things’ (A1)

‘We're using Medicare Locals you can't write to every doctor in Australia, but you can contact Medicare Locals, and try and get them to put it in their newsletters and so on’ (A4).

‘I think one of the things we could do better is to further develop our partnerships with organisations such as the Medicare Locals, with the SA Health Department, and Divisions of General Practice, other not-for-profit, organisations or like organisations, so that we can combine our resources and strengths to get the information to communities’ (C5)

HCOA really utilises the medical advisors. We just had a meeting last week to discuss how they can improve what they do, and what we can do to help, and what they can do to help us. (A2) Medical Advisor

‘We've set a new one [Advisory Committee] up last year, but we have had one over the past 15 years they are a panel of clinicians we do have very strong connections with clinicians. In fact, now we're 15 years down the track, it will be very few clinicians who specialise in (the condition) that don't know of HCOD’ (D1)

Connectedness with academia and researchers

In describing his professional journey from mental health to environmental health, Brown (2013) articulated the value of ‘crossing boundaries and building connections through advocacy’ and interdisciplinary approaches to academic research and practice. (2013: 144).

‘*We partner with researchers at the University of New South Wales and other universities, generally on more what we would describe as the social side of the-- not the scientific research’* (B5)

*‘I think obviously there are partnerships that we don't have … I think having closer links to some of the academic areas, we could do better’ (*B5)

Ways of connecting

The internet has become a key mechanism for facilitating connectedness. Two of the four HCOs have online support groups and all have a presence on social media platforms. Growth in online information seeking behaviours and support communities is reported by Zielband, 2004; Eysenbach et al, 2004; Lieberman et al, 2003; 2006; Potts, 2005; Rada, 2007; van Uden-Kraan et al, 2007; Lieberman, 2008; Thielst, 2011; Ellis et al , 2012. Some participants expressed concerns about the quality of information available on the internet.

More recent literature exploring social capital and social networking in non-profit organisations (Saxton et al, 2007; Saxton and Guo, 2014; Chung et al, 2015) is relevant to HCOs seeking to engage with their stakeholders via the internet. The impact of the internet on doctor-patient relationships between doctors and patients, and the possibility of patient self-management was explored by Smith and Manna, 2004; Bull et al, 2005; Stevenson et al, 2007. Content and design issues feature in more recent literature (Harrison et al, 2007; Lemire, 2010; Robins et al, 2010) as do articles on social network sites and motives for using these (Ellis et al, 2012; Yli-Uotila et al, 2013; Guo and Saxton, 2014).

'The other thing that we could do a lot better is to improve our online presence, because that's the way people are accessing information' (C5)

'Our online network has been really a good demonstration of success whereby it's filled another void, where no matter where they're living, can connect and they do. And, as I said, over two and a half years, we now have 7,000 members' (D1)

'We live in a different world and media isn't that expensive now. YouTube, the social media we do through Facebook and tweets cost us next to nothing, apart from staff time'. (B2)

'It's interesting. The rate of new members is actually dropping off and even the rate of calls to the Info Line has been starting to drop off a little bit lately. But the hits on the website are increasing. The website is a big success. When people ring the Info Line we ask them, "How did you find out about us?" 90% would be the web these days' (A5)

We're increasing our traffic on Facebook and social media. What we're now measuring every day is the reach of those articles. How many people actually saw that? Whether they read it on ours or read it on one of the people that likes ours, who they're friends with, and hopefully you can build that traffic. If you get that to a big enough number, you can start doing surveys. You can start engaging the community in a different way, finding out what's important to them' (C8)

'We're really going down the path of using social media more effectively, as a way of creating larger forums for consumers to engage with us and for us to engage with

them. Even though we say we've got good consumer networks, I think we've got to find ways to broaden that out' (B5)

'Through the newsletter and website we're trying to engage with people, and that does seem to be somewhat difficult. So I think we need to develop better strategies about getting our membership to engage'. (A1)

'We know we need to get on social media. We're only playing at the edge of it. The idea is that we produce a TV ad - a short YouTube, if you like - that's two or three minutes just something attractive. Anybody who's looking through social media might pick this up, and all that then refers you to a more significant bit of education on a longer educated-based video. So, one flicks you to the other'. (A4)

'Through communication and media, we've been able to release a number of publications. Awareness Week is an activity that happens every year, and along with that are international speakers. It's a combination of things. It's attacking the problem from many layers, both with the general public, with our communications, with the academic sector through our publications and research, and through government policy and our connections with government' (B1)

5.1.4 Credibility

'An organisation like this has to have a good public face. You need staff who are intelligent, who do relate well to others' (B2)

Credibility mediates success in Profile, Purse and Performance in the creation of social capital. Credibility a key mediator of success across every dimension, is derived from all forms of capital: intellectual capital generated within the HCO, human capital or the credentials of its Board, CEO and employees and social capital or trust between stakeholders. Figure 5.6 illustrates the credibility/capital links discussed in this section. Section 5.1.5 discusses Capital as a mediating factor in more detail.

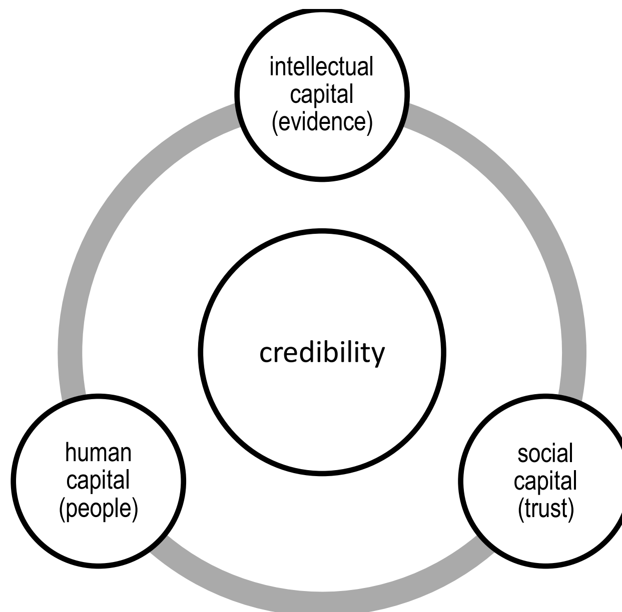


Figure 5.6 Credibility derived from intellectual, human and social capital

In this research the definition of credibility is closely aligned with Suchman's (1995) well accepted definition of legitimacy (Walker and McCarthy, 2010; Drees and Heigens, 2013), as 'a generalized perception or assumption that the actions of an entity are desirable, proper, or appropriate within some socially constructed system of norms, values, beliefs, and definitions' (Suchman,1995: 574).

‘Legitimacy affects not only how people act toward organizations, but also how they understand them’ and ‘involves the existence of a credible collective account or rationale explaining what the organization is doing and why (Jepperson, 1991)’ (Suchman, 1995:575). Baum and Oliver (1991) argue that ‘an organization is more likely to survive if it obtains legitimacy, social support and approbation from external constituents of its institutional environment. This external legitimation elevates the organizations’s status in the community, facilitates resource acquisition, and deflects questions about an organization’s rights and competence to provide specific products or services (1991:187 cited in Hager, 1996:979)

Credibility mediates HCO success in terms of Profile and Purse or its ability to raise funding required for achieving its objectives. It also enables performance in the creation of social capital. Members join HCOs when they believe it can provide the support they need. Belief in the HCO enhances its ability to create social value, whether bonding social capital among its membership, or bridging social capital achieved by working with other similar organizations. Credibility also enhances the HCO’s reputation or Profile and is evaluated by assessing the credentials of those working within the HCO and its Board, the legitimacy of its claims and the evidence it presents, as well as the acquittal of and accounting for its funds and how well is it governed.

Hall et al. (2011) note two forms of source credibility, that of ‘the endorser or presenter (such as a celebrity); and that of the company or organization identified with the product (Lafferty et al., 2002; Pornpitakpan, 2004). This latter form of source credibility is commonly called corporate credibility, and includes the dimensions of expertise and trustworthiness (Goldsmith et al., 2000; Newell and Goldsmith, 2001). Expertise refers to a company’s capacity or competency in producing and delivering a product, whereas trustworthiness refers to whether or not a company can be relied on (Newell and Goldsmith, 2001)’ (Hall et al., 2011:9). This is important for HCOs when considering partnerships with corporate sponsors particularly pharmaceutical companies given ‘scepticism regarding pharmaceutical industry influence over health NPOs (Angell, 2006; Jacobson, 2005; Moynihan and Cassels, 2005)’ (Hall et al., 2011:8).

Drees and Heugens (2013) note the potential impact on credibility of choice of partners in their meta-analysis of Resource Dependence Theory, advising organisations 'interested in improving their legitimacy (cf. Suchman, 1995) ' to choose for interorganizational arrangement types that create highly visible linkages with reputed outsiders (Certo, 2003; Pollock et al., 2010' (Drees and Heugens, 2013:1688).

Von Schnurbein (2014) highlights the link between social capital and credibility citing the case presented by Helmig et al (2010), of 'a drug addiction aid agency whose competitive advantage is based on the knowledge and expertise of its collaborators and the reputation of the organization itself. (Von Schnurbein, 2014: 363).

Credibility derived from Human Capital: the Board

If having 'the right connections' is a mark of legitimacy or source of credibility, the role of the board in facilitating these connections is reflected in the addition of business executives to boards and the adoption of more businesslike practices (Brody, 1996: 488-489). Including other well-networked professionals on boards is also believed to enhance efforts of HCOs to secure grants and sponsorships as illustrated in this recent description of a new board member: '*He is also on several Pharmaceutical Company advisory committees and is invaluable at opening doors into this important funding source'* (downloaded from website 1/8/2016).

I think that's really important, to have the right board in our organisations, because they will have the business networks (C5)

The credentials of medical and scientific advisory board members are also thought to contribute to the credibility of HCOs, the information they develop and advice they provide.

'One of the things that we do have is enormous respect and trust from bureaucrats and politicians that what we say is backed up, and is sound evidence. As a former bureaucrat, that's one of the things that you do like is trustworthy NGOs. I think why we're so successful at attracting funding and growing so much. We're a sensible proposition, and we're a good organisation to deal with' (B7)

'One of our difficulties is that a lot of people tend to think we might be a bit alternative or weird and wonderful. It's the name as well isn't it. It's a different language for a start. I'll say, "No, we're really mainstream, credible. Look all these professors, they've written in our book. This is real."' (A4)

'I think one of the other things we do very well is use expert advice very well. I think we have got the structures in place to be able to insure that the information we are providing is always up to date, evidence based and informed by research. We do draw on the expertise of professionals very well, I think that's right' (C2)

Credibility derived from Human Capital: the CEO/management team

Previous government, public service or political experience on the part of the CEO and other key people, is considered to enhance a HCO's credibility.

'The federation was there before, but I think since [the CEO's] been in that position, it's strengthened over the years. A lot of that is (due) to his ability to lobby and do all of those things for us' (B8). This CEO was previously a senior state politician.

*'If you compare us with most other NGOs, we probably have a partnership style with government that's unique, and that's partly because I used to be a deputy secretary in health, and I think we've got almost a unique relationship with the department, where they regard us as policy advisors and take us into their confidence. So that doesn't mean to say they agree with everything we say, but we do have a remarkable relationship' (*B2).

'*The successful ones are more than passionate. They're savvy. They know how to bring people together. They're inclusive. And it's remarkable how many of the really successful ones have government experience'* (A2)

'We're also very, very highly regarded by the Commonwealth government for the way that we've managed the funding of projects' (C2)

‘We have strong teams, particularly in the research area now, and our research policy. Each of those managers has come with wonderful experience and they talk knowledgeably whenever we're in government meetings, and people trust them’ (B1)

Credibility derived from Intellectual Capital

‘What matters in that is the credibility of the organisation as a consumer-focused organisation. And as being credible in the services it delivers through its state and territory organization. We have a service role, but from a national perspective that service role is primarily useful to give me credibility as an expert. So, consumers value the services and that's good, but for me the services and the organisation is simply instrumental to achieving that broader advocacy goal.’ (B2).

‘You'll see if you go to read the reports that we use very much social research, qualitative methods to use these papers to give voice to their hopes, their dreams, their concerns, their aspirations, their frustrations, etc. They're the micro-stories that resonate with the politicians and the bureaucrats, so there's the twin elements of the campaigning, if you like, of the sheer volume and the numbers with the stories, and so we're trying to relay the stories but also put some sound evidence behind the papers that we produce. (B7)

‘GPs were also selective about the SHOs with which they collaborated. The SHO’s professional credibility was of vital concern as was evidence of tangible benefits to patients, ease of contacting the SHO, and a correspondence between the GP’s own personal and professional interests. SHOs in the study were keenly aware of possible reservations held by GPs and had taken steps to address barriers to collaboration by developing positive and professional communication strategies, promoting a credible and reliable service, and recognising the context within which GPs operate’ (Boyle et al, 2003:77)

‘‘I met a woman whose husband basically thought she was a hypochondriac because she'd been unwell for a long time without being diagnosed. Then, when she was diagnosed, he said, "Well, I've never heard of this thing. Clearly it's not such a big deal. You're still a hypochondriac." He would not come along to the public information session we had here at the town hall. When we had the AGM in Sydney this year, I got another professor to speak, a guy from Sydney. The husband said, "Oh, another professor is talking. These people know something (A1)

'We have valuable information that's quality information that is accurate and meets the needs of consumers'. (B1)

'Having data, robust data, whether that's data from Access Economics or whether that's some research data we've generated ourselves with a strong consumer focus mixed with that, is really important in terms of being able to formulate discussion papers (B5)

'Our booklet (is) very popular with patients and doctors because it's popular to patients. It's written by the experts'. (A5)

'Over the years we've generated a huge intellectual armoury of publications across a range of issues. The first plank has been intellectual capital'. (B2)

'We are known for that, and that is why money flows our way, because people trust us, and know that we will deliver on that, and produce that quality of research that the bureaucrats want'. (B7)

Credibility derived from Social Capital

Drees and Heugens (2013) present a number of arguments supporting the idea that sponsors and funders 'prefer to liaise with organizations of impeccable social standing because such linkages tend not to threaten their reputation for sound judgment (Baum & Oliver, 1991)'. 'Organizations that are seen as legitimate are also seen as understandable and reliable (Meyer & Rowan, 1977), such that resource providers tend to think of them as less prone to failure because of unanticipated risks. (Drees and Heugens, 2013:1674).

'The perception of others who have had relationships with the (State organisations) in the past, because there was no (national organisation), now look at us and they're saying, "You guys have moved so far in the last five years. You've got the respect of the whole health community now." That's a huge shift just in terms of perception of the people at the highest level' (C2)

'We work well in the space of government-- partnering, collaboration and government relations. We're seen as an organisation that has integrity and is independent, and has knowledge and wisdom, and our strong consumer network' (B5)

Bonk (2010) noted the value of good media coverage and its links with connectedness another enabler of success. 'Good media coverage is a prized commodity, and it is built on a foundation of strong working relationships with key journalists and media gatekeepers and pursued through a well-thought-out plan of action.' (Bonk, 2010 in Renz, 2010:329-330). In addition to connectedness with key media gatekeepers, Bonk (2010) listed a number of strategies to ensure good media coverage including one adopted by every HCO in this study, namely 'telling stories that will resonate with target audiences' (Bonk, 2010 in Renz, 2010:329-330).

Each HCO participating in this research recognised the importance of real stories and celebrity experiences' of the respective condition and these were often posted on their websites.

There's the numbers, then there's the stories, and stories work best if there's a personal connection with it. (B7)

'I think there's nothing that any of them like more. They obviously don't want anyone to get their condition, but if someone has to, if it's a politician or a politician's child, that's the most wonderful outcome that could ever happen (and) there's many examples of conditions. There was one of those incredibly rare conditions included in newborn screening in America, which didn't fulfil any of the criteria except that a very famous American footballer's child got this condition. It's the reality of life.' (A2)

'Our medical advisers have provided us with two reasonably well-known people with the condition who they are going to approach to see if they'll be in the video. We've been trying to get some face who's well-known, who's willing to talk about it, even if it is only in an advert, because people know these people, you see them in the media all the time' (A3)

'We know for a fact that there are definitely three people in Federal politics who have the condition. We know that through our network and hearing things so we can't say, "Would you like to be our face?' (A3)

5.1.5 Capital

Capital in all its forms is a key mediator of success in Performance and Purse. Figure 5.7 illustrates each type of capital required for success.

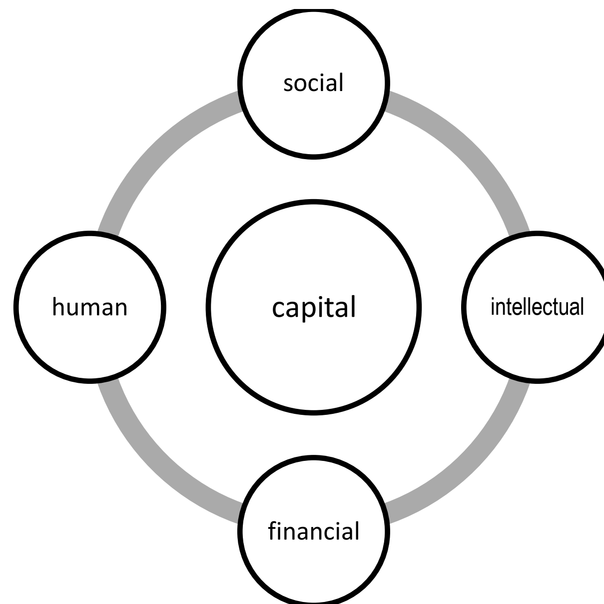


Figure 5.7 Types of Capital mediating success

Financial - working capital and sustainability

According to Booth et al (2015), financial sustainability is defined as 'the ability of non-profits to diversify their funding base and subsequently grow their operating budget over a five-year period' (Besel et al 2011, p. 54). This incorporates the notion of financial capacity, which Bowman defined as consisting of resources that give an organisation 'the wherewithal to seize opportunities and react to unexpected threats (Bowman, 2011, p. 38)'. (Booth et al in Hoque and Parker (eds) 2015: 112-113). However 'the view that a NFP organisation plans to earn a yearly surplus, and accumulate surpluses, does not comfortably align with general expectations about NFP roles and behaviours (and) has attracted academic attention (e.g., Weisbrod, 1975, 1988; Hansmann, 1980).' (Booth et al in Hoque and Parker (Eds) 2015: 110-111)

Sustainability is a constant concern for each of the HCOs participating in this research driving them to seek out additional sources of revenue. In the broader non-profit sector social enterprises are another source of income but were not a feature of the HCOs in this study.

Different HCO stakeholders have different information needs in relation to financial capacity and sustainability. As Booth et al (2015) report, 'For management boards, there is a need to communicate the level of reserves, and balance the prudent hedging of uncertainty against donors' perception of resource hoarding (Charity Commission, 2006, 2008, 2012; NORI, 2008). For the public, NFP reserves are a significant indicator of commitment to purpose and organisational effectiveness. Funders, especially governments, are interested in knowing the appropriate level of reserves to facilitate the ongoing sustainability of organisations and the sector, particularly when organisations provide essential public goods and services (Productivity Commission, 2010; Akingbola, 2004; Brock, 2000; Golensky & DeRuiter, 1999). (Booth et al in Hoque and Parker (eds) 2015: 109)

According the definition of non-distribution constraint (Hansmann1980:838 cited in Booth et al, 2015:111), while an NPO is not barred from earning profits, it is prohibited from distributing them. Reporting on research by Chang and Tuckman (1990, 1991), Keating et al. (2005) and Bowman 2011, Booth et al (2015) note that 'while in practice it would appear that savings are essential to the ongoing viability and sustainability of NFP entities, many organisations have survived in the long term with very limited savings' (2015:111). Bowman's (2011) research into 97,500 non-profit organisations, revealed that 25% had coverage of 20 days or less of normal operating expenses, and 16% had negative short-term capacity, i.e., their liabilities exceeded their assets' (cited in Booth et al 2015:111).

'How much of your investments do you pull down for programs? How far do you cut back on what you're delivering, before the service is affected to the point that we can't do anything well? That's sort of a cultural mindset as well with the board is, when I first started, investments. We don't touch investments. They're for a rainy day. Well you know, a rainy day's here now. And that was sort of a mental change in some board members over time. But I'd say pretty much now, we've got a board that is good at that sort of balance, of realising, well that's what your investments are. You don't sit with a million in the bank and yet you're struggling to - not that we've got a million in the bank but you know - you're struggling on the ground. (C7)

Human Capital

The overall message from each of the HCOs in this study was of pride in the expertise, professionalism and personal commitment of the people involved, including volunteers, paid employees, board members and executive teams. Membership based HCOs face particular challenges in the face of declining numbers of financial members both as a revenue stream and as a source of volunteers. This is particularly so for HCOA where older people diagnosed later in life are often quite ill and lack the personal resources to volunteer. Younger people on the other hand can take preventive action if diagnosed early and don't need the HCOA's support so don't join. The condition is only one of many 'causes' they can adopt should they choose to volunteer. Growth, organizational capacity and succession planning are all challenges experienced by each of the HCOs, albeit to different extents and in different ways. Interviewees saw greater scope in the NFP sector and for the most part, enjoyed the challenge of 'doing more with less'.

CEOs and leadership roles

CEO roles varied depending on their political and management experience. If as Kwon and Adler (2014) suggest 'social skill is a critical ingredient in the successful mobilization of potential social capital' (2014:417), we would hope to see this demonstrated by HCO leadership. Indeed the social skills of the CEO were acknowledged by every HCO as critical to their success. Leadership skills noted included caring about people, bringing people together and on task or mission, engaging stakeholders, driving the organisation.

'We just had a meeting earlier this week about our staff survey results. The consultants (gave) feedback (that) there's a halo effect around (the CEO) and that's hardly surprising given who he is and what he's done. He is a very decent human being, and he's very highly regarded and respected for that, and has a lot of time for people, and cares about people, and always has an ear for you. He'll never shut the door and tell you, "Go away, come back."' (B7)

'Because of the landscape, because of the nature (of nonprofits), personal qualities matter as well as the essential skills and knowledge, and obvious words like resilience and maturity' (C1)

‘The key to all of these organisations are the drivers. And I think that they're all successful in their own way because of their drivers. (This organisation) now has a new president who is incredible person, who is fantastic at bringing people together and fantastic at bringing the professionals and the individuals who are affected by the condition together. And when he's in the room, there's an enthusiasm on all parts and I think that's a wonderful asset. (A2)

In addition to personal qualities and social aptitude, the leadership, strategic and operational skills of the CEO and management team were considered essential.

‘The successful ones (leaders) are more than passionate. They're savvy. They know how to bring people together. They're inclusive and it's remarkable how many of the really successful ones have government experience. You would have to be the ultimate diplomat to succeed in that job’ [referring to a previous role of HCOA chair] (A2)

‘We have great leadership from our CEO. We all have our own sort of particular interests, so sometimes we can get diverted, or states and territories have got a great idea and then I get diverted. But the CEO will say, "No, these are our priorities," so we keep getting realigned’ (B1)

‘It wouldn't be where it is today if it wasn't for Lou in particular. Not only because she's the founder, she was incredibly dedicated to it and she drove it for many, many years. It absolutely wouldn't be where it is now without that.’ (A1).

‘I'd gone through a process of downsizing and merging two organizations, and there was an opportunity to do something different, which was about building, and I did that. Then when I came here, it was because they were looking for a CEO at the time that I wanted to see what it would be like if the buck stopped at my door rather than someone else's’. (C8)

‘I'm a not-for-profit careerist. I've worked throughout the sector for some time, but when I joined the organisation's values aligned with my own personal/professional values. That's something I look for. My area of particular interest is in organisational reform, so organisations that are looking to make a transition to more effective service delivery is something I'm really keen to do. (C9)

'One of the challenges when you have an all lay group, we come from very different backgrounds, and so we have very different perspectives and ideas and where we'd like to see things go and so, it's a big challenge for us to operate cohesively and I think we do it very well. Rob is an exceptionally good leader/manager. He keeps us all under control, because it would be very easy or too easy to have people running off with all sorts of their own agendas.' (A1)

'We've built a strong senior management team with areas of expertise, technical skills. We've got a very good leader' (B6)

'Personalities drive a lot of it so you can't pretend that's not happening. But having said that, I think a capacity to be strategic and tactical' (C1)

'The characteristics of success are very strong leadership, inclusiveness' (A2)

'I think as well that that success is partly to do with the CEO's leadership in giving people their heading, and going, "Okay well I trust you to do your role", and allowing us to contribute and be part of that growth, which is really important. We've got a really good executive team here as well which is, everyone's here for the same purpose and it's not about egos which is even, (in) not-for-profits is quite rare. It's very hard to get a whole team together where every single person is just working for that one cause and they're more concerned about that than their own egos' (B11)

'The vision, the work ethic, the passion -they're just all exemplary. She's the whole package and then some, and then some' (C2)

'We do operate as a business. That was one of the reasons why I was recruited into the role, because I had some private enterprise (experience). The idea was for me to move in here and change from the cottage industry into a business, where we would actually make money and we wouldn't run deficits. And change the whole scope, if you like, of what a not-for-profit really means'. (B10)

'I think if one person grabs hold of it and sticks, the system jams up a bit' (A4)

Each of the participating HCOs believe a supportive balanced board is instrumental to CEO and leadership success.

'You have an idea and initiative, and you can put it out to the board, and we're not stopped. We haven't got too many obstacles that actually stop something being implemented if it's a good idea'. (C7)

'You can just achieve so much more when your chairs allow you to-- they've got confidence in you to run the business so they let you do it' (B10)

'One of the factors for the success is the board. We've got a very committed and well balanced board comprising people with expertise in finance, government, business, legal, and medical .so we've got a balance of skills, they're very dedicated, they'll assist in setting the strategic direction (C5)

'The board was aware that what they were asking me implement here, was going to be a massive change management program. We had major issues, but we stuck it out and we just stood by what we wanted to do. it was a completely different mindset and the board were fantastic because, to go with all those changes, it was huge the first 12 months'. (B10)

People, opportunities and variety

The willingness of HCO people (paid and volunteers) to take on additional work to achieve the organisation's objectives is evident across each of the participating HCOs.

'Everyone's had to work extremely hard to get the organisation to where it is now. A lot of dedication has gone in, and knowing that we'll take on different roles, and in some cases maybe a couple of roles into one, basically to save money so we could provide some cash surpluses within the organisation for that future growth'. (B10)

Speaking of her team the CEO of HCOC said *'They're brilliant people. They all have the capacity to think big - great people, smart, committed, resilient - I'll say that word as many times as you need' (C1)*

'People are really challenging themselves to operate at a higher level and get on, and that's being well recognised' (B6)

'Certainly a good team. Certainly your dedicated staff who are prepared to swings and roundabouts with their job and their roles. And if they understand that they're not going to get absolutely fantastic salaries (but) there is salary sacrifice which helps things, they should have a very satisfying and rewarding job, where they're able to deliver what they're employed to do. They're able to put forward new ideas and initiatives, and often be able to act on those. You've got minimal red tape and you actually can see the result of what you do. I think that's why I've stayed on for so long because things are forever changing, good and bad, but never a dull moment kind of thing' (C7)

'*We'll take on different roles. And in some cases maybe a couple of roles into one, basically to save money so we could provide some cash surpluses within the organisation for that future growth' (B10)*

*'He came from an advertising background in one of our big advertising companies here, but he's actually a copywriter by profession. I've known him for some time and he wanted to make a difference in his work. He didn't want to continue convincing people they have to drink Pepsi over Coke' (*C7)

'My job here is general manager marketing and communications. My background is marketing, comms, PR, media, advertising, all those sorts of areas. Marketing strategy, business development, that sort of thing. I've been a consumer marketer for many years … Having worked most recently (in the) last seven years in Asia in healthcare, it seemed to be a good fit to my skill set (in) which I saw that as an organisation there was a lot of upside. And I guess I had relevant technical expertise'. (B6)

*'I do the communication stuff, the Facebook website, the newsletter … I'm not a developer or a programmer (but) I understand how businesses work and how IT works and how they can go together. 'I've had a bit of background in web design. I used to work in the Tax Office and I was on one of the groups that were reviewing the structure of their website I know how it should work and keeping it simple, and making things work' … . As the Secretary, I run the business of the organization and also I'd be one of the three, I guess, people involved set the direction, the strategy and do most of the running around sort of stuff'.(*A5)

‘My role is to work with the corporate sector specifically to try and engage them in initiatives and also corporate fundraising, for corporate support and partnership and sponsorship, fundraising things like that. My role is also to look at the development of sustainable programs, so that things that we do aren't reliant on corporate funding, or sponsorship or donations’. (C3)

Developing people: opportunities and variety

‘So the job, to some extent, has changed and there's been opportunities to do different things, so it's not as if it's been exactly the same selling widgets for the whole time’ (C8)

‘If they need the skills we're happy to develop those skills. Sometimes we can't do that with some roles, but when we can we will.’ (B10)

‘One of my Directors is one of the marketing people at (a well-known sales and marketing firm) and I said to him, "Can my young guys come and talk?" He facilitated that for me and they now keep in touch. That's how they get ideas. In exactly the same way with everybody within the organization that I've got a development profile for, I'm trying to find them an external person that they can go and have a coffee-type meeting with’ (C8)

‘Depending on the individual, it might be people who are very used to sitting on committees. It might be those that have a very strong interest may not be as used to that experience. So our policy team members will support that person: look at the papers with her, help her identify what some of the key messages might be if she needs that - really offer support prior to the meetings’ (D1)

‘I've got a young lady down there who I've found some money so she can go and do a Cert IV. I've found (another) person that I can start to develop and I've said to her, "Look, in three or four years I don't want to be here. If you want to, we can hang around and you can work marriage and babies, and everything around that, I think you're not ready now, but by then, you could be. How are we going to go about doing that?’ (C8)

HCO views on recruitment were mixed While finding people with values to match the HCO’s was considered important when recruiting new staff, just as important was recruiting people with the required skills.

‘The culture is really important … You’ve got to employ for culture and the right fit in the organisation … skills and expertise are important but you can teach those. And we've certainly had people that I believe haven't had that not-for-profit culture. If they're not prepared to down their pen and stuff envelopes for an hour because that's just the job we got to do or even take the rubbish out or wash the cups, then you know ...’ (C7)

’We're mindful that sometimes people may have the best intentions and have a real commitment to the condition, but may not have the required skills and experience. People don't have to have (specific) experience (with the condition) when they come and work here, but we look for people who have a sensitivity to this cause and a potential commitment to the cause, and an understanding’ (D1)

‘I recruit my communications people for the most part, straight out of college, before they learn bad habits in the public service in Canberra. They know social media, they know how to think, they just need mentoring and sophistication of the messages and understanding that they do what they're told. I've recruited people fresh from their doctorates to do remarkably responsible work in policy and running our research organisations, and they've been hugely successful and respected by people outside’ (B2)

‘We're recruiting a fundraising coordinator so we'd be looking at someone who has good skills in that professional area. It wouldn't be much different than recruiting for any other organisation. However, we're mindful that sometimes people may have the best intentions and have a real commitment to the HCOD, but may not have the required skills and experience. People don't have to have (direct personal) experience when they come and work here, but we look for people who have a sensitivity and an understanding’ (D1)

‘I recruit on skills. I don't care whether they're male or female, whether they're 80 or whether they're … I don't care about age, anything. If I think that they're a good cultural fit and they can do the job, in this organisation they get employed. We had a 80-year-old accountant that I employed last year’ (B10)

'And it's an industry that seems to be generating a lot of Gen-Y women rather than young men. Sometimes it's a bit hard to make sure you've got that balance. And then (if) you're an old bloke like me, and sometimes you need somebody to talk to … they're not many of them around' (C8)

'One of our challenges is attracting young people into the organization because traditionally it's been quite a mature workplace' Young people don't particularly want to work in the community services sector. So you tend to find that the age group you get is that over 40s. On our last EA (Enterprise Agreement) we implemented even more things around a flexible working environment and being able to work part-time and increasing those things and different attraction strategies to appeal to a wider range of people. So young married mums coming in can work three days a week. We have flexible working hours. Two-thirds of our workforce are part-time but we also have strategies for coping with that. Eeveryone works on a Wednesday. So if we have staff meetings, if we do group professional development, if we have any important announcements, if we have any important functions, any team building activities. We do all that on a Wednesday so we capture as many people as possible (B11)

'When I first started, the majority were all social workers, even the management team. That was one of the changes I wanted to make because I believe, that an organisation needs to have that diversity in its staffing model' (B10)

'A potential problem for us is how you create vacancies. How do we end up with a rotating membership of the committee and potential new presidents, and so on? Somehow we have to get them coming in... I think it's important in terms in the nature of organisations' (A4)

'He's been a strong presence for a number of years now - basically built the whole organisation around him, and I'm sure whoever comes next will be up to the task but they'll have a different approach, and a different set of priorities' (B3)

'I can imagine someone like possibly a Jeff Kennett type of person coming in from Beyond Blue, a similar kind of profile or role. It would be the natural next step. I'm not sure about our next president, but a succession for a CEO would have to be either someone like Jim with a very, very strong, respected policy background, or a more national figure. Particularly, if the profile of the president was less, maybe the CEO would step up into that profile kind of thing' (B3).

Volunteers, motivation and contributions

Retired people volunteer, academics and other professionals do ProBono work, trainees and cadets or young people starting out in their career all help in a wide variety of activities. For some volunteers, working with the HCO becomes the job they wished they had when working for wages, indicating the social value or capital of 'working' with other like-minded people. Their generosity is exceptional and often they have more than one volunteer commitment.

'Volunteers never do one thing. I'm president of (another local environment group), and through that I'm also the Chairman of the local community festival we have once a year at Christmas. And what else? I'm an adult literacy tutor. The others are only fairly small really'. (A5)

'*How much time do I spend … an awful lot. I do something pretty much every day, whether it's only looking at my emails. I read about something peripherally related every day because I find it interesting. I'm genuinely interested in the whole thing. Around the AGM time, probably 30 hours a week. I'll be organising information sessions hopefully in Coffs Harbour, Wollongong, and the Central Coast in the next few months, so around the time of each of those, it'll be fairly busy' (A1)*

'I do the bulk of the phone calls and there's some days I can have ten calls in one day, so you may as well say that's a full-time job by the time you've done all of your calls' (A3)

HCOA is a completely volunteer organisation and research participants recognised many limitations, especially in relation to recruiting volunteers where there are skill gaps and in more recent years, where there has been uncertainty about superannuation and retirement incomes.

'*We are all still volunteers, and that's a fairly big limiting factor, not in regard to our time because I think some people in the group put in huge amounts of time - more time than they would if they were working*' (A1)

It can be very hard to say, "Well, can you do this?" If they're from Bourke (a remote town) and they want to be a volunteer, what can we ask them to do, if they don't have specific skills. They've got to have special skills to go on the Info Line and a fair bit of knowledge and understanding of situations (A5)

We could say, "Do you want to go and talk to your local radio station. Get a story on about HCA." "Oh, no, I couldn't." "Could you organize a meeting?" "Oh, I don't want to do that." It's a real problem' (A5)

'I think if we had maybe someone who could sit there and dream up projects - we do dream up projects ourselves - but put a lot more detail and work in to finding what people could do, we might be able to use volunteers a little bit more effectively' (A5)

'If you ask volunteers to do something specific, you get results. We do have some very good volunteers' (A5)

'I would prefer some income, but I can do it as a volunteer. I intend to be fairly active, and possibly even more active this year because I don't have particular time constraints that I've had previously.' (A1)

'I'm probably the only one out of the group that still does a bit of work, and that's not going to last forever, so it won't be long before I'll be fully retired as well. There's no extra income, unless you're really wealthy, so the organization's got to meet our costs as well' (A3)

'Now it's harder because people are less secure about their superannuation so they keep on working...instead of taking voluntary jobs, take paying jobs, instead of voluntary ones' (A4)

'One of the things (we) discussed was they had had those support groups still in existence in a number of locations and they're saying, "We're thinking about the possibility of building the support groups", all that sort of stuff. I actually talked about the work of Putnam and said, "Well, this isn't the modern way of volunteering and maybe don't put all your time and energy into developing the groups. If people want to do them, that's fine. Instead put your time and energy into developing people who will actually do the work." And that's what they did, and it's worked for them' (A6)

'Volunteers do need to be well supported, recognised, serviced and sometimes weeded out, filtered, monitored, all that stuff' A4)

In addition to contributions of volunteers, HCOs are successful in securing pro bono professional services.

'One of our successes has actually been to get work done pro bono by academics and clinicians and others, and to successfully outsource the management of many projects … 'I have to say, I can't remember anybody ever saying no. People normally want to help; sometimes I pay, sometimes I don't. If I do pay, it's normally not very much.' (B2).

"I suspect most chronic disease organizations have clinicians and researchers who are just only too willing to support and help' (B2)

'*I went looking on the net, as you do, for information, and found out that there was an Australian organization. Joined up, got their newsletter, those sorts of things. One year when I was paying my subscription, I thought, "I really should just give them a ring and let them know that I'm a consultant who specializes in not-for-profit issues." and if they were interested, I could do some freebie work for them. When the new team came on board, I popped an email to the President saying, "Hey, just wanted to let you know I have HCA myself, I have this experience and we caught up in person and we had a number of discussions over the phone and by email about how HA might be able to work more effectively' (A5)*

Social Capital (as input)

Scholars have shown that social capital as an organizational phenomenon is a powerful factor that accounts for several organizational concerns such as innovation, intellectual capital and turnover (Cohen & Prusak 2001, Flap & Vo¨lker 2001, Gabbay & Leenders 2001, Ibarra et al. 2005) among others' (Garriga Cots, 2011: 331). Leana and Van Buren (1999) use the term 'associability' to label "the willingness and ability to define collective goals that are then enacted collectively' (Coleman, 1990; Nahapiet and Ghoshal, 1998) (Leana and Pil, 2006:354). This 'willingness to participate in collective action is partially dependent on the belief that individual efforts benefiting the whole directly will also benefit the individual indirectly' (Leana and Van Buren, 1999:542).

Leana and Pil (2006) suggest that 'social capital can enhance performance at the organizational level, and that its benefits are a result of both the relationships among individual members - referred to as *internal social capital* - and the links between the organization and its external stakeholders - referred to as *external social capital.'*

Citing Adler and Kwon 2002, Leana and Van Buren 1999, Nahapiet and Ghoshal 1998, and Hansen 1999, they outline the advantages ascribed to social capital including 'better group communication; more efficient collective action; enhanced stocks and use of intellectual capital; and better access to resources' (Leana and Pil, 2006:353). This was evident in participant interviews with reports of great generosity among their teams creating a positive environment for working together. Another observation was the way they valued each other's strengths.

'In other organisations I don't perceive that kind of internal generosity. This is the place to be'. (B2)

'I enjoy the not-for-profit sector, and I enjoy working with young people who are keen to have a go and make a difference' (C8)

'And one thing I've found in the not-for-profit is, we're actually quite generous with our knowledge and our skills with each other, more so than I found in the corporate sector' (B10)

'I think collectively we're all pretty committed to doing what we need to do. My observation is that we all do what we need to do to get what we need to get done happen' (C3)

'We work in a very collaborative environment and that's really supportive. We've got a really good national office, a lot of whom are new and … are still getting their mind around the challenges, but work very, very hard and we've got great technical skills and all of that is starting to build a momentum' (B6)

Von Schnurbein (2014) reports that although social capital is 'a valuable resource that can enhance an organization's effectiveness' (Schneider 2009) and 'a benefit that non-profits contribute to society' (Huntoon 2001), the process of how it is created within non-profit organisations is a mystery. 'The value added process of social capital has not been academically investigated thus far (King 2004)' *(*2014: 370). It is beyond the scope of this current research to offer any additional insight into how social capital is created for HCO stakeholders and it remains an intangible value for interviewees.

'You could just describe it as serendipity, but I don't see it in those terms because to maintain that virtuous spiral, you have to have the valuing of the individuals and the faith that they're actually making a difference. I've seen any number of good people come on to boards, including boards of which I've been a member, seeing the inappropriate dynamics and the lack of impact, and leave after 12 months. That hasn't happened with this group. I think the spiral metaphor is actually the appropriate one because they're building to each other and off each other' (A6)

'Could I do this with another organisation? Probably yes, as long as it had a social purpose. It had to have a social purpose. I mean I've been offered other jobs in service provider advocacy organisations and I've always said, "I'm sorry. I'm really a consumer person' (B2)

'It keeps you challenged, keeps you motivated, keeps you interested and working with like-minded people, because the majority of people here are. You go home with a sense of purpose. You go home with knowing what you've achieved is something more than a shareholder increase and it does, it gives you an enormous sense of satisfaction that you know what you're doing is making a difference' (B11)

'It's in some ways serendipity that the Board Chair's a former CEO of a Government department, that (another committee member just happens to be the partner of a Pro-Vice Chancellor of a university, who is himself a medical research scientist of course, that thing of stars do start to align when people make use of the opportunities available to them. In some ways, what they've been able to do is a classic example of community building, and a classic example of building social capital' (A6)

'When I leave here at night, I feel that it's not just a management role I've been doing. I do feel like I've actually helped someone. So I've been on the end of the phone talking to a consumer about issues that they've been facing and I go home and I think, "It's great to be able to be a CEO, but still have that personal contact as well with consumers that are going through whatever it is." It could be anything. That's what keeps me in the not-for-profit sector, and I'll continue to work in the not-for-profit. I'd much prefer to work in the not-for-profit than corporate, because I also sense around me - and especially when you're leading a team - that majority of people have that same sense of purpose. To me that's what the difference is for me personally, between working in a corporate organisation compared to a not-for-profit', (B10)

'We've gone from saying, "Join because we'll give you info," to saying, "Join because you'll be supporting us to do good things."'(A4)

"It's also a very nice model of community building because we link up our community liaisons with the (franchises). We like to foster that very local connection so (the franchises) and the member group support one another. The (franchises) are very happy to have the members there during the campaign period and for them to bring information there' (D1)

'I just think they (HCOs) could all learn from each other; we can learn from them. I just think in life, there's no black and white. There's no perfect and there's no completely terrible' (A2)

'*We have about 300 community liaisons, and over time that group has grown. They will either generate their own local initiatives, which might link to our fundraising initiatives. It's a bit like a jigsaw, really. Or it might be that they see an opportunity to go and talk to their local school or to put on an event. Basically we're a capacity-building organisation. We, in (the office) are not set up to provide services to every (person) in the country. That's not our model. It's about us building the capacity of our champions to do so. And these are the layers of opportunities we give them*' (D1).

It's not too dissimilar to a lot of other NGOs, but I think is better in terms of the fact that people are invariably happy here. They get why we're here, and they want to be a part of it. They buy into it. They're very dedicated and committed to the cause and what they're doing, (B7)

Intellectual Capital

Kong and Prior (2008) described different components of Intellectual Capital (IC) as Human Capital (HC), Relational Capital (RC) and Structural Capital (SC), suggesting that 'IC is an important resource that NPOs need to develop in order to gain sustained competitive advantage' (Kong and Prior, 2008:119).

Relational Capital was defined as 'the flow of knowledge from an organisation to the external environment' resulting from 'an organisation's formal and informal relations with external stakeholders (Marr and Roos, 2005)'.

It reflects bridging and linking social capital in that it 'acts as a multiplying element that creates value for the organisation by connecting all IC components with other external stakeholders (Ordonez de Pablos, 2004)' (Kong and Prior, 2008:119).

The logic has been to establish an evidence base. To do that through access economics then was primarily to ensure that there was a connection between the development of the evidence base and the publication, the executive summary, media release, and communication strategy. We never looked at the evidence base or publications as an end in themselves, but as part of a communication strategy. And over the years, we've generated a huge intellectual armoury of publications across a range of issues - from palliative care to ... risk reduction, to hospitals, to primary care. So, I think the first plank has been intellectual capital. (B2)

'We've created more awareness by doing research, and then having the evidence to demonstrate the growing numbers of people with HC B and highlighting for the government how they need to be prepared, and highlighting those issues'. (B1)

'The long-term strategy of this particular organisation of moving from a collection of … support organisations to a national body, and with that starting to develop quite a lot of intellectual capital the table of some of the back-end committees within departmental processes etc'. (B3)

'Our budget submission this year - which has just gone in, you'll see it on the website if you have a chance to look - is really all about that very sophisticated program of research funding over five or actually over nine years to build the capacity of research in Australia.' (B3)

'We've done an awful lot in intellectual capital, but we're probably still light on in terms of policy resources' (B2)

Capacity, another mediator of success identified in this research is reflected in the concept of Structural Capital, reported by Kong and Prior (2008). Structural Capital, 'includes all of the non-human storehouses of knowledge in organisations such as databases, process manuals, strategies, routines, organisational culture, publications and copyrights which creates value for organisations, thus adding to the organisations' material value (Bontis et al., 2000; Ordonez de Pablos, 2004)' (2008:120- 121).

5.1.6 Capacity

Capacity mediates success in Performance and Purse. As noted in the previous section, Capacity is reflected in the concept of Structural Capital, which according to Kong and Prior (2008), 'includes all of the non-human storehouses of knowledge in organisations such as databases, process manuals, strategies, routines, organisational culture, publications and copyrights which creates value for organisations (Bontis et al., 2000; Ordonez de Pablos, 2004)' (2008:120 – 121).

This section presents the research findings relating to HCO capacity as reported in terms of its form as a state, federated or national organisation; ts infrastructure, systems and technology and the roles within the organisation, illustrated in Figure 5.8.

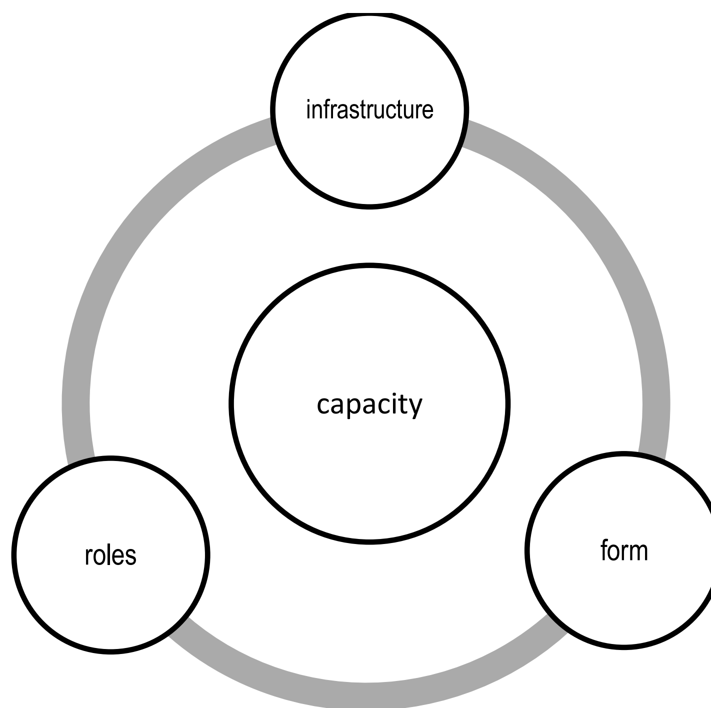


Figure 5.8 Capacity: structure, infrastructure, systems and processes

Form Follows Function (A6)

Function refers to the purpose or mission of the HCO. In Chapter 1 mission was defined in three areas: Care, Connect, Cure. The form of each participating HCO whether a state based, federated or national organisation run by volunteers or paid executives reflects their different functions.

Infrastructure: systems and technology

The glue connecting people in the two national organizations HCOA and HCOD is communications technology. By necessity, HCOA operates as a 'virtual' office, with the 8 volunteer members of the management committee connected via emails, voice calls and video conferencing. Similarly while HCOD has a national physical office, its extensive network of member groups and champions is supported through use of social media and online groups, without infrastructure operations. This reflects the findings of a case study undertaken by Helmig et al (2010) (cited by Von Schnurbein, 2014:365), on a network established by a foundation to campaign against bowel cancer.

'The Management Committee operates really as a virtual - not virtual - but on line basically. Just about everything's done via email, Skype, or teleconference. We get together once a year in person at the AGM. Occasionally, one or two of us might meet at some other event. That's the only time we ever get together and it's a major expense. It's 10 grand to bring everyone together, and that's pretty tight budget stuff too. But it functions well because we've got a small group, eight people on the Committee, volunteers. There is always the issue of sustainability. How long can we keep doing that?' (A5)

'The way we operate - is very largely by email. We have monthly voice meetings, which I do Skype, but my connection's so poor, we very often end up using the telephone - conference calls. There's a lot of email. We do use Huddle as a cloud program, so effectively we don't have a filing cabinet. We don't have an office. We don't like to tell people we exist in the cloud. It sounds as though we're a bit more sophisticated than we are probably' (A4)

'We use Microsoft Office 3 Enterprise 365. We've signed up on that. They're amazing with their software. It's designed for companies who have got thousands of employees. We've got eight people, but it just works for us. It makes it an easy job' (A5)

'We're like an organisation of teams which do work and have different levels of involvement. That's how we work here' (D1)

'Form follows function and governance arrangements need to reflect the context of the group. No ongoing funding, therefore no staffing, therefore to get the work of the organization done, they need this body. They work very effectively by telephone conference and Skype, and those sorts of things. Very low-key, but they're extremely capable individuals. Other organizations trying similar approaches may not be so effective because it really depends on the quality of the people they've been able to attract' (A6)

'There was a bit of sort of dispute about that, but it actually makes sense to have - we've discovered, since we're so dispersed - to have the Secretary and the Treasurer in the same place with some proximity in terms of authorise people signing cheques and various other paperwork things that need to happen. So even if it doesn't have to be the case, I think there's merit in that being the case' (A1)

In contrast, the two federated organizations with infrastructure at both state and national levels, acknowledge the duplication within their organizations and the need for and benefits of shared or centralised back office support. In addition, they face difficulties and tensions around issues of identity, funding and national influence while recognising the need to change.

'We can't have interstate rivalries or problems if the problem is just so huge, and if we're only serving the needs of 5% of the people in the State, we have to get past these hurdles and have a structure that will support the size of the problem we're facing.' (B4)

'Growth is an issue so we're determined to improve our business systems, our structure within this organisation. We've got a good culture, we've got good employees, but we've let that down sometimes by not having the business structures in place, so good payroll, good IT, good client capturing systems, all of that' (B4)

'That evolution of constantly changing with the growth and not staying stagnant, has been vital for the success of the organisation' (B10)

‘Here we've been reinvigorated four times in that we've changed our focus from being an information, education service provider to being a registered training organization, to embracing linked conditions.’ (C8)

‘If you were to compare us with a profit organisation that had the money to spend for example, on quality systems, document control, all of those back-end or back room processes, then we're probably lacking and we can probably improve. Even in the financial area, we've been using a system that's designed for small to medium business. It doesn't meet our needs. It's not very efficient. Our finance team spent a lot of time doing manual processes, because the system doesn't fit our requirements any more. And we're looking now at a new finance program to help us with the program management and streamline it’ (B1).

‘We have 1500 members. They are financial members. So, we are an incorporated not-for-profit body, incorporated in Queensland, registered with the ACNC to operate nationally. And under our constitutional rules we have a committee, which has a membership of eight. And that has a president, vice-president, secretary, treasurer, and other committee members. That's the management committee of the organisation, and it's elected by an AGM, and that's all the formal, fairly standard associations incorporated process’ (A4)

‘During those seven years we've had three internal reviews of structure which I think is really healthy. I wouldn't like to see an organisation with the same structure it had seven or ten years ago. We actively change the structure to go with the growth.’ (B10)

‘An example of that is something that we've applied for recently. We have a plan should it happen, but it will impact the structure yet again. Then we're going to have to look at restructuring again to fit this into this area. When that happens, then it's a big time impact on a couple of managers to be able to get it all up and running, and then pick up, go back, pick up where they left off’. (B8)

‘The way that it's structured here is we have a CEO and we have teams. My area is the programs area, and that encompasses the forums and the member groups and the community liaisons our online engagement strategies, the website - we've got an online community now, we've got about 7,000 people who connect via the Internet’ (D1)

'Lou designed the organization to publish a newsletter, to publish a booklet, and to answer phone calls on a limited basis, and speak to doctors who'd got it wrong on an individual case. If that was the vision for the organization, it was the perfect structure to enable her - and her alone - to do that work, or with the handful of volunteers she had there' (A6)

'It (employee survey) was pretty comprehensive, done by an external party, and it was good. It was very positive, I have to say, but it also indicated some areas where we needed to do some work, especially in the middle management area, business systems, communications. And some of that comes from the fact we've got regional offices, and that's always a problem, how you communicate, actually that would be a shortcoming of the organisation, communications and ensuring that regional offices see themselves as being part of the whole' (B4)

'I see a huge amount of effort going into system maintenance. It really was my observation in (another HCO), that a vast amount of effort was going into maintaining the organisation. Very little was really going into output. That doesn't seem to me to be a successful organization' (A4)

Roles

In addition to appropriate infrastructure, systems and technology, certain roles were identified as essential to a HCO's capacity, notably fundraisers, marketers, administrators, researchers and policy people, and stakeholder relationship managers.

'You need well-trained people. It seems to me that most groups and most similar health-consumer organisations have a designated fundraiser, which we don't have and maybe it's the only way to go these days. You do need someone that knows their way round the health system. I think the group needs not only to be passionate about the condition (but) they'll benefit from a reasonable level of health literacy and an understanding of the system'. (A1)

Citing Duronio (1997), Frumkin and Kim noted the added obligations around accounting for and reporting of fund acquittals, resulting in an increase in the professionalisation of fundraising functions in non-profits. (Frumkin and Kim, 2001:276).

‘For a while I was also fundraising for about 18 months and then recruited a new fundraising manager who now reports directly to Fred (the CEO), which is great that we've able to bring on talent who've been able to grow into those roles’ (B6)

‘We've also appointed in the last three or so years a community relations and bequest officer. That person is part-time (and) will go out and build the relationship with our high-end donors and our regular donors’ (C5)

‘Members of the senior leadership team represent each of those three areas (finance, communications/marketing, policy/research/advocacy)’ (D1)

‘There's my role (CEO) and then there's a finance and admin manager. She takes the financials to the level that they go to the board. I oversee that as well, and our treasurer does too. We've got somebody in marketing and communications. He's actually been here about seven years. It's a reasonably senior role, if I go on leave then he is acting CEO. Then we've got a full-time educator and a part-time educator.’ (C7)

‘We have a finance manager that runs our finance area. We've got a subcommittee of the Board that look at all our finance and investments and so forth. So it's a pretty tight ship in terms of how we run that part of our business’ (D1)

‘Fundraising is another area which we could do better. We don't have an actual fundraising resource. I look after some parts of fundraising and our media manager looks after other fundraising areas’ (B1)

‘We have a sponsorship, communications, and marketing area, and that includes all of the relationships with our partners, our funding partners’ (D1)

‘If we had a marketing person and a communications person, a fundraising person, all of those things would be wonderful, but we just don't have the capacity to do that so what happens for us is that it ends up on the end of someone else's desk. It's the other things that you do off the side of your desk that would be better done if we had the resource to do it. That's one of the things we probably don't do as well as the other states and you look at all the manager structure here, and they're all doing, doing. There's no sort of sitting back and being solely strategic’ (B8)

‘We've got three different sections within our organisation. We have an administration section, and that comprises our finance and administration, and she's highly qualified, she's an accountant. We've got what we call a business development area, and that area's responsible for our communications with consumers, our newsletters, our media releases, our publications, our compliance to the branding, our lotteries, our appeals, and our fundraising. So that's the fundraising, partnerships, and communications - again, people with appropriate qualifications and skills there. Then we've got the health services, which is where Mel works. In the health services team we've got a number of coordinators of programs that deliver services to schools, children's services, sports clubs, workplaces, childcare, and to health professionals. And we provide the telephone 1800 information, and delivery of resources, face-to-face consultations, community sessions’ (C5)

‘We've only had a media person for the last three or four years. We've now got three people in that area. It's a very important part of the organisation’. (B2)

‘My role is a national partnerships manager (and) to look at building awareness in the marketplace, raising the profile of the brand’ (C3)

‘My job here is general manager marketing and communications. My background is marketing, comms, PR, media, advertising, all those sorts of areas. Marketing strategy, business development, that sort of thing. I've been a consumer marketer for many years’. (B6)

‘In Victoria there's a media and communications manager. It's at a different level technically, it doesn't report directly to the CEO. It reports to the CEO but it doesn't sit in the (senior) management team. It's a bit of a strange one. There is a similar one in South Australia, general manager marketing, communications and fundraising. (B6)

‘[Consumer meetings are] all managed through my team. I have someone who does that for me because I'm too busy to do that job. Because it is quite a large undertaking, but it's one of the things that Fred and the board are very passionate about, so it's one of those things - we'll do it right, and I can't do it right because I'm too busy. I've got too many staff and too many projects, so give it to one of my most trusted people, and she's doing a great job of it’ (B7).

'The powerhouse of operations is probably Sam He really operates like an executive officer. Sarah carries that huge load of the 1300 number now, and Meg, Sam and I have come to operate as an executive group in effect. We've been delegated various things like Awareness Week, and various other tasks. That's shaped up according to people's preferences, availability, attributes and commitments'. (A4)

'My focus is more on the business support, making sure that these guys have got the tools that they need to do their job, and really being able to focus on that but very much integrated not working in isolation' (B11)

'As the largest State with the longest history, I think I'm in a beneficial position of having such resources at my disposal, and being able to be a manager in this role. There's no one in other States and Territories, or the CEO assumes the responsibility entirely for policy work, or it just doesn't get done, or there might be a single part-time lone agent reporting to the CEO, who's not in management, for instance …I've got four researchers or evaluators …, and two librarians, one coordinator and one library assistant … six staff. That's grown enormously since I started. I had the two librarians and one researcher when I started, so I've been able to attract a lot of income and grow the team, so that's been good' (B7)

'Our policy team (is) a small team looking at what the issues are, what's the research saying? What's the latest in treatment and care? They have a lot of links with clinicians and researchers. They develop up all of our resources: fact sheets, position statements. They design our advocacy strategies' (D1)

Limitations related to staffing numbers were expressed across each HCO. B9 drew a parallel to his own experiences in HCOB with that of performer Robyn Archer who said, *"I keep getting asked to do things. I'll get asked to do a new show or whatever," and she said, "I always say yes, and then I learn on the job".*

'(We're) good at that. That's exactly the way we used to work in the accounting firms. You put in for a tender - you've got all the skills there, you might not have actually done that job before, but you can put it together when you get it. At least you've got a track record with something similar, it might not be exactly the same but that's the fun of it, isn't it' (B9)

‘Say if I worked for Santos, I would be an Employee Relations Specialist or I'd be a Remuneration and Benefit Specialist. (In) an organisation like (this) I can be doing recruitment one day, organisational development the next day. I can be managing the fleet of vehicles the next day, organising to get the water pumps fixed the next day’. (B11)

‘To cover off all the things that we want to cover off, you have to be a jack of many trades’ (B6)

‘What we try and plan for is that we've always got someone here to answer the phone calls. So if Mel, for instance, is out delivering a community information session, we will have another educator or qualified capable person to answer the phone. I mean, it works. We've just got to take a phone call, a number and say, "We'll call you back," but it's nice to have the information on-hand. So we have two educators in Mel's role, and then our program coordinators are also very knowledgeable and able to give basic information to consumers’ (C5)

‘About half of my time is doing telephone counselling on the (HelpLine), and the other half is going out into the community, raising awareness and training’ (C6)

In NSW we've got a head count of about 100, almost exactly 100. Full-time, that would work out to be about 70, I suppose. We're about to expand by another ten or so positions in the next six months. We're growing’ (B4)

‘We've got a small staff - 16 staff. A number of those are part-time, and that's the nature of being a family friendly organisation. Like most charities, we can't compete with the government or the corporate sector salaries, but we can make up for it in offering different perks, including the salary packaging and the family friendly nature. Mel, for instance, starts her workday at 8:00 in the morning and works until 5:00, and has a day off each week in lieu of those extra hours, and that works for us’. (C5)

‘There's a number of part-time staff. One of the positions is a job share. We have an individual working Monday through Wednesday, and the other person working Wednesday through Friday, so there is a day where there's a crossover, where that information can be shared. We have staff members who will have finished their nominal day at 3:00 or 3:30 to allow for child pickup and that sort of thing’. (C5)

'Bodies, it's 16. Some of those are part-time, but 16 bodies. It's equivalent to about twelve-and-a-half, 13 EFT. In addition to that, we have two volunteers who come in to the office on a regular basis and they've been with us for over 10 years and they have their own specific roles within the place. Then we've got all the contractors, so about twelve-and-a-half EFTs and 16 bodies' (C8)

'The numbered publications you'll find on our site - there's about 30 of them now - most of those have been managed on a budget of no more than 10,000. So I pay a researcher or somebody 5,000, (plus) 5,000 for publication distribution, other costs, and it's very minimal. I find increasingly, especially with social media and the website that a lot of what we do in intellectual capital area now can be done really very cost-efficiently' (B2)

'We have a raft of contractors which are either other registered training organizations that we have licensing agreements with. There're over 40 of those, and then there's about 300 individual contractors that we have. So if a school in Benalla or a childcare center in Bairnsdale wants a session, we facilitate it, we organize it, but we get a contractor who'll do it' (C8)

'We've also ramped up over the last three years our pool of trainers, so we've got now between 40 and 50 qualified trainers. Most of them have a nursing, or a health, or a paramedic type of background. We accredit and review those accreditations annually. These people out in the community now are delivering a lot of our training for us, so rather than our staff being stretched and going out, we're using this network'. (C5)

'We're actually paying someone to do something. We're all volunteers, but it's a special task doing projects. We think of it more of a consultancy not an employee, media relations. We wanted someone to sit on the phones and ring the radio stations around the country and say it's HCA week, specifically for that. We've got a big list of radio stations and last year we sent out a bulk email and half a dozen said, "Oh yeah, we'll do something." But, obviously, it just sat in their inboxes. There were 300 emails. This time, we want someone who has experience in the industry. She's worked in the ABC, and Red Cross and a few other charities and things. She really does understand' (A5)

Federations or national organisations

'I really do like the architects' mantra of form follows function and that's where, in my own consulting work, I got people to focus in on what they wanted to achieve in the context of their work. Many national organizations in Australia are federations and they suffered enormously from the tyranny of State Divisions. Even if they're a State-based organization, they then suffer the tyranny of capital city versus a non-capital city, or within Queensland and Tasmania, all of that sort of stuff. So often it comes down to people who are simply mature enough to actually understand that wider vision and what needs to be done for all people in the country, rather than for people in their region or their State. The line I've used in my own consulting work is that good people make a bad structure work, but bad people will not make a good structure work. So often I see organizations absorbed by the issues of structure and really it will go nowhere really anyway because either they're great people and they'll make it work regardless, or they don't have the skills to make any structure work.' (A6)

HCOB at national and state levels shared the view that they operated successfully as a federated organisation.

'I think the fact that we're part of the federated body makes us a much stronger organisation. We have a lot of expertise across the country' (B8)

I genuinely can't think of another federation that's as equally represented as we are across Australia. I mean, some organisations are stronger than the others, but we all accept each other as equals. So whether it's Tasmania or ACT or New South Wales, and we cross-subsidise, so New South Wales cross-subsidises ACT, Tasmania and Northern Territory' (B2)

'If you can actually get a federation pointed in the right direction, in terms of ground-level events, promotions, if you can actually get your communication messages unified, if you can get all your resource materials unified for various events, then you become remarkably effective'. (B2)

'It's good to see that they follow, or are prepared to accept a view or some expertise that might not exist in their organisation. (In) a small state like Northern Territory or Tasmania, the CEO does everything (and) might ask me to help in terms of marketing or branding issues that she might be facing or to overcome an issue' (B6)

'The (federated) structure actually works extremely well because the CEOs in all the states are dedicated to work together, and dedicated to the cause. We're looking at how we can streamline different things and work together more' (B10)

'There are some shared services. We have a national shared server system, so we do share some of the IT infrastructures but there could be far greater efficiencies in that. There's a lot of green field opportunity for us to do a lot better'. (B6)

'There's been a lot more that's been committed to nationally, like marketing and communications, like national IT, like the national political campaign, those sorts of things that have really pushed us ahead'. (B1)

'The structure actually works extremely well, I think, because again the CEOs in all the states are dedicated to work together, and dedicated to the cause. We're looking at ways, how we can streamline different things and working together more. We share job profiles with other states, and whatever policies and all of that. So there's that sharing and knowledge gaining. We're our own entity so we basically do our own thing, but from a business perspective we take on the federated model in areas that we need to, or we feel that we'll gain benefit. We've just, for example, moved over to a shared server environment with the IT, and we're sharing that. So we can see mutual benefits, cost savings and all those sort of things'. (B10)

'While federations are difficult to make work effectively, we've probably been as successful as any NGO in making the federation model work. And that gives you a peculiar advantage in arms and legs, both volunteer and staff, state boards, and all the networks they have to actually support your cause' (B2)

'There's a kind of gentlemen's agreement around what are national issues and what are State issues, but at the same time there are so many things where it's just blurring. We're an independent organisation, and so we make our own decisions and do our own thing, but try to keep them informed of what we're up to but we certainly don't touch things like pharmacy and drugs, we'll leave that to national, thanks very much. All the engagement with Federal Ministers around a campaign, we'll leave that to them, and support them where we can' (B7)

'We probably look to national to lead us in policy, because again we don't have any policy officers. We look at them to help and support us with policy. Or if something comes up (like) the debate that's happening right now, I would go to national and talk to them about it to reply to the paper and because they've got the skills. The marketing and communications team that was developed a couple of years ago by the national organisation has been absolutely wonderful and has increased our awareness in the community - it's been amazing, a major benefit for us' (B8).

'We've come together and realised, " We're all doing the same thing" So, now that group is desperately trying to consolidate their resources, share their resources, revamp something so it's nationally consistent. It's the same with our national programs. We have to very carefully manage that program, really from a distance but to ensure that we've got quality frameworks in place that are nationally consistent, the states and territories know how to deliver a service and all of those sorts of things' (B1)

'Victoria is the most interesting and, from my point of view, easily the most supportive of national, and I use their staff as if they're my own, it's a nice relationship. I used to have that relationship with South Australia. They've just changed their style to be slightly more entrepreneurial and management-based, and less into policy than they used to be, so that's just the way things go.' (B2)

'Our role in the national office has always been advocacy, policy and management of programs. Jim (the CEO) is passionate about advocacy and policy, so his goal is to effect change at that higher level with government, whether that's policy change or getting more funding for this particular area' (B1)

'There's the challenge with costs and procurement, because if we had IT as one of these areas, if we had the ability or the commitment to say, have a national leasing program for cars or have a national procurement for telephone systems or PCs, we would probably all be saving a lot of money. We're doing that in a way with some things' (B1)

'*National Office coordinates insurances for the states and territories. By doing that we are saving them thousands and thousands of dollars. So they don't have to have t heir own insurance. We have a group insurance, and they share the cost'* (B1)

‘[The state organization] is a member of [the national organization]. We're separately incorporated, but there is an organisation in each State and Territory, and we work with various degrees of success under the umbrella of [the national organization]. In (this state), we are committed to driving a single voice for people, for consumers, and therefore aligning with national key messages, national vision, and national mission’ (C5)

‘We're now applying a Centre of Excellence model. We're inviting (the state organisations) to take up core responsibilities on behalf of us all, where they have a particular expertise and they will deliver that particular expertise on behalf of us all through a very carefully negotiated contract’ (C9).

‘For each of us there is that connectivity with key people in (the state organisations). Our coordinators know that they have a responsibility to communicate as necessary within their (state organisations) about things that we raise with them and we highlight that to them as well, so that they're very clear about those responsibilities’ (C2)

‘I think we could have a bit more of a business approach. There's a lot of waste, I believe, throughout the (state organizations) because of the federated model, a duplication of efforts and use of resources. So every (state organization) has its own marketing team, its own accounts team, its own HR service and things like that. I think that as we grow and evolve and mature, that those things really need to be on the table to say, "Okay, well, how we can benefit from economies of scale and not duplicating things”’ (C4)

‘HR services could be provided out of one (state organization), or risk management out of another. I see an awful lot of waste and duplication, and essentially that's money that's being tied up on the admin, but could be doing work on the ground’ (C2)

‘Our aim is to try to get all of our back-end work under a central model - HR, payroll, IR, IT, possibly communications, and possibly fundraising, actually centred in so that that work is organisational facing rather than patient facing. We want (the states) and they see themselves as being patient facing, excellent providers of localised service’ (C9)

‘(There are now) national working parties in programs, communications, and productivity. CEOs can chair those but there are no CEO representatives on it. They are either a board member with an appropriate skill, or a staff member with an appropriate skill, and it's fascinating to watch the dynamics in those rooms, because CEOs are facilitators of processes, not contributors. That started to change what I call the value proposition of HCOC in the eyes of its own members. They're starting to go, "You guys do some good work! We hadn't thought about that. We didn't know you were doing that. Why haven't we got access to that resource?" All of a sudden we've become visible to our most important constituent’. (C9)

We're inviting (state organisations) to take up core responsibilities on behalf of us all, where they have a particular expertise and they will deliver that particular expertise on behalf of us all through a very carefully negotiated contract’ (C9)

‘In state/national separation the role [of the national CEO] is relationship management, national quality assurance, policy and so on’. (C1)

Federations: Tensions

Regardless of the success reported by HCOB participants there were also instances of tensions within the federated organisation. Similar tensions were reported across HCOC and generally related to either the implementation of change or funding arrangements. A couple of instances reported on different stakeholder expectations at state levels.

‘It was set up in ‘82 and it's federated because it grew up in fits and starts. National office was only formed 12, 13, 14 years ago. But we need to move to the next stage of our development. We need to have one national organisation. Now, there's lots of organisations that have fallen at the hurdle because of interstate resentments and we have all sorts of inefficiencies in our organisation because of that. We're trying to address it as a Federation, to see if we can improve our efficiency and so forth, but every one of those paths you walk down hits the hurdle of, "Yeah, but what are we going to have to give up? This is always about New South Wales and Victoria telling the rest of the world what to do," which is exactly what we should do because it's where the problem is. Melbourne and Sydney is where the problem is’ (B4)

'We have cross-silo partnerships and as a federation we don't work tremendously closely with each other in all areas, it must be said. In some areas there's good work, but in others, no. Even where people work closely with each other they might not agree with each other but they're working closely across the federation' (B7)

'Then there's a third one (a client database) which seemed like a good idea at that time. That infrastructure's all been put into place, because it required a common server, which was basically a system whereby everyone would be able to log onto virtual desktop environments. Everything's on a common drive, all the emails, common, it required a bit of extra infrastructure. Not everyone was able to buy into that at the time, only five of the nine members. It was poorly planned, poorly executed as was the website. It didn't work as well as expected, it took three years to get it running properly, costs blew out, costs continued to blow out. Other states and territories in the meantime have needed to upgrade their local systems, while still considering whether or not to come on board with the other on … I think the real big issue is the fact that we have nine separate organisations who are, in principle, more or less trying to work together on a common IT platform which involves common resources, and servers, and databases, and all that kind of stuff … There's multiple components, and … they were poorly planned and implemented back in 2008, 2009, when they kicked off and it's caused all kind of headaches and costs blowouts. There's ongoing argument about who pays for what.' (B3)

'The fundraising relationships don't work very well. The Research Foundation, that's our funding arm. It's been around since 1985 in various forms, taking donations and giving out research grants. Back in mid 2000s, it was about 2004 or 5, it used to be located in Western Australia, but with the national body we took that over over here. And there was an agreement put in place at the time that each of the member organisations would, basically, pass on at least 50% of any donations or fundraising that was intended for research. That happens in some cases, that doesn't happen in others. As a part of that, there was an agreement that the foundation wouldn't do any active fundraising on its own. The members would fundraise on behalf of the foundation so that HCOB nationally could fund research. Each organisation has got its own funding requirements, you know, money comes in and is it for research or is it for something else? That's an ongoing tension, as well. We're trying to get an understanding about who does what in terms of fundraising' (B3)

'Getting the state and territory organisations to ditch what they had in the past, and come onto this new system which isn't necessarily as good, has been challenging'. (B3)

'It is a federation, so there is a structure where each state territory is a separate legal entity and separate business unit. That's one of the tensions in any federation, I think. The state based organisations are members, and because of that, we have to manage those relationships carefully and sensitively. And at any moment, any of those, depending on the personalities leading that state territory, they could decide not to be a member. But we do have a shared vision, and we do have a commitment of working together in a lot of different areas. The growth of the organisation over the last ten years, and particularly over the last two or three years has been huge, and our profile with government has increased significantly, and our reputation'. (B1)

'I suppose I've been lucky in the sense that the states, for the most part, haven't interfered with the policy work. I've always been careful to let people see documents and so on, but for the most part I've been left wonderfully alone to determine the national agenda and the advocacy along with the consumer advisory groups' (B2)

'I think part of the problem is we sort of barrelled along thinking that we are this great organisation, when in fact and the principal difference is that the organisations voted to stay a federated structure. For me, that's an ineffective structure, so I've got to make the best of what's the opportunity. I've been very clear since I arrived on day one that I believe it should be one single entity. There are significant savings. The organisation lacks the maturity to be there just yet. Hopefully this hybrid model that we're operating in now, will prove to people that you don't lose local identity and local capacity by working centrally.' (C9)

'[This] community likes to keep things local, likes to believe that the dollars are going and staying here. And they don't want to think the decisions are all being [by a national office]. They know there's a national influence, there has to be a national structure but if an organisation in (this state) becomes nationalised, then it can often lose a lot of its support. That happened with Red Cross not long ago. At the end of the day, I'm responsible for this state. We do what's best for this state so we don't really ask that the other states understand. They have to accept it'. (C7)

'There're some things you do together and some things that you don't take on. (C7)

‘The national branding’s had a couple of reviews and revisions. It must be about two years old now. We're the last state. Victoria has only just adopted it. A couple of the states were in straightaway. They were remodelling, new CEO, no reason not to. Lots of different circumstances at the time and they went, right, let's go for it. And I think unfortunately it was the time when the National CEO started. And my belief is that it shouldn't have been one of the issues that was dealt with first up, because it drove everything else which was unnecessary. And because we didn't take on the branding, there was a perception that we weren't taking on the national agenda, which wasn't the case’ (C7)

‘It's a small bone of contention nationally that we're all here for the collective good of the person with HCC. Yes, we are but we're responsible for people in (this state) with (the condition). And if we need to do it this way which is a little bit different to you then that's the way we should be doing it’. (C7)

The idea of moving from federated organisations to national organizations was expressed as a positive if problematic shift.

‘About 13 years ago now, my understanding is that there was a consensus amongst the various state and territory groups that there was a need for a national presence, a national representation, particularly to undertake some of the advocacy and policy roles at a national level. That's where our part of the organisation came into being.’ (B3)

‘We have to face the shortcomings in the Federation if we're actually going to have a really good approach at dealing with the HCB problem. Now, you could continue to do that within a federated structure but I don't think it's as good as probably what a united national approach should be, but it's going to take us a while to get there if we're going to go down that path’ (B4)

‘There's too many personal interests and personal agendas on the line and (becoming a national organisation) it's not really a priority, to be honest. There's a lot of distractions around trying to be successful with the here right now, to concentrate on that. We're all separately incorporated organisations, and with our own boards’ (B7)

‘The issue never goes away, but the politics really are against a single organisation in terms of its negotiability. That doesn't trouble me greatly, but it's an unresolved issue, so we do have issues about how to make the federation work even better’ (B2)

‘The problem with the Federation is that there're really only four players in the Federation. There's New South Wales and Victoria, and there's Western Australia, and there's national. The others are there but they're so small that all they basically can do is, "Here's a bunch of money - go out and deliver some service." That's not a criticism, it's just nature of federations. If we're really going to cope with the avalanche of HCB we need to have one national organization’ (B4)

‘I'm much more in favour of federated structured than the single entity. I support the federated structure, supported by a national secretariat, where the members come together to do a few things excellently that add value, rather than a national group with State branches. I'm much more for a federated structure with a secretariat, where you come together and you do some things excellently, for example lobbying in Canberra, consistent messages and consistent information that you can use. We should have, in our case, the national HCOC lobbying in Canberra and a common set of medical statements, a common set of brochures. Where a State has a specialty, don't replicate it, use it’ (C8)

‘We're still in the federated model, the development of HCOC as a national entity, as a sort of framework for the operations of all of the states, and getting everyone on board with that. There's still a perception amongst some people that means there's now nine identities within HCOC instead of eight. Really, there's one - it's HCOC and everything sits under that umbrella. A lot of people are on board with that but some aren't. That's just the challenge of change and time because it's all relatively new, and you're also dealing with people who have had things their own way for a long time and it's taken away some power’ (C3)

‘It just seemed to be a much more sensible thing to become part of a national movement, to be more powerful than simply to be a state body, and more powerful in terms of an overriding desire to not just (provide) people support, but to get the word out, so people can be diagnosed early - a timely diagnosis’ (A4)

‘Even though we have had, perhaps for the last ten years at least, this commitment to work together we haven't really done it in an active way until the last five years (B1)

Summary

Capacity was enhanced by alignment of state organisations within federations, where there was a strong national focus on policy and advocacy work, on managing the relationship with federal government and the HCO's reputation, and on quality assurance of services and programs, and on providing business support, infrastructure and procurement services.

Marketing, communications and fundraising were contested functions with some state organizations believing they were better managed at the state level. The national organizations are responsible for managing the relationship with federal government, and for policy, advocacy, research and overall quality assurance and reputation. As in all relationships, where states are more closely aligned to the national office, it is an easier relationship. Lack of infrastructure and systems, while a source of frustration and tension within larger organizations and federations, is managed through 'work arounds'. Moves from federated to national organizations are challenging and take time.

Having established a national office with a well-respected and well-networked public servant as its CEO, and recruiting a well-known celebrity as its champion, HCOB worked on building credibility through intellectual capital and was rewarded with generous funding from government and private donors. Success in purse together with a high profile in the community and strong performance in policy and advocacy work helped establish its place as the peak organization, with good relationships with the state organizations, which see their roles principally as service providers. Tensions still exist in relation to shared services and infrastructure but overall these are not considered show-stopping. The CEO at the time of this research has since retired and it remains to be seen if the momentum towards a truly national organization continues.

'It would take a very courageous national CEO with a lot of time on their hands, and a lot of goodwill and capital to force that through, and willingness from all the States and Territories to actually go along with that.' (B7).

HCOC on the other hand was in its early days along the road to establishing a national identity. Although it had established a national brand and national programs, tensions were evident in key areas of funding and responsibilities.

The CEO of the national organisation at the time of this research resigned after 3 years and the new CEO, who is equally committed to establishing a national organization, appears to be taking a different approach to change management.

'I've watched very carefully what [another HCO] did and I'm unashamedly trying to replicate that in many respects. And that took a very, very egotistical, autocratic CEO to go, "This is the way we're doing it," and two States joined, and then other States had to join, and then they competed and rolled the national office, and then the final two or three States rolled in and they became a national organisation. So they did it in a completely bloodthirsty way. They probably wouldn't describe it like that, but that's certainly my observation as someone that's watched that process, and actually interviewed CEOs, General Managers and State Managers at the time to get my head around how that happened. They basically went from a federated structure to a national entity over a period of time of what I call forced amalgamations. You don't want to join? Great. No problems. You'd be accountable for that decision, but we're now competing for State Government funding along with you. It was a very, very powerful way of doing it'. (C9)

5.1.7 Creativity

'*Necessity is the mother of invention and discovery*' (A5)

Creativity was described as resourcefulness, flexibility, responsiveness, innovation, improvement, and as engaging with others as illustrated in Figure 5.9. Creativity was reported as enabling success in Performance, Profile and Purse.

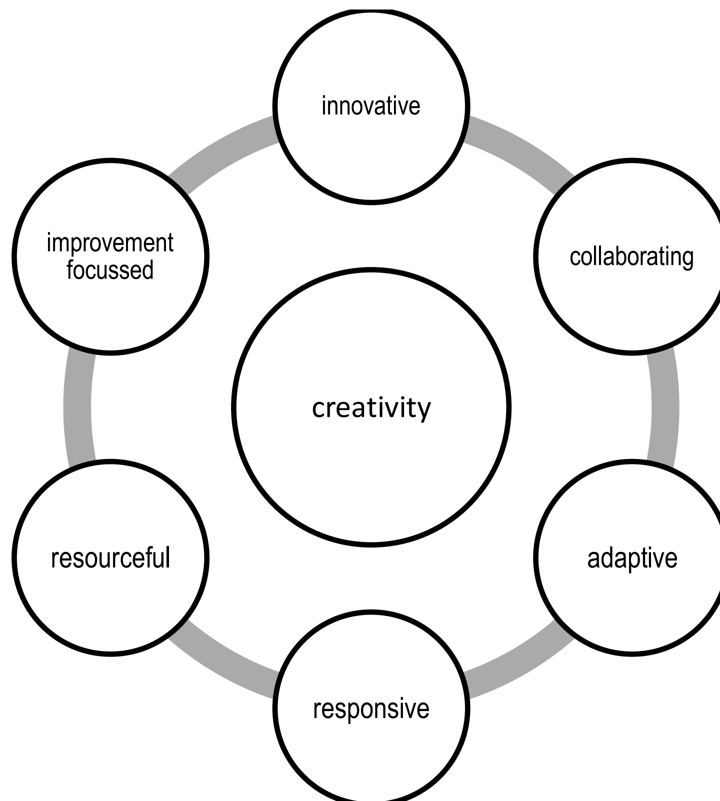


Figure 5.9 Creativity is a key mediator for success in performance

Resourcefulness

I think having the ability to be able to think on your feet, and to think laterally about ways of doing things with limited resources. Not-for-profits are good at functioning off limited resources. (C7)

'It's partly just getting things done with very little. It's just working out how to do it. We just get a challenge and then we don't know how to do it usually. We just work out how to do it and usually it works' (A5)

'A key thing about why it is a success is that all of us tend to be very solution-orientated. Like, "Here's an idea, how can we make this work?"' (C2)

'*It's about culture and it's about being able to flexibly do something in a hurry and get it done. That, to me, is a measure of how good an organization is, if you can pull something off like that so quickly. (C8)*

'It's a consumer group, but a consumer group that probably looks at every opportunity. We've always been innovative because we've always been so small, we've had to do things differently. Starting off as such a small organisation then expanding, we've had to look at every opportunity. We've always been fairly strategic in how we've done it' . (B8)

Engaging and collaborating with others

'The majority now understand that if we don't make the money, then they don't have jobs. I mean that's down the hard line. They're understanding it better now, but that first two years was difficult. And in the last couple of years, actually having them understand. And actually have a real depth of understanding around, "Okay, well this is why you have KPIs. This is why you have key performance indicators," and how they align to our funding contracts. Because the more that they understand that, the more they engage with what we can do and how they can deliver and look for other ways' (B10)

'It's actually engaging the staff in, "Okay how can we do this? because we don't have the funding for it" and the staff then become engaged and creative as well' (B10)

‘The two videos we've got, that was a success. We wanted to make those videos. We didn't have the money. Fortunately, at the same time, we found Joe Smith. It was his company made them for us, but it still cost us $4,000 (which) we didn't really have. So we just asked the members for the money and they gave it to us. No-one was more surprised than we were and it's not a lot of money. For us it was, because that's probably about 20% of our annual turn-over. They've been quite popular as well.’ (A5)

Anticipating change and being responsive

‘That creates a lot of energy and a lot of excitement in the organisation’ (B8)

‘It's a farming saying, “the cows are all fat, we're all happy, nothing's going to change. The next drought comes along, change of Government comes along, maybe (the condition's) not a priority anymore, maybe you don't get your money anymore. It's only when they see that as a looming risk do they start to mobilise, and you go, "That's crazy. Why weren't we considering this as a strategic imperative 6, 12, 18, 3 years ago?’ (C9)

‘We need to shift some of our focus to really embrace the opportunities around the consultation and the innovation that people are asking us to work on. We have this dilemma where we have a lot of government contracts for service delivery, it's always that dilemma of the expertise is sitting here and we want to transfer some of that over to other agencies, or to the community It's a whole model of do you run music therapy sessions for ten people in Sydney or do we use our very skilled trained diversional therapist to teach other people how to do music therapy? We're in a transition phase at the moment, because we've got a bit of a legacy of being stuck here but actually want to turn it around and leverage that’ (B5)

‘We've had significant achievements with few resources in the last few years in particular. The campaign that we had in 2010 was significant. That was a milestone. Without the creativity to think about "Let's do this," and then the resources and thinking about planning, it wouldn't have happened’ (B1).

Doing things differently

Differences between not-for-profit organizations and the Government sector were noted with more freedom and autonomy perceived in the not-for-profit context 'rather than the stultifying air of Government'.

'We're fairly innovative. It's very much don't just stick to the same old same old all the time. Always try something new. It doesn't always work, but you've got to try a few things.' (A5)

'Some of the committee members do read extensively and are starting to look at the way other groups do things. There's more willingness to look at other groups to find out how they do things such as fundraise'. (A1)

'We're sitting in the medium not-for-profit area. A lot of the ones that we strive to meet are the larger ones because we wouldn't look at the medium ones for improvement. We think bigger all the time and try to strive for improvement. It's not so much about the providing of services. It's actually how they run their organisations. So I don't look at it as what they deliver. It's how they operate, from my perspective what I look at is wat can I streamline, what can I refine? What can we do that enables us to spend less money on overheads, and put more money back into the business? Because to me, most people can just pick up the service and deliver it. They may not deliver it extremely well, but they can deliver services. But what makes it successful is that business model that they have in place'. (B10)

'I think being continually aware of ways that we can improve and strive to improve it, is critical. We never rest on the laurels. We're always going, "Okay that worked really well. Now how can we apply that strategy to this. What message can we learn from that for this'? (B10)

'We always work on the premise that we can always do better. We never think that we are there, if you know what I mean. We push goals and we push boundaries. We never think we're good enough, and I think that's part of our success too. Not thinking that we're great and that this is it' (B10)

5.2 Challenges

According to Renz (2010), 'one of the most challenging tasks of non-profit management is to select a course of action that strikes a reasonable balance among the divergent expectations and demands of the organization's multiple stakeholders. This requires that management be especially politically sophisticated and sensitive to the external environment' (Renz, 2010: 801).

This study identified challenges relating to Purse (challenges of funding operations and of ongoing sustainability); challenges relating to Performance (challenges of managing stakeholders' expectations around mission and of securing the capital (human, social and intellectual) and capacity required to accomplish its mission); and challenges relating to Profile (challenges of achieving and maintaining stakeholder credibility, in a changing environment).

These challenges are similar to the stresses facing non-profit organisations in times of uncertainty outlined by Shea and Hamilton (2015). According to Shea and Hamilton (2015), responses include 'creating new revenue streams (Besel et al 2011; Bush 1992; Marwell and McInerney 2005; Wolff and Schlesinger 1998), hiring more professionally trained managers (Bush 1992; Lammers 1990), mimicking rivals' policies and practices (Galaskiewicz and Wasserman 1989; Tucker and Parker 2013; Tucker, Thorne, and Gurd 2013; Wolff and Schlesinger 1998), and creating interorganizational alliances (Abzug and Webb 1999; Biel 2002; O'Regan and Oster 2000)' (2015:383).

A major challenge the two federated organisations, HCOB and HCOC relates to their current form and the energy required to change to a national organisation or to make a more effective federation. While benefits associated with centralising back-office support functions are recognised, the current model of service delivery at state levels was said to work well. The main challenge is how to manage the funding of state services and the accompanying tensions.

'I don't think you can deliver service delivery as you need to, based on the needs of your state with a one size fits all' (C7)

Other challenges relate to how to manage sensitive relationships between separate legal identities and separate business units, and how to reduce duplication of effort and ensure consistent quality of programs and services offered by separate state organisations.

‘I think the other sort of challenge that's sort of part of that is that is there lack of recognition of how much national office is doing, and the capacity to be able to do all of that, I guess, as we are and the limitations of resourcing at a national level as well, or the capacity to’ (C2)

‘It's part of a federation that presents a whole lot of issues. I think that presents a couple of issues in terms of our success and potential. I remember going to one conference where Professor Ian Oliver (then Chair of Cancer Council of New South Wales), presenting the question, "What do you get out of being a federation?" I would struggle to answer with anything that we get out of being a federation, so that's just my view on the federation. I think it does cause some issues in limiting our success as an organisation. It is good from the perspective of HCB and HCZ not just being a Federal issue - there are certainly buy-ins to State-based issues in terms of the way the Constitution separates the powers of the Australian and State Governments. So from that perspective, there are some things that the federation perhaps does help us with a little bit, but I think there are better ways around it’ (B7)

*‘Many national organizations in Australia are federations and they suffered enormously from the tyranny of State Divisions. Even if they're a State-based organization, they then suffer the tyranny of capital city versus a non-capital city, or within Queensland and Tasmania, all of that sort of stuff. So often it comes down to people who are simply mature enough to actually understand that wider vision and what needs to be done for all people in the country, rather than for people in their region or their State’. (*B6)

We're still in the federated model. There's still a perception amongst some people that means there's now nine identities instead of eight. Really, there's one - it's (the national organization) and everything sits under that umbrella. A lot of people are on board with that but some aren't. That's just the challenge of change and time because it's all relatively new, and you're also dealing with people who have had things their own way for a long time and it's taken away some power.’ (C2)

‘I have the challenge of getting consensus to enable us to move forward. Probably one of the things we don't do so well is, essentially, the roadblocks, the delays, the time it takes to take individual (state organizations) on a journey, and then wanting the outcome before-- and also managing their perceptions of what our role actually is. I think they see from Jill down, that we're their PAs to an extent’ ‘(C2)

‘I saw what a destructive federated structure could do - coming together, not working together, going apart. The busting up of that federation, the dismantling of the national body, cost them dearly. It's taken them a decade to bounce back to where they rightfully should be’ (C7)

‘However we would use the resources we had better if the small P politics didn’t get in the way, everything has to be excruciatingly articulated and essentially bureaucratically managed. Which on the one hand, some (state organisations) criticise because they say, all you do is write policy and send drafts of progress whatever. But if you don't do that in a federated structure then (they say), "You didn't tell me that’ (C1)

‘That then leaves the final question as a business decision, because if you've actually got a national identity, you got national quality assurance and you've got local relationship management, it becomes a business decision. What do I think? I think it's very hard to say that it wouldn't be cheaper to have one organisation. And remember I came from (another NFP) which was national. It's cheaper, doesn't mean it's better, you can easily go into a bureaucratic mode because of distance. But what would you lose in those relationships locally? There's risk, because of some people have properties, some people have debts, so there's risk. But also, what would you lose? The cold hard facts are, without government funding I'm not sure what the sustainability is, but even then you don't move to something it just for financial reasons. (C1)

‘*At the moment I'm working with a national pharmaceutical company who have point blank said to me, "We want to work with (the national organisation).We don't want to work with eight individual (state organisations)." But the (state organisations) still contact that company wanting support, and it completely undermines the relationship and they don't realise that a very substantial national partnership is being jeopardised by them asking for a sponsorship of a golf day’* (C3)

Smaller state organisations showed some resistance to the perceived 'bureaucratisation' of their national organisations seeking to ensure consistent quality of programs and services. National offices defended the need for policies and procedures to support the growing organization and expressed concern about the potential negative impact on the HCO's profile of states acting independently without communicating or consulting them. Problems were reported in implementing new infrastructure and systems across state organizations, resulting in cost overruns and frustration.

'Basically the momentum of the organisation as a whole has watered down a lot of those tensions. If, after next year, we stall, that progress and momentum stalls, then I think all of these tensions might flare up again'. (B3)

'I find it a frustration that the organisation is not evolving in a national direction as quickly as I would like it to evolve. Things like national websites, for instance, can be achieved very easily with goodwill, but there seems to be road blockages' (C5)

The challenge facing federated organisations is similar to the challenge facing HCOs considering merging with or entering alliances with umbrella organisations. In addition to governance and funding arrangements there are deeper concerns around identity, representation and 'share of voice' As the peak organisation in its area HCOB acknowledges the difficulties representing a broad church of people with variants of the condition, noting the emergence of new groups to fill perceived gaps in the way it addresses the needs of particular stakeholders. While its stated concern is about the quality of information new groups can provide, there is also potential for it to lose traction as the peak organization over time.

Survival and sustainability are key challenges for HCOA since it currently does not receive any government funding or sponsorship and relies on subscriptions from a declining membership. It also faces the challenge of renewal and succession planning relying solely on the personal efforts of a small group of very committed volunteers over many years.

'Being membership based, we're very vulnerable, I think. If, all of a sudden, we stopped becoming relevant to our membership, we're in big trouble, and we've already noticed a drop off in new members for the last 12 months. When we first came in, we saw a dramatic increase in numbers by 25 to 30% but in the last 6 months, 12 months, that's dropped off quite dramatically. Part of the reason for that is that we're giving our information so freely. In the old days, it was, "If you join our membership, we'll send you all this info." Now if they can come to the website, we can send them a booklet, we don't say, "Give us some money first." And also part of it I suspect, is that we haven't reached everybody who needs to hear about this. We've reached - I don't know how to describe it - ones who, I guess, are at high risk. Then we've got the low hanging fruit. I don't know what the future is for the next few years. It won't affect us for a while because we've still got loyal membership and a couple of nice donations, yes. Maybe we've got to change our funding model and look for more grants. We're not good at fundraising. We don't have people who have natural fundraising talents or skills on our group. Some people would think it's a wonderful idea to go and organize a ball to raise money - to raise $50,000 - it just wouldn't occur to any of us how to do that - so we wouldn't. Also, again, how to get money out of government. You see all these little groups that are being funded by the local or state government. How the hell do they do that? There's that sustainability, the financial sustainability'. (A5)

Capacity challenges are linked to Capital challenges which influence a HCO's success in relation to Purse.

'The area of fundraising though is very sensitive, and I'm sure the others will tell you this too, because one of the concerns of the states and territories is that they have - the biggest states and territories - have fundraising managers, and they are very dependent on the income from the fundraising targets that they have. They don't want anything to jeopardise that, and they feel that if National Office starts a fundraising campaign, we may then cut into the donations that they would get. Although, our intention is to say, for example, if New South Wales has 2 million in fundraising every year, we hope to make it 4 million for them, it'll take a bit of persuading and reassurances and a proper strategy' (B1)

'That's probably the biggest challenge I have, is the fact that they see me as I should be out there fundraising for them, and if they're having a golf day, can I get them some prizes. That's not my role'. (C3)

We can't manage our business hoping to God that someone dies and leaves us something in their Will' (C9)

Where programs and services are funded on short term contracts HCOs face the possibility of losing experienced employees as they approach the end of a contact because of the uncertain availability of future work.

'Who knows what, anything. I actually met with four staff members yesterday because they're on time-specific contracts that run out on the 30th of June, which is the date the Federal Government runs, and I was upfront and honest with them. I can't guarantee. Some of them are out looking for jobs now and if they want me to speak on their behalf, I will, and they know that. I can't say to them, "Hold off, hold off, hold off. I'm sorry, you're going tomorrow." What I've tried to do is I've given them four months notice, effectively… (if it turns around and the funding is continuing, then you've potentially lost) … That's a risk, but that's what you've got to understand when you've got government processes. To me, I think government should have been able to act earlier' (C8).

Governments also change focus areas and priorities. This was expressed as 't*he mental health effect'.*

'When Pat McGorry was Australian of the Year, they got that big $2 billion dollar package that went through and it did lots of useful things. But in the end, the government had the line that, "Well, okay, we've done mental health now. Nothing more to do' (B3).

Weerawardena et al, 2010 note the increased competition among non-profit organizations for funds, resulting from changes to the government-non-profit relationship which saw the entry of ' for-profit firms to service markets that were traditionally served by NPOs, e.g., health care (Ferris & Graddy, 1999; Kessler & McClellan, 2002). (Weerawardena et al, 2010 346).

Anticipating and planning for funding cuts and changes to bequests and donations was seen to be a strategic priority for HCOs and responses included advocating for preservation of funding, introduction or expansion of fee for services and creating social enterprises or businesses.

While this was not an option taken up by any of the HCOs in this study it was raised by one state organisation as a possibility, highlighting yet another challenge of potential mission drift and donor alienation. According to Eikenberry (2009) 'there is a growing body of literature critical of the marketization of nonprofit and voluntary organizations (e.g., Dart, 2004b; Edwards, 2008; Eikenberry & Kluver, 2004; Foster & Bradach, 2005; King, 2006; Weisbrod, 2004). James (1998) asserted that nonprofit and voluntary organizations that undertake commercial ventures weaken their appeal to donors because individuals think their donations are not needed by an organization that is commercially successful'. (Eikenberry, 2009: 587). Establishing the balance between commercial activity was also recognised as a challenge;

'If we are dealing with corporates, if people are using our resources and they are using it in a commercial capacity, then we should be getting some financial return on that, and it's not just about us doing good things for everyone. I see that as a challenge going forward, just getting that balance' (C2)

'I think they've become a little bit corn fed. It's a farming saying, but I just think like (if) the cows are all fat, we're all happy. Nothing's going to change. The next drought comes along, change of Government comes along, maybe the condition's not a priority anymore, maybe you don't get your money anymore. It's only when they see that as a looming risk do they start to mobilise, and you go, "That's crazy. Why weren't we considering this' (C9)

Tuckman and Chang (1991) had earlier noted the vagaries of donations. 'Donations are voluntary and contingent on the good will of contributors. A non-profit that does a good job of satisfying its consumers will not necessarily increase its donations... Instability in the donor base can emanate from several sources. To the extent that a non-profit relies on donations, it is subject to changes in the tastes and preferences of donors. If, for example, it is fashionable for donors to fund AIDS research one year and cerebral palsy the next year, the non-profits working in these areas will experience considerable fluctuations in their revenue base. (Tuckman and Chang, 1991:448).

HCOs also reported the challenges of growth and sustainability, which relate to the availability of capital.

'There is a big challenge for us in thinking how we get from where we are, to wherever we want to be in that sort of structural change. There's a real cap on growth where we are. It's a significant issue. I mean, if we can achieve all we want to achieve without, that's fine. We put in for grants from DoHA just a bit over a year ago, for about 600 grand. There are people would say if you start accruing money of that order, you will need to have it. There are other people who would say you're not going to get money of that order unless you show you've got the substance' (A4)

'The point is, if you're in small business on your own, there's a great lump to get up to the next step, where you start employing people. And you've got to really grow quite a large step, before you're back to being as profitable as you were. If we get a little bit bigger, and we need to have an office and an executive officer, we'll spend a lot of money to actually get back to where we are'. (A4)

'Like a lot of organisations, we struggle balancing funding and resources. We're all running pretty hard. In some not-for-profit sectors there's a bit of reputation of well, look, you know, you don't pay very much and therefore you're not going to get very much. Certainly, HCOB has a fantastic team, very dedicated but we're stretched. There's a huge epidemic of HCB and we're just at the tip of the iceberg, so there's obviously a lot of need for investment in research, staff, and delivering services. There are a lot of gaps in our service delivery. (B6)

'I think there're the growing, teething challenges of expanding from a relatively small organisation. So back in 2000 when it began, it was Jim plus half a support person. We're now probably at about 25 and looking to expand to-- maybe just about-- I don't know the exact number, maybe 20 to 25 at the moment, and we've got another 4 or 5 people due to start in the next month or so, so there's that growing process. Our operating budgets have expanded commensurately, I suppose. And there's been all the challenge of developing appropriate policies and procedures, and housekeeping stuff to deal with that growth' (B3)

'The biggest challenge is all that internal capacity building. Our demand and our operational requirements are here, but actually our systems and internal capacity is lagging. And that's because we've had quite fast growth (B5)

‘The biggest challenges? I think the fact that we've grown. We grew quite rapidly over 15 years, it's not a really long period of time. Our membership has grown to 75,000 members. Our staff has grown-- I think when I started in 2006, we had 12 staff. We've now got 36o to support all the work that we're doing, and because we have become more well-known and we're now reaching 80% of all newly diagnosed (people). I think it's that continued growth, and looking ahead at what we're expecting over the next few years and how we sustain that. That of course goes hand in hand with funding and making sure we have a good fundraising strategy with different streams of income’ (D1)

‘If you look at it from an organizational point of view, I think that five or six years ago was a challenge. The group was in danger of folding and as the only organization in that space, it would have stopped. Nothing would happen because Government's not doing anything, no-one else is doing something about it, and we stopped that from happening. But I don't see it as a huge challenge. We just got in and did it. I don't think it was. It was a crisis. I guess the biggest, I don't know. Personally, I see the sustainability thing as one of the biggest challenges, for all of those aspects of it. Where do we go next? Or where do we go in five years time? We're always thinking about it, talking about it. We haven't come up with the answer.’ (A5)

‘The biggest challenge is really the continuation of the growth without the resources to support it. Every not-for-profit has that’ (B10)

Challenges associated with conflict and tensions were evident at organisational and individual levels.

‘One of the challenges when you have an all lay group-- we come from very different backgrounds, and so we have very different perspectives and ideas and where we'd like to see things go. So, it's a big challenge, I think, for us, to operate cohesively. (A1)
*‘Put two people together, there's politics. Humans come into it. Patient support groups are definitely no different to any other one’ (*A2)

‘As we started to ask those questions, that's created tensions in the organisation, which is not about putting down the quality of the work - indeed, it's great quality work - but it's merely about saying, how do we know we're actually making a difference in the lives of people, and having an impact ‘ (C9)

'I don't think we've really got a common agenda across the group. Language and framing that sort of thing is very difficult when we have group meetings because the longer-term members become quite offended if you said to them it's only early days in the development of this group. There has been quite a bit of friction because of different viewpoints. That said, we all respect each other, and we all bring to the table very, very different skill sets, and I think it's that combination of differences that actually has seen the group really progress and still exist after 20 years' (A1)

'I've had issues over the years because of this immense emotional involvement [of volunteer committees] and so we've had many difficult discussion about research methodology and access to unproven treatments and that's been a source of angst from both sides, which I think is much less the case in organisations that have professional (managers' (A2).

'It went from a condition where there were no treatments, to a situation where treatments became available for some. These treatments are exorbitantly expensive and millions of dollars a year, per child, or at least maybe half-a-million per child per year. And that's certainly, I think, changed things in the organisation. I think there were the haves and have-nots. There were certainly tension that arose that I saw when I was involved'. (A2)

'We ran a day-long strategic planning day, and it was the first occasion where we've had board chairmen, board members, CEOs, staff from all departments across the organisation, volunteers, come together in a room. What was immediately apparent to me was that the board and our staff were universally in agreement, and there was this bottleneck in the middle called CEOs. They could not agree' (C9)

The link between profile and the ability to raise funds was expressed by every HCO. Strong association of a celebrity champion and HCO profile can present a challenge when the relationship ends. In the case of HCOB, its two top representatives in the government and public spheres faced retirement at the same time, raising uncertainty about the impact on the organisation and its profile.

'Overall awareness of the organisation is still relatively low. We're building that, we've been pretty successful but it really does take large investment and a long time. You can do it quicker if you've got an even bigger investment, but we run on the smell of an oily rag, and we do things as cost effectively as possible'. (B6)

‘Y*ou have to be so careful of negative media. I don't know what's gone on with Surf Lifesaving Australia, whether it's a whole lot of media hype or what, it can be damaging and puts a question mark on, what are they doing locally?. And then bang, there's a break that's put onto potential bequests or donations or whatever. All of that kind of media's really really damaging’* (C7)

‘The other big challenge tested our positioning on a topic. We copped a bit of a slamming because we were accused of sitting on the fence, because we didn't have a strong position’ (C7)

‘The other big challenge for us with our getting our message out, I think, is we're not very dramatic. HCA isn't a dramatic thing. I'm being cynical here, but we don't have any pictures of sick children, starving children in Africa, or things like that, that can grab people's attention’ (A5) .

‘The big bottleneck really is the delivery of services at GP level - their awareness. We've created an innovative campaign which is directed to GPs about awareness of the condition and early diagnosis and the benefits of that because there's certainly a very large sentiment that, "you can't do anything about. There's no cure, so why bother even telling the person 'you've got [HCB]." But there are many, many things that a GP can do and so we're trying to shift that perception about that playing a very vital role in early diagnosis to ensure that person gets onto the best level of support services, advice, help to get their affairs in order ‘ (B6)

The strength of a HCO’s profile presents challenges in connecting with stakeholders.

‘A real challenge for us, is who should we be partnering with and how do we respond to everyone else who wants to be associated with us? As the external environment changes and we move to more of a situation where people would be able to choose their own providers and pay for their own services, everyone wants to (our) tick of approval. I think that's challenging for us to think about’ (B5)

‘We need to be able to engage with the system. But how you do that from a small lay group with no money, to in a sense take on the health system’ (A1)

A more recent challenge confronting HCO’s is that of ‘personalised medicine’, its impact on a HCO’s intellectual capital and resources, and on its medical currency and relevance.

‘We're going to have a challenge in the next couple of years where the medical diagnosis of HCB is removed from the diagnostic manuals. People will no longer have HCB. They'll have major or minor Neurocognitive Disorder which all kind of rolls off the tongue. Referring to all these different kinds of diseases is very rarely as clear-cut aswas thought to be. There're factors like some people can have quite advanced disease and function perfectly normally, but never be diagnosed but the same person with the same damage was incapacitated and couldn't talk. Another person was still driving their car, you know? The disconnect between the symptoms and the disease makes things difficult to talk about in terms of HCB, so that's part of the reasoning behind this shift. And, again, I suppose just thinking broadly about challenges, as knowledge advances, that does shift us as an organisation around a little bit, as well. Up until very recently, and more or less at the moment still, we talk about 100 different forms of the condition, but just over the last 12 months or so, the medical knowledge is starting to shift back towards more of different contributors to HCB symptoms. And there are a whole range of diseases that contribute to a range of HCB symptoms, but they very rarely occur in isolation, so the whole process of diagnosing different types of HCB is probably not as accurate as it used to be. As our knowledge advances, our messaging is going to have to change. And a lot of our resources and documents - we've got reams of documents, going back 15 years - they progressively become out of date. So we have to try and keep a handle on that.’ (B3)

‘Keeping up to date with all of that, I think another challenge is going to be treatment, which 20 years ago, again, was standard. There was a standard type of treatment. It's moving, as a lot of health issues are t a very targeted approach, which also means more options, but more cost. So that's challenging in a number of ways’. (D1)

‘And the other struggle is making sure that we are medically relevant, that we are contemporary, that the information that we have is always up to date.’ (B6)

Benchmarking their performance against that of other HCOs competing for funding and resources is yet another challenge for HCOs.

'But one of the big challenges is really knowing how effective we are. It's a really hard thing to measure - awareness. I believe - we all, I think, believe - that we have been very effective because you do hear more about HCA in the day-to-day life, and I believe we have played a large part in that, but how you measure that is beyond us, unfortunately. You can't measure people diagnosed because no-one collects that data. We can't afford to monitor the national media full-time. We don't really know, we believe, we're doing right just from anecdotal (feedback)' (A5)

'For the first time we benchmarked our end of year tax appeal, and again this is part of the transparent reporting back to the members. I've got 40 other charities that I'm aware of their data, and we came 37th. So for an organisation with the significant number of individuals that we care for, to get less than 0.003 of a percent in return … it's well below industry benchmarks, and we have (it's not a crisis) but we have a young team, an eager team, but not very experienced in the area of fundraising and capability, and that's a huge strategic priority for me' (C9)

Chapter 5 has presented what the HCOs participating in this research identify as factors mediating success. The presence of a factor enables success while its absence restricts success. Thick descriptions were presented of factors identified as important:, namely: Clarity, Contribution, Credibility, Creativity, Connectedness, Capital, Capacity. Examples from the collected data indicate that some of these factors – connectedness, contribution, capital and creativity are closely aligned to definitions of social capital presented in Chapter 2. The data suggests that when present together, these factors build momentum, enabling the achievement of success in its different dimensions, in a similar way to the creation of social capital. Together with the literature from Chapter 2, these findings form the foundation for frameworks presented in Chapter 6.

CHAPTER 6: RESEARCH OUTCOMES

As concluded from the literature review in Chapter 2, the notion of identifying a single list of definitive factors influencing success is problematic given the range of Health Consumer Organisations operating in Australia, and their different purposes. According to Sowa et al (2004), 'scholars maintain that developing frameworks or models for the assessment of effectiveness is more fruitful than attempting to derive single measures that encapsulate the construct (Cameron, 1982; Cameron & Whetten, 1983)' (Sowa et al, 2004:714). Based on the findings of the research presented in Chapter 4, practical outcomes to guide HCOs are presented as a series of strategic planning frameworks; a process for stakeholder analysis and strategic planning, and process for evaluating success.

One outcome of this research is an attempt at such a framework for HCOs developed from the experience of other HCOs. Drawing on the work of researchers in the fields of non-profit effectiveness, strategic management and marketing practice, together with insights from stakeholder and social capital theorists, I have constructed what I hope will serve as a practical model for HCOs seeking to work with their many different stakeholders to succeed in their shared goals. I do not anticipate there are any great surprises for people working in the field. Indeed as Sowa et al (2004) observe citing Herman and Renz (1998, 1999), 'generally, scholars find that more effective non-profit organizations have similar management practices, certain structures and processes that are generally accepted as the best practices within the field ' (2004:717). Nevertheless newly formed HCOs and those at a crossroads in their history may find the checklists and templates presented in this chapter, useful additions to their management toolkits and of some help in guiding their planning.

Undoubtedly there are oversights and gaps in this research, caused by the limitations of data collected from a small number of HCOs, and by my own capability as a researcher and writer. One opportunity for further research identified would be to investigate to what extent these enablers influence success. Other potential studies might explore the strength and value of stakeholder networks in primary healthcare in Australia, particularly in light of the establishment of Primary Health Networks.

Other research could focus on identifying ethical challenges facing HCOs working with commercial interests, advocating for access to new therapies. Future research could study the concept of connectedness in federated organisations, national organisations, pan-national organisations, international and global organisations and alliances. s

6.1 Strategic Planning Frameworks

A number of frameworks and models have influenced the process presented here for constructing success around HCO stakeholders. Kaplan and Norton's Balanced Scorecard (1996) provides a way of planning strategy and measuring performance around four perspectives: Financial, Customer, Internal Business Processes, and Learning and Growth. A broad view of stakeholders can be accommodated across these perspectives when applied to the non-profit sector. The Financial perspective can consider resource providers, funders, sponsors and donors in place of shareholders; the Customer perspective enables focus on consumers and members, the general public, the research community, the medical community while the Internal Business processes and Learning and Growth perspectives cover alliance partners, suppliers, employees, volunteers and others providing pro bono services

Paton's (2003) 'Dashboard for Social Enterprises' was specifically designed for nonprofit organisations (Murray, 2010: in Renz, 2010:446-447). According to Murray (2010) Paton's dashboard 'focuses on two sets of questions about the organization's activities: "Do they work?" and "Are they well run?" These questions are then asked in two contexts, the short-term operational context and the longer-term, strategic context' (Murray, 2010: in Renz, 2010:446-447).

Five principles underpin Sowa et al's (2004) 'Multidimensional and Integrated Model of Nonprofit Organizational Effectiveness' (MIMNOE), which reflects Kaplan and Norton's (1996) 'Balanced Scorecard' framework in that it is a hierarchical model describing multiple dimensions of effectiveness within two primary dimensions of management and program effectiveness. These are further divided into subdivisions of capacity (processes and structures) and outcomes. MIMNOE is based on the principle that 'both objective and perceptual measures are needed to fully capture the dimensions of effectiveness '(Sowa et al, 2004:715-716).

This research adopts Sowa et al's definition of 'capacity', which refers to how the organization or program operates, its structures and operating processes. This closely matches Kaplan and Norton's (1996) definition of the 'Internal Business Process' view. Linking 'outcomes', the results produced by management and program activities, with 'capacity', Sowa et al (2004) suggest 'organizations need to understand how their structures and processes enable or hinder those outcomes' (Sowa et al, 2004:715).

A clear stakeholder approach is embedded in Kaplan and Norton's (1996) framework. "Success for government and not-for-profit organizations would be measured by how effectively and efficiently they meet the needs of their constituencies' (1996:180). The stakeholder approach is further supported by Behn (2001) and Ebrahim (2009a). 'Given that nonprofit organizations face demands for accountability from multiple actors, it follows that they are expected to be accountable for different things by different people. These expectations may be broken down into four broad, but far from comprehensive, categories: accountability for finances, governance, performance, and mission' (Behn, 2001; Ebrahim, 2009a). (Ebrahim, 2010 in Renz, 2010:105).

Pawson and Joannidès (2015) also noted the 'multifaceted' accountability of nonprofits seeking to address the ' different agendas' and needs of 'numerous stakeholders' (Connolly, Hyndman, & McConville, 2013; Hyndman & McDonnell, 2009), and the consequent need 'to spend time, energy and resources doing impression management in order to show a good image of their organisation and their actions' (Dhanani & Connelly, 2012). (Pawson and Joannidès, 2015 in Hoque and Parker, 2015: 211-213) Performance Management in Nonprofit Organizations: Global Perspectives.

Leipnitz (2014) highlighted the need for techniques enabling nonprofit organisations 'to evaluate stakeholder satisfaction, identification or loyalty' (Morley, Vinson, and Hatry 2001), maintaining that 'NPOs can measure their performance in relation to their stakeholder relationships (Balser and McClusky 2005) in a way that acknowledges the stakeholders' expectations and interests (Hsieh 2010)' (Leipnitz, 2014:166). Harrison and Wicks (2013) developed a stakeholder-based performance framework for this purpose. Sharing some similarities with Kaplan and Norton's Balanced Scorecard, but including a wider range of stakeholders, the Harrison and Wicks framework adds a 'value' perspective, seeking to broaden the concept from monetary and financial performance (2013:110). This is in keeping with Kaplan and Norton's view that 'financial considerations can play an enabling or constraining role, but will rarely be the primary objective' (Kaplan and Norton, 1996:180).

The Harrison and Wicks (2013) framework is premised on notions of stakeholder utility and value, and incorporates additional measures 'with capacity to recognise a level of utility to stakeholders that exceeds mere satisfaction' with the organisation (Harrison and Wicks, 2013:112-113). Harrison and Wicks maintain that a base level of satisfaction on the part of stakeholders may not motivate them 'to give additional effort, exhibit a high level of loyalty, engage in more value-creating activities or provide more potentially valuable information' to the organisation (2013:112-113), or, in other words, to participate in creating stakeholder social capital (Garriga Cots, 2011, 2014).

Mitchell et al's (1997) framework for stakeholder identification and analysis offers a way of prioritising stakeholders. Coviello et al's (1997) Classification of Contemporary Marketing Practices Framework presents a model for selecting and applying marketing and management practices to stakeholder and network relationships. Knox and Gruar (2007) apply an integration of both models (Mitchell et al, 1997 and Coviello et al,1997) to the development of a Relationship Marketing Strategy for a HCO in the UK.

Frooman (2010) and Garriga Cots (2011) extend the previous frameworks to include consideration of stakeholder networks. Garriga Cots (2011) presents the notion of stakeholder social capital theory through Donaldson and Preston's (1995) three aspects of stakeholder theory. Starting with the descriptive aspect she suggests 'mapping the network of relationships ... determining the quality of each relationship from the social capital perspective... through its four dimensions: structural, relational, cognitive and evaluative' (2011:338)

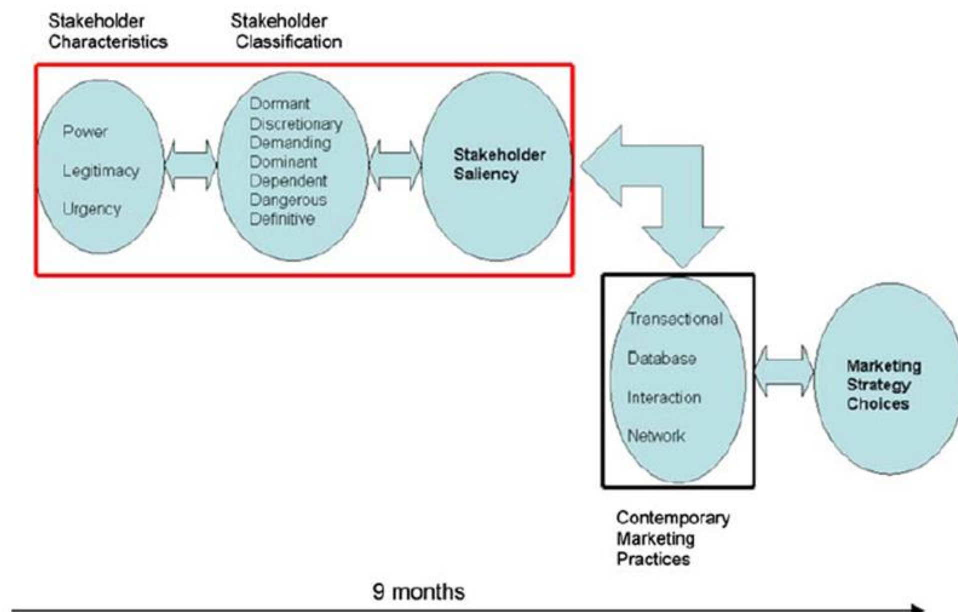
Taking the instrumental perspective, Garriga Cots (2011) suggests that stakeholder social capital is a source of competitive advantage for organisations, identifying four drivers 'relational assets, knowledge routines, complementary resource endowments and effective governance' as 'competitive advantage drivers in stakeholder networks' (2011:338). Applying the normative aspect of stakeholder theory, Garriga Cots (2011) argues that 'stakeholder social capital should be fostered as a way to achieve a relational view of society' (2011:338).

Al-Tabbaa, Leach and March (2014) draw on three elements - context, content and process (Pettigrew 1987, Wit and Meyer 2010), as the building blocks for their strategic framework for non-profit business collaborations 'because they are central in explaining the effects of strategy on organizational performance over time (Pettigrew and Whipp 1991)'. (2014:660).

6.2 Models from the literature

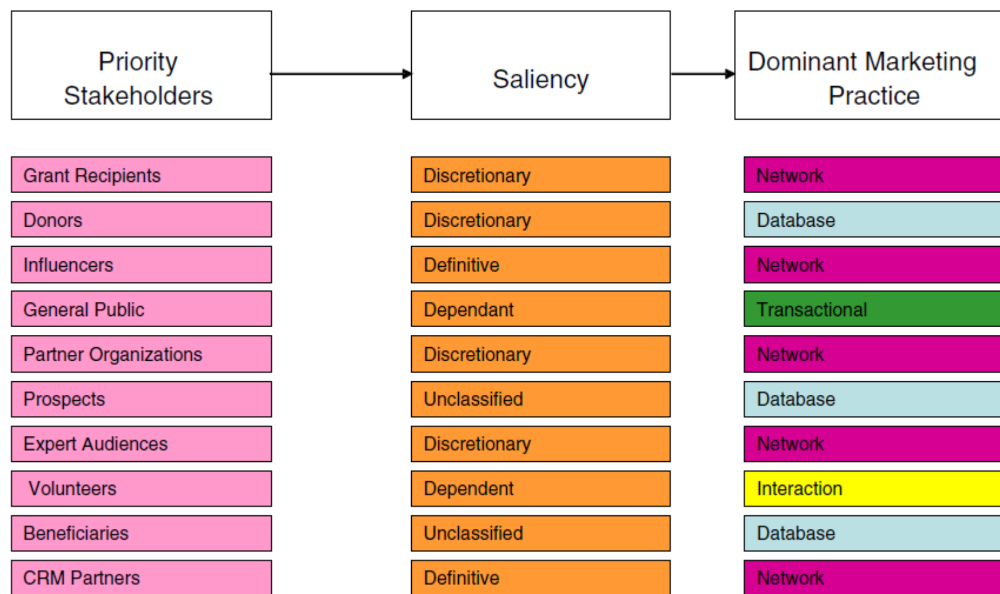
Models revealed in the literature and presented in this section illustrate the bases on which my own model has been constructed. Figure 6.1 presents an overview of Knox and Gruar's model for integrating stakeholder analysis and marketing strategy development, and Figure 6.2 illustrates their application of Coviello et al's Contemporary Marketing Practices classifications to suit priority stakeholders.

Knox and Gruar's (2007) model can be used to determine which stakeholders are most salient to the HCO at a particular time, before selecting the marketing practices most suited to developing and maintaining relationships with those stakeholders.



(Knox and Gruar, 2007:118)

Figure 6.1 Knox and Gruar's model integrating stakeholder analysis and strategy



(Knox and Gruar, 2007:124)

Figure 6.2 Knox and Gruar's model applying Coviello et al's CMP Classifications

Frooman (2010) designed his INSPIRE model to help identify 'the likely relevant stakeholders of any particular issue' including 'social stakeholders' which he defines as those without an economic stake in the issue and among the most difficult stakeholders to identify. 'The model attempts to inspire managers to engage stakeholders constructively and effectively by providing a conceptual framework required for anticipating and responding to stakeholder behaviour'. (2010:170).

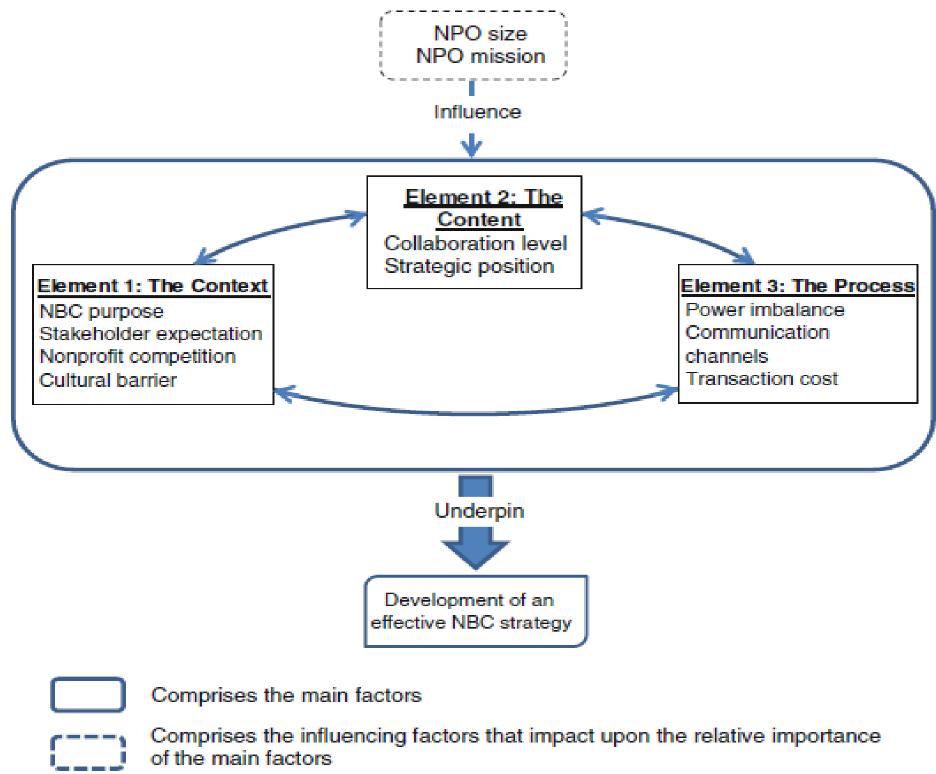
Frooman's (2010) INSPIRE model presented in Table 6.1 'consists of five stages, including: Issues identification, network formulation, stakeholder prioritization, intervention analysis, and response engagement' (2010:169).

Table 6.1 Frooman's INSPIRE Model

	Issues Identification	Network Formulation	Stakeholder Prioritization	Intervention Analysis	Response Engagement
General Question	What?	Who?	When?	How? (Stakeholder)	How? (firm)
Specific Questions	Does the firm have a financial/strategic stake in the issue's outcome?	Who is a stakeholder of the issue?	When will stakeholders influence a firm?	How do stakeholders choose from amongst potential actions?	How ought managers choose from amongst the various response plans?
Tools/Concepts	Agenda setting/Environmental Scanning SWOT PEST	Grievances Resources Opportunities	Salience Power/Interests Life-Cycles Managerial Incentives	Repertoires Resource relationship Institutional setting	RDAP Strategic responses Response patterns
Citations	Hilgartner & Bosk, 1988; Hambrick, 1982; Daft & Weick, 1984; Hart & Sharma, 2004	Rowley, 1997; Mitchell, Agle & Wood, 1997; Rowley& Moldoveanu, 2003	Mitchell, Agle & Wood, 1997; Johnson & Scholes, 1999; Jawahar & McLaughlin, 2001; Elms, Berman & Wicks, 2002	Frooman, 1999; Hendry, 2005; O'Connell et al, 2005; Sharma & Henriques, 2005;Frooman & Murrell, 2005	Wilson, 1975; Oliver, 1991; Post & Altman,1992; Zietsma & Vertinsky, 2001

(Frooman, 2010:170)

Al Tabbaa, Leach and March (2014) illustrate the relationship between factors underpinning the development of a non-profit business collaboration strategy from the non-profit perspective in Figure 6.3. The size and mission of the non-profit organisation influence the foundational building blocks of context, content and process at the centre. 'The fundamental aim of this strategy is to allow NPOs to improve the scale of their collaboration with the business sector both quantitatively, by increasing the number of business partners in the portfolio, and qualitatively, through better partners and agreements'. (2014:661)



Al-Tabbaa , Leach & March (2014:661)

Figure 6.3 Factors underpinning the development of an NBC strategy from the NPO perspective

6.3 A new model to assist HCOs planning for success

Building on the work of Knox and Gruar (2007), Frooman (2010) and Al Tabbaa, Leach & March (2014), I present another conceptual model (Figure 6.4) for a strategic planning process. This model integrates traditional business planning processes such as PEST and SWOT analyses with stakeholder identification and assessment, and evaluation of factors mediating success identified in this research.

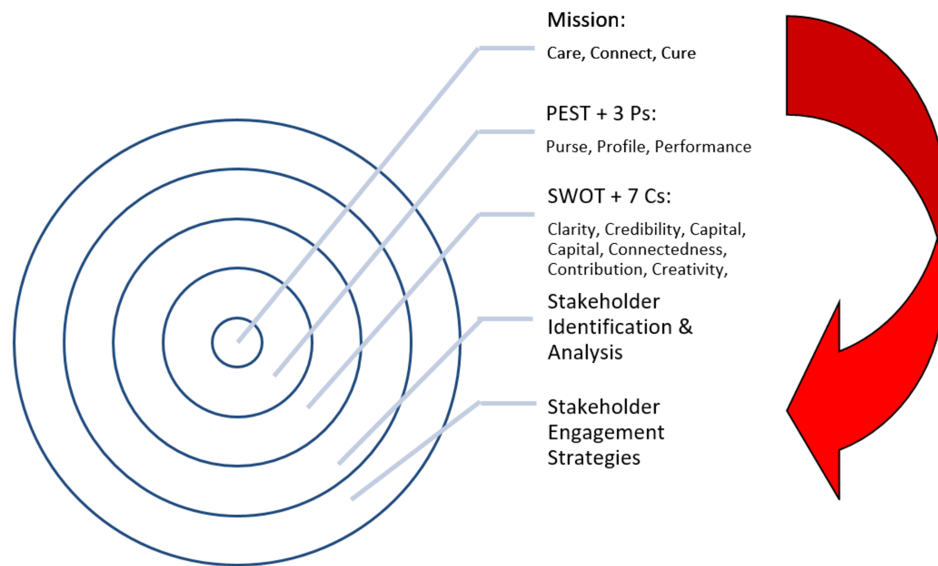


Figure 6.4 Conceptual model illustrating HCO CPC Stakeholder Strategic Planning Process

Placing the HCO mission or condition (Frooman's issue) at the centre of the model, this model shifts attention from the HCO itself to the condition or cause at the heart of its work. With the focal point its mission, the HCO is able to identify those external influences with potential to influence its success by undertaking a PEST plus 3Ps analysis, before evaluating their capacity to succeed via a SWOT plus 7Cs analysis. The final analytical step in this process is the stakeholder analysis, which identifies the stakeholders, their influence and that of their networks on the achievement of the HCO's mission. Section 6.4 presents this process in more detail.

6.4 A new Stakeholder Planning Process

The process for stakeholder planning that I present in this section is limited in that it does not provide specific tools for prioritising stakeholders or for determining the strength of stakeholder networks. However Mitchell et al's (1997) framework, described in Chapter 3, was applied to the participating HCOs in Chapters 4 and 5.

Further exploration of the strength of HCO stakeholder networks was beyond the scope of this study. It is hoped that the process outlined here will be useful as a guide for HCOs and other non-profit organisations, in identifying what their stakeholders value, what value their stakeholders contribute to their endeavours and to their network, and what to consider when planning for success.

The CPC model presented in Figure 6.4 provides an overview of a new planning process. This process integrates the HCO mission (identified in this research as one or all of Care, Connect and Cure), with the three categories of success and seven mediators identified in this research, and Al Tabbaa, Leach and March's (2014) three foundational elements of strategy development, illustrating the stages at which different stakeholder analyses fit. Figure 6.5 below integrates stakeholder analyses with at different stages in the CPC model.

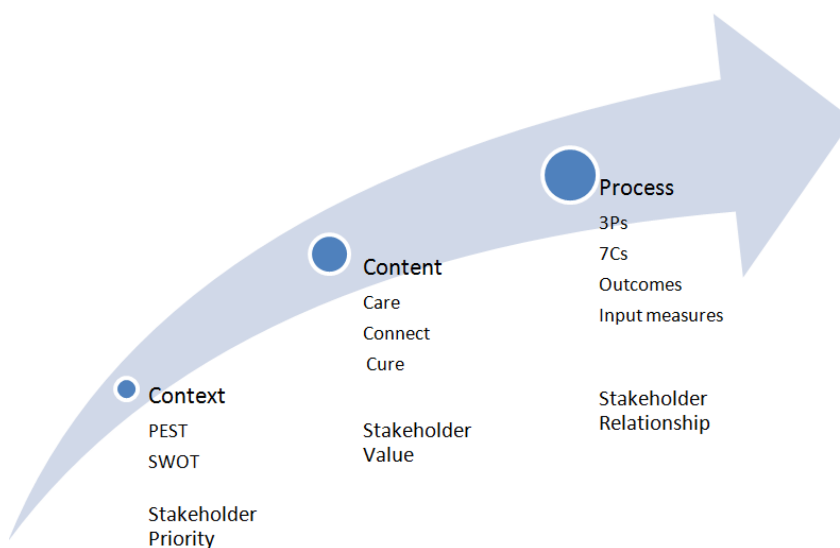


Figure 6.5 Overview of HCO Strategic Planning Process integrating stakeholder analyses

Table 6.2 below details the different stages in the planning process, highlighting key questions and considerations.

Table 6.2 Strategic Planning Framework incorporating Al Tabbaa, Leach and March's (2014) elements

Element	ANALYSIS	QUESTIONS	CONSIDERATIONS
CONTEXT	PEST ANALYSIS • Political • Environmental • Social • Technological	What political, environmental, social or technological conditions or potential changes might impact the HCO profile, purse or performance?	3 levels of government & responsibilities ACNC NDIS NHMRC Reviews Medicare Reviews PBAC submission schedule MSAC submission schedule
	SWOT EVALUATION • Strengths • Weakensses • Opportunities • Threats	What internal strengths and weaknesses might impact the HCO profile, purse or performance? What external opportunities and threats might affect the HCO profile, purse or performance?	7 Cs Funding cuts Collaboration Consolidation National vs Federated
	STAKEHOLDER ANALYSIS • Identification • Salience • Value • Networks	Who affects the creation of stakeholder value? Which stakeholder/s are most important to the HCO? How do they impact HCO success? How do they interact with other stakeholders?	See Table 5.3
CONTENT	STRATEGIC FOCUS • Performance • Profile • Purse	What does each stakeholder value & expect in terms of HCO Profile, Purse & Performance? What can each stakeholder contribute to HCO Profile, Purse & Performance? What can each stakeholder contribute to the HCO stakeholder network?	Stakeholder salience and utility Stakeholder networks and relationships
	OUTCOME MEASURES • Performance • Profile • Purse	How do stakeholders measure HCO success?	Expressed in terms of quality & quantity Quantify benefits & value
PROCESS	INPUT MEASURES • Internal Process • Process Velocity VA/(VA+ENVA+NVA) • Cost Benefit Analysis • ROI	To what extent are the 7 Cs evident? Is cost & effort to achieve success reasonable?	Expressed in terms of quality & quantity Quantify operational, management & marketing costs
	RELATIONSHIP MANAGEMENT PRACTICES • Stakeholder Network Analysis • Contemporary Marketing Practices (Coviello et al)	What's the strength of the stakeholder network & relationships? How do stakeholders interact with each other? How does the HCO engage & manage its different stakeholders?	Evaluate relevance & effectiveness

6.5 Identifying and analysing HCO stakeholders

'Strategic management of stakeholders entails not merely responding to stakeholders but guiding the stakeholders' expectations and their evaluations of the NPO (Kearns, 1996; Oliver, 1991; Romzek, 1996). By influencing expectations so that they are aligned with the non-profit's values, missions, and capabilities, non-profits enhance the likelihood of being perceived as responsive to stakeholder needs and the public interest, and therefore as effective organizations' (Balser and McClusky, 2005:297).

Table 6.3 presents a list of potential HCO stakeholders. While comprehensive, it is neither complete nor definitive, as stakeholders and their salience will vary depending on the interest at stake.

Table 6.3 Potential HCO Stakeholders

HCO Associates & Beneficiaries	Partners, Supporters Competitors, Gatekeepers	Funders, Payers, Donors, Benefactors	Institutional stakeholders
Members Consumers Healthcare practitioners	Other HCOs	Governments Politicians PBAC & MSAC Medicare (MBS)	Government Departments (e.g. Health Family & Community Services)
Employees	Research community	Donors	Department secretaries
Medical and Scientific Advisors	Primary Health Networks	Corporate Sponsors Pathology & Diagnostic Companies Pharmaceutical & Biotechnology companies	Research Institutes (e.g. Research Australia, TRI, QIMR, Garvan Institute, Menzies Institute, Walter & Eliza Hall Institute)
Board members	Local Health Networks	Users/consumers (e.g. NDIS, My Aged Care)	NHMRC National Health and Medical Research Institute of Australia
Advocates, spokespeople, celebrity champions	Professional and industry associations (e.g RACGPs, Medicines Australia, The Pharmacy Guild)	Celebrities & their managing agents	Universities (source of graduates, trainees, volunteers)
Volunteers & ProBono experts	Local Governments (Community centres & libraries)	Politicians	Schools (source of volunteers)
Volunteer agencies	Media	Local clubs	Non-profit suppliers

Table 6.4 provides an example of planning by stakeholder, incorporating content and process elements (Al Tabbaa, Leach and March, 2014) as stakeholder value, outcomes and inputs respectively, and including marketing relationship strategies.

Table 6.4 Sample Stakeholder Planning Framework incorporating stakeholder perspective

	CONTENT	PROCESS		
Stakeholder	Stakeholder Value	Relationship Management Marketing Strategies Engage & maintain	Outcomes (effectiveness & results) & the 3 Ps	Input Effort (efficiency, costs & enablers) & the 7 Cs
Consumers with condition	Information Support Social Capital	Social Media Print material in Medical practices	Satisfaction with services & support Reported value of services Membership renewals, referrals Accurate directory of treatment centres PERFORMANCE	Cost/effort to deliver services & manage relationships Effort to recruit, support & retain members CLARITY CONNECTEDNESS
Volunteer Advocates	Opportunity to contribute Recognition Social capital	Social media Family, social & professional networks Personal letter, email, telephone call Social Media Telephone	Recruitment & Retention rates Easy access to resources & materials Positive media mentions PROFILE	Time & effort to engage, support & develop volunteers Time & effort in managing media CONNECTEDNESS CAPACITY
Individual donors	Worthy cause Opportunity to contribute Feedback on how money spent Recognition	Social media Family, social & professional networks Personal letter, email, telephone call	Satisfaction with use of monies Satisfaction with reports Recognition of condition Number of positive media mentions PURSE	Time & effort in maintaining relationship CONNECTEDNESS CAPITAL
Medical practitioners	Guidelines Pathways Information for patients Support services Education Evidence based, endorsed guidelines	Practice Managers RACGPs expos PHN workshops Medical Liaison as member of team	Frequency of diagnostic tests Increase in medical practitioner requests for resources Referrals PERFORMANCE PROFILE	CONNECTEDNESS CREDIBILITY CONTRIBUTION
Medical researchers	Funds for research Access to patients as research participants Social capital (linking)	Introductions from Medical Advisors Organise conferences with scientific & general streams	PROFILE Recognition as peak body PERFORMANCE Planned outcomes achieved Research projects completed PURSE Funds available for research	CAPITAL Effort to recruit & support new research partners Cost to secure grants
Community sponsors & commercial partners	Legitimacy Support for commercial initiatives Commercial gain Product endorsement (e.g. Tick of Approval) Evidence of good corporate citizenship	Local chambers of commerce Human Resource Depts CSR Managers Sales & Marketing Managers	PROFILE Strength & utility of stakeholder networks Possible negative impact? PERFORMANCE Planned outcomes achieved PURSE Financial measures	CREDIBILITY Cost of negative community perception of relationship CREATIVITY Cost to secure sponsorship & maintain relationship
Pharmaceutical & Medical Technology sponsors/partners	Support for TGA & PBS submissions Participants for Clinical Trials Cause branding	Market Access teams Commercial Managers Clinical Trials Managers	PROFILE Strength & utility of stakeholder networks Possible negative impact? PERFORMANCE Planned outcomes achieved	CONNECTEDNESS Costs to maintain database of members Effort & cost of maintaining stakeholder network & relationships

Table 6.5 examines the HCOs participating in this research in terms of Kaplan and Norton's (1988) Balanced Scorecard Perspectives.

Table 6.5 Balanced Scorecard Perspectives identified in HCOs participating in research

Balanced Scorecard Perspectives		Value/Contributions	HCOA	HCOB	HCOC	HCOD
Stakeholders	Consumers	Information	✓	✓	✓	✓
		Support	✓	✓	✓	✓
		Services		✓	✓	
	Members & subscribers	Network				✓
	Board	Performance Goal Achievement		✓	✓	✓
	Patron/celebrity	Involvement			✓	✓
	Employees	Job satisfaction		✓	✓	✓
	Volunteers	Job satisfaction Social Capital	✓		✓	✓
	Governments	Policy Advice		✓	✓	
	Donors	Social Capital Acknowledgement	✓	✓	✓	✓
	Researchers	Research contribution	✓			
		Research participants			✓	✓
	Medical Professionals	Information	✓	✓	✓	✓
		Referrals	✓	✓	✓	✓
	Partners/Collaborators	Influence			✓	✓
		Capacity building		✓	✓	✓
	Sponsors	Reputation/Image		✓	✓	✓
		Consumer access			✓	✓
		Strategic focus	HCOA	HCOB	HCOC	HCOD
	Financial	Memberships & subscriptions	✓			✓
		Donations	✓	✓	✓	✓
		Sponsorships		✓		✓
		Government Funding & Grants		✓	✓	
		Fees for services		✓	✓	
		Bequests		✓	✓	✓
	Growth and Innovation	Social Capital	✓	✓		✓
		Intellectual Capital	✓	✓	✓	✓
		Sustainability		✓	✓	✓
	Internal Business Processes	Focus on Internal processes			✓	

Table 6.6 provides examples of how the seven mediators of success identified in this research are demonstrated, and outlines questions to ask when evaluating them.

Table 6.6 Mediators of success

Factor	Demonstrated as	What do we ask ourselves?
Clarity	Purpose, mission & vision, strategic plans, leadership, annual reports, financial reports, performance reports, role descriptions	Why do we exist? CURE or CARE or both? Does everyone who matters understand this?
Contribution	Value to stakeholders (see connectedness) through policy and provision of information, assistance, programs, services, support for research, policy advice	What difference do we make for members, for the medical community, for researchers, for the government for those who support us financially? Do they value this? What difference would it make if we didn't do this? Who else does what we do?
Credibility	Stakeholder confidence, consumer engagement, recognition as experts & peak organisation, sponsorship, participation in scientific conferences, reports & publications, accredited information & professional development modules, invitations to participate in consultations or present in conferences & forums, performance results, good governance	How do we best present information to our stakeholders? Who is our 'face' or 'voice'? What are the strengths of our Board members & CEO? Do we deliver on our promises? What research institutes or programs are we connected to? Who do we partner with? Are we aligned with other credible organisations? Which relationships enhance or detract from our profile? Do we have a medical or scientific advisory board?
Connectedness	Stakeholder relationships with consumers, alliance partners, governments as policy advisers & service providers, sponsors, donors, funders, research institutes, healthcare providers and practitioners, colleges of general and rural practice, primary health networks, local health networks, local community centres, consumer health forums, celebrities & their managing agents, pharmaceutical and biotechnology companies, DOHA, PBAC, MSAC, industry associations (e.g. Medicines Australia, the Pharmacy Guild), universities & schools	Who can help us make it happen? Why would they want to partner with us? How do we connect with consumers? What networks do we belong to? Do we engage in social media?
Capital	Human, social, intellectual, financial Volunteer availability, ProBono work, graduate, trainee & exchange programs	Who & what do we have to support us? Who & what do we need?
Capacity	Plan & processes Resources: available & transferable Infrastructure & systems Access to community facilities Access to volunteers Funds Sustainability: financial reserves	Do we have what we need to fulfil our mission? Where are there gaps (resources, skills, knowledge? How can we fill or work around gaps? What's the cost to deliver this service/project/information?
Creativity	Responsiveness, flexibility, adaptability, anticipation, learning	What do we need to do differently?

6.6 Measuring HCO success

This research revealed that reporting meaningful performance measures is of significant interest but also a considerable challenge for HCOs. There was some evidence of reporting outcomes in cases where programs and services were funded by the government, but little evidence of measuring inputs.

According to Kaplan and Norton (1998, p180), 'Success for government and not-for-profit organizations should be measured by how effectively and efficiently they meet the needs of their constituencies. Tangible objectives must be defined for customers and constituencies. Financial considerations can play an enabling or constraining role, but will rarely be the primary objective'.

A Results Based Accountability framework (Friedman, 1996) measuring effectiveness and efficiency is likely to become a requirement in the future for non-profit organisations seeking funding from government with the introduction of the National Disability Insurance Scheme (NDIS) and My AgedCare. Business partners will also be interested in measuring the return on their investment in HCOs.

Interestingly HCOA, the only completely volunteer run organisation, includes performance updates in their monthly management committee meetings. HCOA tracks membership growth, considered a reflection of stakeholder satisfaction as well as an important financial indicator since membership fees are the only regular source of income.

'You can judge its success if you have memberships or membership growth. You assume then that you must be doing something that your membership which may or may not be the general public, but that your membership needs or wants' (A1)

HCOA also tracks the number of calls to its national helpline and website hits as indicators of awareness, one of its key objectives, and records postcodes for every call to the helpline as an indicator of reach.

'Our success is showing in the number of calls we're getting and the increase in the awareness so we're getting there' (A3)

'We've got a new, a refreshed website that scores some substantial number of hits - unique hits - which apparently is quite significant'. (A1)

'*People, how they're coming to us, the span of places they're coming from is increasing which shows we're doing it'*. (A3)

Table 6.7 summarises some of the reported measures which include membership growth, continuing or increased funding, media mentions, service provision growth and evaluations, research grants, community recognition and feedback.

Table 6.7 Indicators of success

Success	Indicators	Measurements
PROFILE	Credibility Stakeholder confidence, profile, reputation, image, media cover, research partnerships, pathways,, policy changes, recognition as 'peak' organisation representing 'voice of the consumer', partnerships with industry sponsors, alliances with other groups Connectedness Clarity Recognised brand Acknowledged experts/peak body Known champions/advocates Accessible Clear Mission	• Growth in memberships • Increase in member donations • Progress to plan (goals achieved) • Results based accountability • Website hits/telephone calls to HelpLines • Money raised in promotional events/activities • GP interactions – referrals, requests for information • Submissions made
PERFORMANCE Care Connect Cure	Contribution Creativity Capital	• # treatments accessed
PURSE Financial sustainability	Capacity Resources: available & transferable; Infrastructure & IT systems, centralised, shared services, virtual office, local, state, federated, national organisations, outsourced support, volunteers Capital Financial reserves, cash flow, crowd sourcing, grants/donations/bequests, investment revenue, donor loyalty, sponsorships, corporate giving programs Contribution	• Return on Investments • Profit/loss statements • Growth in memberships, Increase in grants/funding (number/value), • Ratio of short term vs longer term grants

Summary

This chapter illustrates the development of a stakeholder strategic planning process and framework integrating key elements from the work of Knox & Gruar (2007), Frooman (2010), Garriga Cots (2011) and Al Tabbaa et al (2014) with the findings of this research presented in Chapters 4 and 5. The new 'CPC' model presented here offers a practical guide for HCOs interested in generating stakeholder social capital through the development and execution of a 'mission focused' plan.

CHAPTER 7: CONCLUSION

In the Introduction to this thesis I outlined the research process (Section 1.2) and the research outcomes (Section 1.4). I will reflect on each of these in retrospect as I conclude this thesis.

7.1 Research Sites

Four organisations were chosen to reflect the range and diversity of HCOs in Australia and their different purposes. Eisenhardt (1989) suggests that in case study research, 'while there is no ideal number of cases, a number between 4 and 10 cases usually works well' (1989:545). Since two of the four participating HCOs are federated organisations additional data was available from state member organisations, had there been problems reaching theoretical saturation. Two of the HCOs are federated organisations with professional salaried management teams; one is a national network of affiliated organisations supported by a highly organised national office and salaried executive, and the fourth is a small national group managed by 'grassroots' volunteers. The two federated HCOs provided the opportunity to enable multiple levels of analysis.

The selection of these HCOs has enabled insights from what could be considered as 'polar opposites' i.e. a highly organised professional federated organisation vs. a sophisticated network of small independent groups vs. a small national volunteer run organisation. "Given the number of cases which can … be studied, it makes sense to choose cases such as extreme situations and polar types in which the process of interest is transparently observable". (Pettigrew 1988 cited in Eisenhardt 1989:537).

While there is no external standard by which to evaluate effectiveness of NFPs/HCOs, this research has addressed to some extent, Herman and Renz's (1999) call to 'to uncover the bases that people use to form judgments of effectiveness' by being 'both situation specific and clever in securing responses to probing questions' (Herman & Renz 1999:119).

7.2 Reflections on the Research Process

The advice of Kathy Charmaz, in an interview with Graham Gibbs at the BPS Qualitative Social Psychology Conference in September 2013[1], to 'work with what you find' impressed me as a sensible and pragmatic approach to DBA research, suiting my way of thinking and the topic I chose to investigate.

In the process of conducting the research, I learned a great deal about making sense of what I saw, heard and felt intuitively by noting observations at the end of an interview, on the plane or train and listening and re-listening to recordings travelling in the car. One such observation reinforcing Charmaz's statement was the following comment I had made in an early interview with one participant in the research.

> *That's why it's good, semi-structured, because it's really full of surprises because things that you expect perhaps to hear, you don't. Things that you don't expect to hear, you do, and you think, "That's interesting. Where's that going to take me, and what does that mean?" (Me in conversation with A3).*

I found the most difficult task was not to code, sort and aggregate what I had heard. My previous experience as an English language teacher enabled me to do this reasonably efficiently. The most difficult data related issue for me was trying to separate my own thoughts from those of the people I was interviewing. Another more challenging task related to my concern over the quality of this work. It has been more than 25 years since I engaged in any serious academic work and I struggled with being in the 'academic' world. I wanted to make a practical contribution, which would be of value to HCOs and the past 3 years of connectedness to their world has reassured me that it is.

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[1] published Feb 4, 2015 at https://www.youtube.com/watch?v=D5AHmHQS6WQ.

7.3 Reflections on the Research Outcomes

As stated in the Introduction, my aim in this endeavour was to explore and illustrate what HCOs do, how they operate, and how they define success and its enablers, in order to develop a framework and tools for use in strategic planning and performance evaluation processes. This conclusion summarises the main ideas. My research set out to answer two main questions:

what does success mean for HCOs in a changing health environment, and why do some HCOs appear to be more effective than others?

I was guided by three basic questions identified in Anheier and DiMaggio's "road map" for non-profit sector research, *"Why do non-profit organizations exist? How do they behave? What impact do they have and what difference do they make?"* (cited in Anheier, 2005 loc 2879 of 12375). Anheier and Di Maggio's questions lead me to ask 'What do HCOs in Australia do?' and 'Who has an interest in what HCOs do and how they operate and perform?'

The answers to these questions are discussed in detail in Chapters 4 and 5 and. provide the theoretical and practical contributions of my research. Figure 7.1 summarises and illustrates these answers.

The answer I give to Anheier's first question, *why do they exist*, resides in the mission of HCOs participating in this study and are encapsulated in the top row as Care, Connect and Cure. These are discussed in the Section.7.4.

The answer to what success means for HCOs is found in the middle row and expressed as the 3 Ps: Performance, Profile and Purse. Finally, why some appear to be more effective than others or what enables them to be successful, is expressed as the 7Cs in the bottom row: Contribution, Connectedness, Credibility, Creativity, Clarity, Capital and Capacity. These are discussed in length in Chapter 5.

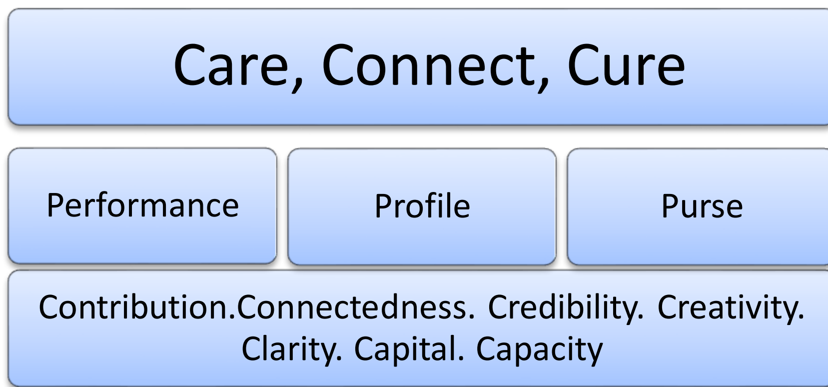

Figure 7.1 The CPC Model: Constructing success for HCOs

7.4 Mission at the core

In Chapter 5 I outlined a strategic planning process (CPC) which ensures stakeholder inclusion. Placing mission at the centre of the conceptual model helps focus HCO attention on 'who and what matters' in relation to the achievement of the mission, and should also mitigate the potential for 'mission drift'. Figure 2.4 is included here again as a reminder of these three missions and brief examples of each 'mission as focus' follow.

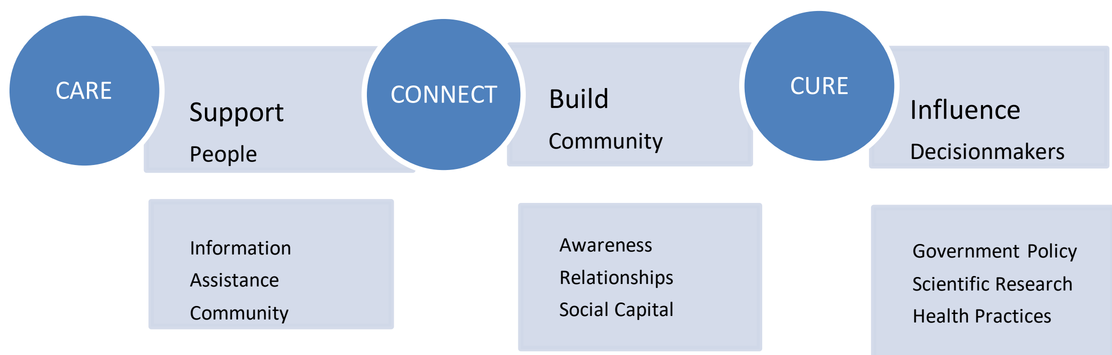

Figure 2.4 Roles of HCOs in Australia

7.4.1 Care

Service provision and information fall under the category of care and important stakeholders are individual consumers or patients, and healthcare practitioners. Changes in funding for service provision from government contracted services to consumer choice through channels such as NDIS and My Aged Care means HCOs now need to market their services directly to service users, establishing and maintaining close customer relationships with individuals and their carers. Some HCOs may already have an established 'client base' but may find they face competition for 'for profit' businesses entering the service provision market. In addition to providing services and information to meet the needs of individual consumers, HCOs need to produce and distribute print materials and online information valued by healthcare practitioners.

Stakeholders in Care:
Local medical practices, community health centres, treatment centres, Community Information Centres, local business networks and chambers of commerce, marketing and customer service professionals, Primary Health Networks, the colleges of general and rural practitioners, The Pharmacy Guild and other allied health professional associations

Stakeholder engagement:
Learn how consumer businesses and other service providers market their products and build customer loyalty.
Work with the relevant agencies to produce quality accredited information for healthcare professionals.

7.4.2 Connect

One of the key roles for HCOs is connecting individuals who share the 'lived experience', connecting them with others who can provide assistance or treatment, connecting medical practitioners and healthcare providers with support groups, and connecting up with other organisations and agencies to build capacity (e.g. people, spaces to meet, support services) and social capital. Ways of connecting include via local networks and support groups, telephone support lines, websites, social media (e.g facebook, twitter), professional online networks (e.g. LinkedIn), referral directories (practitioners, treatment centres, retailers, corporate sponsors).

HCOs benefit from belonging to networks and alliances, and from relationships with universities and colleges where opportunities to engage with medical and allied health students providing the consumer perspective in their programs or involving students in research and volunteer opportunities..

Stakeholders in Connect:
Other people with the condition, other HCOs, CHFs, local community centres, universities and colleges (e.g schools of medicine and health sciences), volunteer registries and agencies, politicians at all levels of government, local councils, local libraries, local medical practices and community health centres, primary health networks, local treatment centres

Stakeholder engagement:
Join cross sector professional networks (e.g CEOs, CFOs, CIOs, HR managers) or other HCO networks
Follow other HCOs, health agencies, research organisations on Twitter
Subscribe to organisations like Connecting Up, Pro Bono Australia and local community centres to receive alerts for events, workshops and seminars of relevance
Join HCO networks such as state and national consumer health forums and to receive alerts for DOHA submissions, seminars and workshops and invitations to participate in consumer consultations

7.4.3 Cure

Cure refers to a HCO's role in relation to support and advocacy for changes to health policy and practice, access to treatment, and for research. Activities that fall within this category include making submissions to DOHA and Medicare, through MSAC and the PBAC, supporting submissions to NHMRC, supporting and participating in clinical trials for new treatments.

Stakeholders in Cure:
Minister for Health, Aging and Sports, Department of Health and Aging, Department of Family and Community Services, pharmaceutical and biotechnology companies, other HCOs, NHMRC, PBAC Chair, MSAC Chair, local members of parliament, research institutes, key opinion leaders in therapeutic area.

Stakeholder engagement:
Register for alerts for DOHA submissions and invitations to participate in consumer consultations
Ask Medical Advisors for introductions to key researchers
Organise conferences with scientific & general streams
Share reports/scientific publications of interest

7.5 Observations

7.5.1 Future Forms

While the question of the best form of organisation was not asked directly, it underlies discussions of capacity.

‘I think it's very hard to say that it wouldn't be cheaper to have one organisation. It's cheaper, [it] doesn't mean it's better, you can easily go into a bureaucratic mode because of distance. But what would you lose in those relationships locally? (C1)

‘I think so many things are being nationalised and dragged into Canberra, things are being sucked up within national health, and Hospital Reform Commissions, and COAG changes, and Productivity Commission reports, and there's this trend of States becoming a bit irrelevant, it seems. Even disability is being nationalised in five years' time by the looks of it, so that has repercussions for us as well ‘ (B7)

My view coincides with that of A6,

‘Good people make a bad structure work, but bad people will not make a good structure work. So often I see organization absorbed by the issues of structure and really it will take them nowhere really anyway because either they're great people and they'll make it work regardless, or they don't have the skills to make any structure work’ (A6)

National organisations are joining up under broader umbrella alliances resembling health social movements, reflecting the movement across the three mission areas from Care through Connect to Cure.

Interestingly two interviewees in this study have since retired from their local roles to take up CEO roles with international HCOs and the trend towards national alliances is also evident in the international arena.

'I'm just thinking of all the Council of Social Services. They all have their NCOSSs, and VCOSSs, and QCOSSs, and an ACOSS. Cancer Council have their federation, Parkinson's, and all the other neurological organisations have State and a national, and then all of us get together under a neurological alliance of the six major neurological disabilities.' (B7)

7.5.2 Future Research Focus

Fertile grounds for future research lie at the intersection between HCOs and health social movements, building on the work of van der Zeijden (2000), Williamson (2007), O'Donovan (2007), Dill and Coury (2008), Van de Bovenkamp and Trappenburg (2010), Rabeharisoa and O'Donovan (2014), Britten et al (2014) and Borkmann and Munn-Giddings (2015). Research could explore the concept of connectedness across federated organisations, national organisations, pan-national organisations, international and global organisations and alliances.

Research in bioethics, genomics and personalised medicine (Triggle, 2004; Yarborough and Sharp, 2006; Swan, 2012; Terry 2013) also provide opportunities for further study on HCOs, as do developments in health sciences marketing (Stremersch, 2008; Stremersch and Van Dyck, 2009). Research to identify ethical challenges facing HCOs working with commercial interests, as they advocate for access to new therapies would be useful and could explore the concept of connectedness

Additional opportunities for future research include exploring the implications of the findings of this study, in particular in relation to how HCOs apply the frameworks presented here to their organisations and the impact of doing so; or investigating to what extent these mediating factors influence success. Other potential studies might explore the strength and value of stakeholder networks in primary healthcare in Australia, particularly in light of the establishment of Primary Health Networks.

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APPENDIX 1 Key Journals Accessed

Marketing:

European Journal of Marketing
Journal of Marketing
Marketing Theory
International Journal of Medical Marketing

Management and stakeholder theory:

Academy of Management Review
Journal of Business Ethics
Administrative Science Quarterly
International Studies of Management & Organizations
Journal of Business Research, Philosophy and Organization Theory

Non-profit organisations and social capital theory:

Nonprofit and Voluntary Sector Quarterly
Voluntas
International Journal of Voluntary and Nonprofit Organizations ISTSR
Nonprofit Management & Leadership

Health Social Movements and patient advocacy research:

Social Science & Medicine
Sociology of Health & Illness
Anthropology & Medicine
Advances in Medical Sociology
Health Expectations
Science, Technology & Human Values

APPENDIX 2 PABC Record of Consumer Hearings

Consumer meeting with Australian Melanoma Consumer Alliance (AMCA), Melanoma Patients Australia (MPA) and CanSpeak Australia.

The meeting covered the upcoming PBAC consideration of pembrolizumab. The March 2015 meeting will be the PBAC's first consideration for this drug for metastatic melanoma.

The following points provide a summary of the discussion between AMCA, MPA, CanSpeak Australia and the representatives of the PBAC:

1. Patients have a high level of belief in the effectiveness of pembrolizumab, and are extremely eager for early access to the drug. Perception of the drug is that it is seen as a significant advance, with better safety than alternatives. This is in the context of a predominantly younger patient group who are dealing with a very serious prognosis – these patients are willing to take risks with new treatments, and to find ways to pay for the drug if needed. In addition, these patients are very willing to participate in clinical trials but not necessarily in *comparative* clinical trials – they are not willing to risk not receiving the trial drug.
2. Consumers have a high level of concern about the equity of rules governing patient eligibility – ultimately, patients with melanoma would expect to have access to the drug regardless of any prior treatment they may have received.
3. The Department and the PBAC have accommodated to a significant extent the sponsor's requests to be able to provide the latest data at several points outside the standard process. This has included submission of hitherto-unseen clinical data and a revised economic model within days of the March PBAC meeting commencing.
4. The representatives informed PBAC that there is a perception that up to 90% of patients could expect to respond to pembrolizumab, even if this is not reflected in the data presented by the sponsor to the PBAC. Consumers also believe that the response to pembrolizumab is "durable and sustained". The PBAC was extremely concerned at the substantial mismatch between the public expectations of the drug and the data submitted in support of its subsidy application.
5. With regard to the high cost of this drug, consumers do not feel empowered to question or challenge how sponsors arrive at their asking prices. Patients are willing to go to great lengths to self-fund treatment, and will sell or mortgage their family home, hold fundraising events and access superannuation if needed.
6. The future of other treatments for melanoma, including ipilimumab, would need to be considered. It is not clear whether patients would expect to be able to access ipilimumab should pembrolizumab fail – patients believe that the development of these drugs represents new options that simply were not available until recently.
7. It was noted that patients believe that the risks associated with early access to this drug was accepted by many, because of the perception of gaining a life-saving response.

APPENDIX 3 Information for research participants

Invitation to participate in research into Health Consumer Organisations

Dear (insert name of HCO Executive),

As a well recognised HCO I believe the (submit name of HCO) could provide valuable insights into what makes your group and others like it successful and invite you to participate in research I am undertaking as a Doctor of Business Administration student at the Sydney Business School, University of Wollongong. The purpose of my doctoral research is to identify factors critical to the success of Health Consumer Organisations (HCOs). On completion of this research I hope to develop a framework for self-assessment and evaluation which can be used by Health Consumer Organisations seeking to enhance their performance, and by external stakeholders with an interest in HCOs.

The research will be based on case studies of several HCOs which have been selected to participate on the basis of the level of public awareness of the group, its profile, national presence and cover, and length of time established. Semi-structured interviews will be conducted with group leadership and advisory board members, and key documents such as mission statements, websites and annual reports will be reviewed. Input from external stakeholders with an interest in HCOs, such as industry organisations and umbrella groups will also be included in the data analysis.

If your organisation agrees to participate I hope to interview each member of the executive leadership group and advisory board individually and seek your help in recruiting interviewees. Each interview is likely to take up between 30 and 60 minutes. During these interviews I will explore questions such as why people belong to HCOs, what the interviewee considers success to be for these groups and why some are more effective than others. In addition to these interviews I am requesting access to documents such as the mission statement and strategic plan for your organisation, and its annual report. In order to protect the privacy of all participants only de-identified data will be used when reporting the research outcomes.

This research is being supervised by Professor John Glynn, Dean of the Sydney Business School and Associate Professor Gary Noble, Sydney Business School, University of Wollongong. If you have any questions about the research and your participation you can contact me or Professor John Glynn (jglynn@uow.edu.au or tel: 61 2 4221 5779). If your organisation agrees to participate, please call or email me. See below for contact details. If you have any concerns or complaints regarding the way the research is or has been conducted, you can contact the Ethics Officer, Human Research Ethics Committee, Office of Research, University of Wollongong on 4221 4457.

I look forward to hearing from you and would appreciate your response by the end of next week. I'd like to thank you in anticipation of your participation! All participating stakeholders will receive a copy of the full report which I hope will be useful for HCOs seeking to enhance their performance, and by external stakeholders interested in HCO effectiveness.

I look forward to working with you on this research.

Dianne Prince

DBA Candidate, Sydney Business School

APPENDIX 3 Information for Research participants cont

RESEARCH INFORMATION

As a Doctor of Business Administration student at the Sydney Business School, University of Wollongong, I am undertaking research on Health Consumer Organisations (HCOs). The purpose of my research is to identify factors critical to the success of Health Consumer Organisations. On completion of this research I hope to develop a framework for self-assessment and evaluation which can be used by Health Consumer Organisations seeking to enhance their performance, and by external stakeholders with an interest in HCOs.

The research will be based on case studies of several HCOs, drawing on interviews with group leadership and advisory board members, and reviewing key documents such as mission statements, websites and annual reports. HCOs are being invited to participate on the basis of public awareness or profile, national presence and cover and length of time established. Input from external stakeholders with an interest in HCOs, such as industry organisations and umbrella groups will also be included in the data analysis.

This research is being supervised by Professor John Glynn, Dean of the Sydney Business School at the University of Wollongong and Associate Professor Gary Noble, Sydney Business School, University of Wollongong. If you have any questions about the research and your participation you can contact me Dianne Prince (dmp945@uow.edu.au or dianne.prince@brydi.com), tel 0418 494 113) or Professor John Glynn (jglynn@uow.edu.au or tel: 61 2 4221 5779). If you have any concerns or complaints regarding the way the research is or has been conducted, you can contact the Ethics Officer, Human Research Ethics Committee, Office of Research, University of Wollongong on 4221 4457.

INVITATION and CONSENT to PARTICIPATE

As a leading member of a well recognised Health Consumer Organisation I believe you could provide valuable insights into what makes your group and others like it successful and invite you to participate in this research. Participating would mean making yourself available for a semi-structured interview which I anticipate could take up to an hour. The interview will seek answers to questions such as why people belong to HCOs, what you consider success to be for HCOs and why some are more effective than others.

If you consent to be involved your personal details will be kept separated from your interview data and comments you make or opinions you express during the interview will not be attributed to you. Only de-identified data will be used when reporting the research outcomes so as to protect the privacy of all participants. Your participation in this research is completely voluntary and you are free to withdraw at any time. Rather than taking extensive notes while we are talking I would like to audio-record our discussion and will seek your consent to do this before we start the interview. However if you prefer not to have the interview recorded I will need to make notes and may need to contact you afterwards when reviewing what I wrote to clarify something.

If you agree to participate in this research and consent to the information collected during your interview to be published in a research thesis and related academic publications please sign the consent form attached and return to within the next week. On receipt of your consent I will be in contact to arrange a time and place for your interview.

Thank you in anticipation of your participation!

University of Wollongong Consent to Participate in Research form removed for privacy reasons

APPENDIX 3 Information for Research participants cont

Questions for semi-structured interviews

1. How does your organisation engage with HCOs?
2. Tell me where your organisation sees HCOs in the Australian healthcare environment. What's their role/purpose?
3. Does your organisation have a position or policy on Health Consumer Organizations (HCOs)? Tell me more about this.
4. Which HCOs would you/your organisation say are most effective?
5. What makes this/these HCOs successful?
6. What do they do well?
7. What could they do better?
8. What's the future for HCOs in Australia?
9. What sort of structure/governance etc should they adopt?
10. What's the place for national /international alliances of HCOs?

Thank you for your time!

APPENDIX 4 CHF Projects

https://www.chf.org.au/current-projects.php; https://www.chf.org.au/completed-projects.php accessed 23/10/2015)

Current projects
Real People; Real Data
The *Real People; Real Data* project will develop and pilot a cost-effective and easy-to-use tool for capturing and analysing consumer narratives of health, illness and the health system. The aim is to equip health services and consumers with a relevant and practical tool that can assist them to gather and assess consumer stories, and use this often-overlooked evidence base to inform decisions about health services, policies and reforms.

Completed projects
Community Quality Use of Medicines and Medical Tests (CQUM/MT) Project 2011-12
CHF began working in collaboration with *NPS: Better Choices, Better Health (NPS)* in 2000 to provide a consumer perspective on issues relating to the quality use of medicines (QUM). CHF welcomes the opportunity to continue working with the NPS and is now working on the 2011-12 Community Quality Use of Medicines and Medical Tests (CQUM/MT) Project.

The Medical Benefits Policy Project 2012 – 13
The Medical Benefits Policy Project 2012 – 13 is funded by the Department of Health and Ageing. The project aims to maximise opportunities for consumer perspectives to be adequately and effectively incorporated within the work of the Department's Medical Benefits Division (MBD).

The project will have a particular focus on the Medical Benefits Schedule (MBS) and private health insurance.

Review of Chemotherapy Funding Arrangements
CHF has been funded by the Department of Health and Ageing to consult with our members on the Review of funding Arrangements for Chemotherapy Services. The initiation of the Review followed talks between the Government and the Pharmacy Guild of Australia over appropriate subsidies for dispensing chemotherapy after the reduction in the PBS subsidy for a key chemotherapy drug, Docetaxel.

Diagnostic Imaging and Informed Consent
As part of the Commonwealth Government's Diagnostic Imaging Quality Program, the Department of Health and Ageing has funded CHF to inform and consult with healthcare consumers about current diagnostic imaging practice.

Facilitating consumer input to the PCEHR
CHF receives funding from the National E-Health Transition Authority (NEHTA) to facilitate consumer input to the national eHealth record. The aim of this project is to support health consumers and other community members engagement in the implementation of personally controlled electronic health records (PCEHR), and to keep them informed about the progress of the program.

Australian Health Practitioner Regulation Agency: Working in Partnership to Engage with the Community
CHF began working with the Australian Health Practitioner Regulation Agency (AHPRA) in August 2012 to build and sustain effective community engagement with health practitioner regulation and the National Scheme.

Provision of Consumer Input into Health Workforce Australia's Initiatives and Programs: 2012-13
CHF began working with Health Workforce Australia (HWA) in March 2012 to facilitate consumer engagement across a range of HWA projects and support consumer representatives on HWA Project Advisory Groups.

APPENDIX 4 CHF Projects cont

Provision of Consumer Input into Health Workforce Australia's Initiatives and Programs: 2013-14
The *Provision of Consumer Input on Health Workforce Australia's Initiatives and Programs Project*, funded by Health Workforce Australia (HWA), aims to provide CHF with the capacity to contribute to the work of HWA and to ensure that consumer input is provided on HWA's initiatives and programs.

Consumer Guide to Clinical Trials
CHF has recently released a factsheet for consumers providing information on clinical trials. The factsheet, which was developed by CHF with funding from the Department of Innovation, Industry, Science and Research, aims to provide consumers with a basic understanding of clinical trials, including the benefits and risks of participating in a clinical trial. It was released formally at the Joint Medicines Policy Conference on 30 August 2011.

Joint Medicines Policy Conference 2011 - Pre-conference consumer workshop
On Monday 29 August 2011, prior to the Joint Medicines Policy Conference, Medicines Australia and the Consumers Health Forum (CHF) will be co-hosting a pre-conference consumer workshop, *Medicines, Health Technologies and Reform.* This workshop will aim to:

- Consider recent health reforms and the review of health technology assessment
- Explore the importance of collaboration in the development and implementation of reform
- Identify consumer issues to take forward to the Joint Medicines Policy Conference.

Personally Controlled Electronic Health Records (PCEHR) Project
Through this Project, CHF will be engaging its members and networks on the consumer issues associated with the development of the PCEHR system planning, implementation and other eHealth initiatives.

Private Health Insurance Policy Project 2010-11
This project aims to facilitate ongoing consumer input to the development and implementation of private health insurance government policy and to develop and disseminate improved consumer information in relation to private health insurance and the Prostheses List.

Our Health, Our Community Project
During the 2010 election campaign, the Minister for Health and Ageing announced funding over three years for CHF to train and support a network of 120 consumer representatives to contribute to the governance structures of the National Health and Hospitals Network.
The Project involves four stages to build and sustain effective community engagement with health reform through health consumer activities consisting of:

- Interactive Consumer Health Platform
- Consumer communication and engagement strategy
- Recruitment and training of 120 health consumer representatives
- Ongoing support and engagement.

Consumer Impact Statement - intermittent claudication 2011
CHF has been contracted by the Department of Health and Ageing to develop a Consumer Impact Statement for the Pharmaceutical Benefits Advisory Committee (PBAC) on intermittent claudication. Intermittent claudication is pain or cramping in the lower leg due to inadequate blood flow to the muscles, caused by poor oxygen supply due to a temporary narrowing of the arteries that supply the leg with blood. It is most commonly associated with peripheral arterial disease, and is more common in people with high cholesterol, high blood pressure and diabetes, and people who smoke or are overweight.

Fifth Community Pharmacy Agreement Consumer Consultation Project 2009-10
The objective of this Project is to facilitate consumer consultation about the Fifth Community Pharmacy Agreement and provide input to inform the negotiations between the Pharmacy Guild of Australia (the Guild) and the Department of Health and Ageing (DoHA). The project also aims to provide consumer input to strategies for implementation following the finalisation of the Fifth CPA.

Quality Use of Diagnostic Imaging Consumer Consultation Project 2010
CHF has been funded by the Commonwealth Department of Health and Ageing (DoHA) with guidance from the Quality Use of Diagnostic Imaging (QUDI) Program to undertake consumer consultation on diagnostic imaging. CHF has been asked to provide consumer views on their experiences with diagnostic imaging in order to develop and improve current diagnostic imaging practice and ensure consumer-focused, accessible and coordinated services that promote informed choice and meet consumer needs, and which are affordable for all Australians.

The Medicare Benefits Schedule (MBS) Quality Framework Project 2010
Consumers Health Forum of Australia (CHF) has been asked by the Department of Health and Ageing to engage, inform and consult with CHF members to ensure consumer perspectives are adequately and effectively represented for consideration in the development and implementation of a new MBS Quality Framework.

Acute Care Policy 2009-10
This project aims to provide a mechanism to facilitate consumer consultation on private health insurance reforms announced in the 2009-10 Budget, and to provide consumer input to the development of reforms to acute care policy and systems. The project will consider areas including the implementation of private health insurance incentive tiers, the National Health and Hospitals Reform Commission Report, the development of new registries, the Private Health Insurance Ombudsman's website www.privatehealth.gov.au, prostheses issues and other policy input and communication.

Chronic conditions self management project 2008-10
Chronic conditions can affect anyone, but disproportionately affect disadvantaged members of our communities, which heightens health inequalities already experienced in Australia. Consumers with chronic conditions may find themselves needing to forgo basic services and needs, such as heating, food and medicines, in order to pay for the substantial out of pocket costs of their health care.

Community Quality Use of Medicines (CQUM) Project 2010-11
The project aim is to promote better understanding of health issues and effective health decisions by and/or in relation to Australian consumers.

Quality Use of Pathology Project 2009-10
This project seeks to engage, inform and consult with CHF members about current pathology practice. It will establish an evidence base through consumer consultation to identify consumer issues, including gaps and opportunities and facilitators and barriers to quality use of pathology, and suggest strategies that would make the pathology experience more appropriate for consumers.

Community quality use of medicines project 2008-09
The Community Quality Use of Medicines (QUM) Project 2008-09 supports health consumer organisations and other community groups to obtain this information and help people with chronic conditions share strategies about safe and appropriate use of medicines and talk about their information and support needs. The project will assist support groups and organisations to network with each other about QUM.

Consumer Participation in the Review of Health Technology Assessment in Australia 2009
This project aims to provide consumer input to the Review of Health Technology Assessment (HTA) in Australia. Consumers recognise the importance of having HTA processes that expedite Australians' access to safe, high quality health technology; are economically sustainable; and protect the Australian public through robust event reporting and post-marketing surveillance.

Shaping the Health Workforce 2008-09
This project will involve consumer networks in the implementation of the Intergovernmental Agreement for a National Registration and Accreditation Scheme (NRAS) for Health Professionals, which has significant implications for improved safety and quality for consumers. CHF has been involved in workforce issues since its inception in 1987.

APPENDIX 4 CHF Projects cont

E-health for consumers project 2006-08
A key emphasis of the project was to involve and encourage consumers to participate in creating a demand for e-health initiatives that enabled them to be active partners in their own health.

Private health insurance reforms – Consumers have a say 2007-2008
The project aimed to raise awareness and gauge the impact of the legislative changes to private health insurance among health consumer organisations and their networks and consult them on key issues related to the implementation of the legislation.

Safety and quality project 2007-08
The project involved health consumers seeking improvement in safety and quality in health care through opportunities arising from a work plan of the Australian Commission for Safety and Quality in Health Care.

Community quality use of medicines project 2005-07
The project aimed to support consumer engagement, participation, consultation and capacity building within the National Prescribing Service (NPS) Community Quality Use of Medicine (CQUM) program.

Consumer representatives training and support project 2005-07
The project aimed to ensure that the views and interests of health consumers were represented in national health policy development through recruiting, supporting, training and coordinating consumer representatives for national committees.

Private health insurance reforms – Consumers have a say 2006-2007
The project undertook broad consultation with a range of health consumers across Australia to inform CHF input into the proposed reforms to private health legislation.

Electronic health records project 2005-06
The project's aim was to help CHF identify consumer priorities for further work to ensure that electronic health records would contribute to safe good quality healthcare.

Community quality use of medicines project 2003-05
The project supported consumer engagement, participation, consultation and capacity building within the National Prescribing Service Community QUM Project by supporting and working collaboratively with NPS staff, CHF members and related community organisations.

Consumer Representatives Training and Support Project 2004-05
The project provided a program of training and support for approximately 100 consumer representatives who sit on approximately 200 Departmental or Ministerial appointed committees or other national health groups and are involved in the CHF Consumer Representatives program.

Electronic health records project 2004-05
The project sought to improve communication with health consumer organisations about electronic health records which will contribute to consultative processes in relation to consent, electronic security and privacy.

Research project 2004
The project developed a model framework for collaboration between researchers and consumers by working with two pilot sites from research institutions where there is an interest in and commitment to building stronger partnerships between consumers and researchers.

Consumer Forum on the Draft Personally Controlled Electronic Health Records Legislation
In October 2011, CHF received funding from the Department of Health and Ageing to deliver a consumer forum on the exposure draft legislation for the Personally Controlled Electronic Health Records (PCEHR) system.

APPENDIX 5 Examples of Pharmaceutical company support for HCOs

Advocacy Development
Sponsored the *Inaugural Supportive Care Leadership Conference- Leaders in Supportive Care: Linking us Together.*
Corporate sponsorship to support their advocacy, education and research programs which provide support to patients with bleeding disorders and their families
An unrestricted grant to support pain education, awareness and advocacy activities relating to Pain Australia's objectives.
An unrestricted donation to support education, advocacy and research activities undertaken by HFA according to HFA objectives
Grant to support formation of Diabetes Australia Youth Ambassador Program – registration at IDF World Diabetes Congress
Positive Speakers Bureau 2013: Speaker talks (30) and speaker professional development workshops (2)
Financial support of patient advocacy and support programs
Funding of national advocacy coordination & communications programs.
Novartis partnered with another pharmaceutical company to provide funding for ZEST to develop and host an education weekend for Health Consumer Advocacy Organisations. All agenda content and speakers was developed by a steering committee involving three HCOs.
IDF Parliamentary Diabetes Champions
provided funding for the Vision and Leadership Awards ($10,000.00); provided funding to the HFA Melbourne Congress Education Fund to support people affected by bleeding disorders to attend the World Congress ($20,000.00); and for a number of education and disease awareness activities to raise community understanding of haemophilia ($40,000.00) by: Advocacy and representation that improved access to treatment and care for people with bleeding disorders; Education and peer support activities that increased independence and the quality of lives of people with bleeding disorders and their families; and Encouraging clinical excellence in haemophilia care and research.
Financial support for the National Advocacy Training Workshop
Support to enable the patient group to pursue its stated objectives - Parliamentary Champions Diabetes Forum. Grant
To support objectives to enhance the quality of Life of Children with Rare Diseases in Family Relief, Case Management Service, Research and Advocacy and Awareness.
Funds donated to support the Youth Leadership Epilepsy Camp
Grant to Arthritis Australia from the Medicines Australia Community Chest towards a key project that will support the advocacy work of Arthritis Australia.
Event partnership with AIDS 2014 Melbourne Youth Force meeting
HIV Positive Speakers Bureau
Community Advocacy Project
Attendance at American Chamber of Commerce luncheon 28/5/14 (1 representative)
Attendance at post-Budget breakfast briefing (2 representatives) 15/5/15

Lundbeck was a co-sponsor (with Janssen) of an event organised by patient advocacy groups with the Parliamentary Friends of Mental Illness in Parliament House, Canberra on the topic of caring for someone with a mental illness. This was a breakfast meeting and included launch of "My National Voice", a new online resource for carers Australia wide, enabling them ot tell their stories to the wider community
Financial support of patient advocacy and support programs
Financial support of patient RAS brochure, bowel cancer atlas and Parliamentary Event.
This funding supported an event to facilitate consumer groups already in Melbourne attending the World Cancer Congress and Clinical Oncology Society of Australia Meetings to come together to discuss the current issues facing access to cancer medicines in Australia. It also provided an opportunity for HCOs to hear a preliminary report on the findings of a survey of consumer groups exploring consumer positions on issues related to consumer input into the regulatory review of medicines in Australia. This was a co-funded event with additional funding provided by several other pharmaceutical companies.
This funding supported an educational workshop 'Health Consumer Advocacy' to facilitate linkages and capacity building between small health consumer organisations. The two day workshop program, developed by a Steering Committee comprised of CEOs of four health consumer organisations, focused on capacity building and knowledge sharing for small health consumer organisations. In addition expert speakers presented information on processes for consumer in put into the regulation and review of medicines in Australia as well as updates on using social media to assist the flow of information between consumers. A workshop report was provided to all attendees. This was a co funded event with funding provided by six pharmaceutical companies as well as an IT company. One representative from each sponsor company was invited to attend the 2 day workshop.
This funding supported the launch of a report – 'Advanced Melanoma, The Real Cost of Australia's National Cancer'. The report, conducted by KPMG and commissioned by MPA, assessed and analysed the financial and non-financial burdens of melanoma in Australia. To ensure the findings were available to Australian's, MPA sought funding to support a public launch of the report at an event in Parliament House Canberra in October 2014. The funding covered the costs of booking a meeting room at parliament house as well as printing and distribution of copies of the report.
This funding supported the logistics and media services required by Melanoma Patients Australia to launch the Report – 'Advanced Melanoma, The Real Cost of Australia's National Cancer'. The launch was conducted as a breakfast event at Parliament House Canberra in October 2014. The additional elements included the services of an experienced external public affairs agency to coordinate logistics and draft materials for media outreach during and after the event. This ensured the findings of the report were available to Australian's, gaining exposure and increased awareness about the report and the associated impact of melanoma in Australia.
This funding supported a workshop for MPA facilitators already in Melbourne attending the Clinical Oncology Society of Australia conference. The workshop, conducted by an expert facilitator, assisted participants in building skills to articulate the patient perspective on important issues affecting them, for example, prevention of melanoma, the importance of a timely diagnosis as well as the continuing need for improved services and programs for people with melanoma and their carers. This was a co-funded event. Additional funding from other pharmaceutical companies was also sought by MPA for this event.

This funding assisted the acting CEO of Melanoma Patients Australia who was already travelling to Zurich to attend an International Melanoma Coalition Meeting, to stay on in Zurich and attend an additional Melanoma Research Conference. The funds contributed to part-payment of the registration and accommodation linked to the Melanoma Research Conference. Attendance at the additional conference provided MPA with valuable insight into melanoma treatment and research as well as an opportunity to build their global network to assist them in their role of advocating for and providing services to Australians with melanoma and their carers.
Support for Patient Advocates Meeting
Lung Foundation Australia supports all aspects of lung health from asthma to cancer to COPD, through research, the development of educational fact-sheets, training health professionals, and undertaking community awareness activity and advocacy around Australia. Pfizer Australia provided funding to support the Lung Cancer National Program over the period of November 2013 to November 2014.
Haemophilia Foundation Australia represents people with haemophilia, von Willebrand disorder and other related inherited bleeding disorders and their families through advocacy and representation, education and research. Pfizer Australia provided funding to support (i) the 17th Australian & NZ Conference on Haemophilia & Related Bleeding Disorders ($29,000); (ii) the Vision & Leadership Awards ($10,000); and (iii) the Pfizer Haemophilia Nurse Awards program, Haemophilia Awareness week and other awareness and peer support initiatives ($45,000).
Rare Voices Australia is Australia's national alliance advocating for those who live with a rare disease. Pfizer Australia provided funding towards a suite of activities supporting public policy advocacy and funding for rare diseases.
The Skin & Cancer Foundation Australia is dedicated to benefiting those who suffer from diseases of the skin. Pfizer Australia sponsored the following events on behalf of Skin & Cancer Foundation: the 2014 Bio Masterclass ($3,000) and the 2014 Gala ball and Health Skin Awards ($2,727). Pfizer Australia also provided funding to support two continuing professional development programs for dermatologists, registrars and dermatology nurses ($6,000).
Health Consumer Advocacy 2014 workshop. Support for running the workshop in partnership with several pharmaceutical companies to facilitate improved advocacy skills amongst patient organisations from several disease areas (August 2014).
Supporting Rare Cancers Australia to develop and promote a policy brief addressing key shortcomings facing Australians with rare and less common cancers.
Support towards the patient group's meeting(s)/seminar(s) - Australian Parliamentary Breakfast Sponsorship
Grant to support formation of Diabetes Australia Youth Ambassador Program – registration at IDF World Diabetes Congress
MSD provided a grant to Hepatitis Victoria to support their HEPATITIS CHAMPIONS Project, which has the following objectives: To increase awareness of hepatitis C and B as a public health issue To increase access to testing for people at risk of hepatitis C and B To increase access to treatment for people affected by or at risk of hepatitis C and B
Support to enable the patient group to pursue its stated objectives - Parliamentary Lunch to raise awareness of rare diseases in Australia and the need for a national rare disease plan.Sponsorship
Sponsorship Grant to assist RVA with their aims of presenting a unified voice for Australians living with a rare disease.

APPENDIX 5 Examples of Pharmaceutical company support for HCOs cont

Patient education & support materials
An educational Grant to enable Arthritis Australia to update and reprint a series of four patient booklets, encompasssing "10 Steps" and three versions of the Arthritis Australia "Taking Control" patient educational booklet series (AS, RA, PsA)
Sponsored MS Societies by funding them to provide support services for people with MS . This the provision of education and resource materials
Provided disease awareness materials about living with HIV.
Educational grants supported a project to develop, translate and distribute a factsheet about stroke in several community languages
Printing of a Myelodysplastic Syndromes Patient Booklet
An unrestricted educational grant of fixed value to support the production of education materials for people with primary immune deficiency
Grant to support 2014 Oncology diaries – printing and distribution
Treatments Publication and education
Kidney Health Australia Sponsorship for Patient Information Project
Support for activities listed in the agreement .including training, community awareness, website development, material development, patient rehabilition support.
10 Steps for Living Well With Arthritis booklet
Printing: *Myeloma, A Concise Patient Guide*, 2012 edition - 1,500 copies
Funds to support print and development of 'Cure our Kids' Oncology Diary for 2014.All content developed exclusively by Cure our Kids.
Funds to produce 30,000 Amsler Grids in October 2013 to help patients with the detection and progression of wAMD
Funds to produce 20,000 Macular Degeneration A4 booklets in November to assist patients with their condition
Funds to produce 10,000 Macular Degeneration A4 booklets in May to assist patients with their condition
Funds to produce 15,000 Amsler Grids in March 2013 to help patients with the detection and progression of wAMD
Design & printing of the 'Blue Book' - an educational resource for people with parkinsons disease
Funds to print and development of written materials and website for World NET Awareness Day campaign;
Unrestricted Educational Grant to fund the Foundation Website and Educational Events Literature
Sponsored the production of a booklet titled 10 Steps for Living with Arthritis
Provided funding towards the development of a patient eBook on JIA.
Funding to develop a phone 'app' and emergency wallet/purse card for people with rare diseases which directs clinicians to the OMIM (Online Mendelian Inheritance Man www.omim.iorg) listings.
Financial support for redevelopment of arthritis booklet