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RECONFIGURING NATIONAL SCIENCE AND RESEARCH SYSTEMS: THE ROLE OF CHARITIES

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Abstract

We have become familiar and comfortable with the idea that the science, technology and innovation (STI) system of countries is constructed around the so called 'triple helix' of government, universities and business. Contrary to the academic interest and government policy, the public is increasingly bypassing this club to impact science funding and innovation outcomes through directly creating and donating funds for research that they want. The charities and foundations coordinating this shift are neither ignorant of strategy or dealing in petty cash. In a significant number of OECD countries, private-non-profits as the statistical category is called, fund the higher education research system at a similar or greater level than business. This result has important implications for how we understand the STI system. This paper explores this gap in the literature, ambiguities in analyzing the phenomenon and suggests a framework for further analysis how charities and foundations are reconfiguring STI systems.

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We have become familiar and comfortable with the idea that the science, technology and innovation (STI) system of countries is constructed around the so called ‘triple helix’ of government, universities and business. Contrary to the academic interest and government policy, the public is increasingly bypassing this club to impact science funding and innovation outcomes through directly creating and donating funds for research that they want. The charities and foundations coordinating this shift are neither ignorant of strategy or dealing in petty cash. In a significant number of OECD countries, private-non-profits as the statistical category is called, fund the higher education research system at a similar or greater level than business. This result has important implications for how we understand the STI system. This paper explores this gap in the literature, ambiguities in analyzing the phenomenon and suggests a framework for further analysis how charities and foundations are reconfiguring STI systems.

1. Introduction

According to Statistics Canada (2013), in 2012 “private-non-profit” institutions, which are usually thought of as “charities and foundations¹” (C&Fs) funded about 3.5 per cent of R&D in Canada, the highest point since the beginning of R&D statistics in the early 1960s. Contrast this with the provinces that contribute about 5% of GERD while the Canadian Institutes of Health Research (CIHR) is 3.5% of the total. More striking is that C&Fs fund more research in the universities than the business sector. As we show in section three (below) this is not exceptional in OECD countries. C&Fs appear to be a fast growing R&D funding sector in the Canadian economy. Furthermore contributions from C&Fs apparently have a strong influence on funding decisions made by others, particularly the federal granting agencies.

Given the number of health charities, particularly those that involve the general public through participatory events such as walks, runs, cycle-thons, (coupled with the associated media coverage) that result in donations to disease/condition specific research funds this topic should surely be one of interest to investigators focussed on the governance of research systems. But surprisingly, the entire non-profit sector, not just the health C&Fs community, has been largely overlooked for its role in national research systems. Nason (2007: 16) in a commentary on the Canadian medical research system expresses the lack of interest well “as the not-for-profit and international sectors are small in terms of funding within the Canadian health research system, they will not be covered in detail”. Leaving aside the poor analysis for the moment, contrast that assessment with Picard’s (2010) reporting that shows that in a recent poll of Canadians a very

¹ A defineable subset of the broader category of non-governmental organisations. Statistics Canada and other countries in the OECD use the term “private, non-profit organizations” solely for research activities.

high percentage supported increasing support for health and medical research. It seems support, is not merely a wish but acted upon out of their own wallets (see Fig 2 for time series from 1996-2010). There therefore a powerful dissonance between the public and policy discourses.

Science, technology and innovation studies have focussed on the role of the three institutional silos of business, government (funding and labs) and universities. The public's involvement as stakeholders in setting research priorities has been overlooked. Their money donated to a C&F for research, whether for health or other research (for example, endangered species), represents a direct expression by members of the public of what they wish to see as research priorities. Within the modern research system that has evolved in Canada other OECD countries; what is the role of the non-profit sector, and why do they succeed in some but not all countries? How much influence do they have on the allocation of research resources?

This paper can not address all these fundamental questions. With the overall lack of landmarks our work is focussed on creating a set of 'road maps' to the sector's involvement in the research sector, both where it directs its funding and how it tries to tilt the playing field in its interests while others attempt to do the same in other directions. The key point behind this paper is to show first that the non-profit sector in some countries is a significant and growing funder of research, second to highlight the complex relations between the organisations and the science, technology and innovation systems of nations and third to map out some important research questions for focussed future work.

2. Literature

In searching through academic literature in research policy, industry and innovation and equivalent journals there are few papers that focus on the role of private non-profits as the Frascati manual (OECD 2002) calls charities and foundations. In the early 1970s the OECD published a three volume synthesis of the state of knowledge on the STI systems of member countries. This document in part reported:

At first sight it is not easy to grasp how these foundations fit into the research system. It is hard to see what objectives even those that are world famous have set *themselves and what effective part they play in furthering research. ... What future can they have, now that the euphoria of the of the post-war years is over, when it is common knowledge that research costs nowadays are mounting ever higher, and that even the vast resources of a national budget are no longer adequate? Has the era of private research come to end? And if there is still an independent sector, is it not wasteful to allow programmes which are bound to be costly to escape national planning at a time when we seem to be entering a period of scarcity (Flory 1973:162)?*

Roughly 30 years later, in the early 2000s the OECD published a similar three volume work which curiously did not appear to acknowledge its predecessor. The governance of innovation systems (2005) essentially ignored the non-profit sector. Therefore, today in sum, we know the answer to only one of the question posed by Flory – the non-profit foundations sector has boomed and not disappeared, but beyond this we know little more. The other questions (implied and otherwise) have gone unanswered.

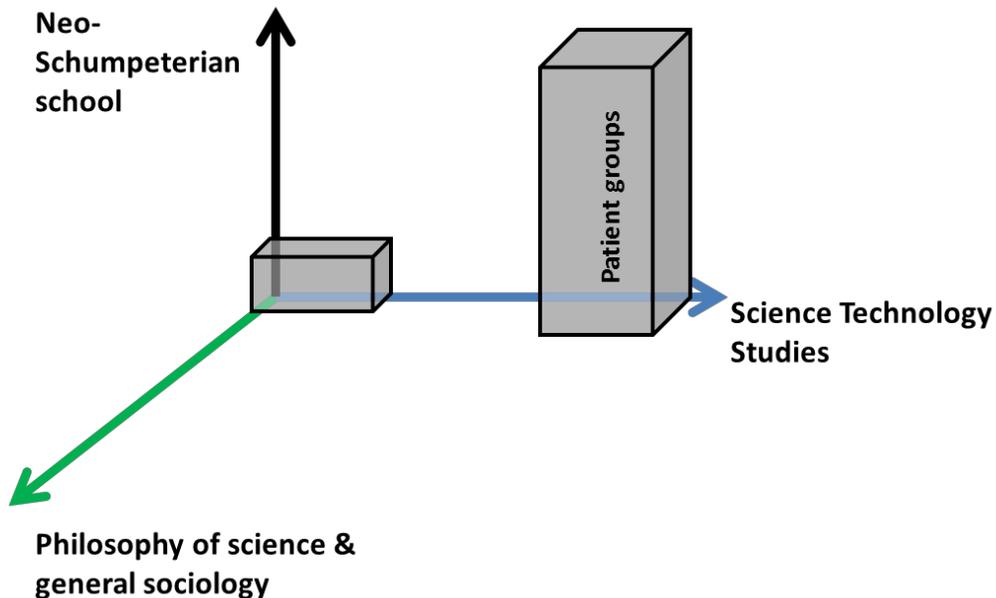
The phenomenal growth of charities focused on funding research has not escaped attention completely. In this paper we need to cross a boundary and integrate the broad domain of

mainstream STI policy and neo-Schumpeterian economics (Winter 2006) with that of ‘science and technology studies’ which focuses on the sociology of science and technology activity. Though these two broad domains are often interested in similar phenomenon their methodologies and perspectives differ and it seems fewer and fewer researchers in either field are aware of the other anymore. The gap between these fields is best emphasised by Hackett et.al.:

The Handbook of Science and Technology Studies is the third in a series of volumes sponsored by the Society for Social Studies of Science that have defined the field of Science and Technology Studies. It will be an essential resource for scholars in S&TS as well as for those in such **neighboring disciplines as anthropology, history, philosophy, sociology, law, political science, feminist and critical theory, and literary studies** (emphasis added, the back cover, 2009).

Literary studies, it seems is a closer relation academically to STS than neo-schumpeterian scholars investigating the science and technology system. However, it is in STS that there has been serious investigation of the rise of ‘patient groups’ as they have been termed. We could characterise the present the structure of the research related to charities and foundations as in Fig1.

Figure 1: Charities and foundations and patient group literatures



Business as usual – the exogeneity of society

Science, technology and innovation studies have focussed on the role of the three institutional silos of business, government (funding and labs) and universities. Whether it is the University-Industry relations concerns of the 1970s, 1980s and early 1990s (see Abelson 1974, Brown and O’Brien 1981 or Mansfield 1991) or its successor the work that falls under the rubric of the ‘triple helix’ (Etzkowitz and Leydesdorf 2000) – where ‘the evolution of innovation systems, and the current conflict over which path should be taken in university–industry relations, are reflected in the varying institutional arrangements of university–industry–government relations’ (2000: 111), the interest is in institutional frameworks. These sectors reflect the major sectors of

knowledge creation –representing a formal perspective on funding and prioritisation. These same authors astutely acknowledged that the public was missing from their model and wanted to acknowledge it.

“Treating the public as merely a fourth helix denies it being the foundation of the enterprise of innovation: the ability of individuals and groups to organize freely, to debate, and take initiatives without state permission is fundamental to the concept of the Triple Helix..... One mechanism for this is, in our opinion, the generation of public demand for innovation” (Leydesdorff and Etzkowitz 2003: 57/58)

Boon et.al. (2011) takes up this issue of demand for innovation and new technologies from the point of view of ‘intermediary organisations’. While the paper draws attention to several patient groups their positioning of these groups within STI is unclear. These ‘intermediary groups’ come across as relatively weak and in an ambiguous position relative to other players. ‘Intermediaries’ is an unclear term, at best. In the literature it has been variously defined but includes that of bridging organisations on the way to market or as Dalziel (2010) does ‘innovation intermediaries as organizations or groups within organizations that work to enable innovation, either directly by enabling the innovativeness of one or more firms, or indirectly by enhancing the innovative capacity of regions, nations, or sectors’. In focusing on a broad range of types of organisations that are non-business, non-government organisations this definition lacks a focus on the particularities of charities.

Related to this discussion, but distinct is the term democratisation which has emerged in connection with user developed innovation (see Von Hippel 2001 and 2005). ‘When I say that innovation is being democratized, I mean that users of products and services—both firms and individual consumers—are increasingly able to innovate for themselves’ (2005:1). Alternatively, the democratisation of science (Kleinman 1998), is defined as the public’s involvement in the analysis and acceptance of technologies (particularly controversial technologies such as biotechnology). In their introduction to a special issue on democratisation of science, Griessler et al. introduce the topic this way:

The perceived democratic deficit at national and EU levels is a much discussed and lamented policy problem of our times. Citizens, policy-makers and social scientists often call for citizen participation in policy analysis or decision- making for reasons of democratic legitimacy and effectiveness. In the field of science and technology policy calls for increased citizen participation have gained strength over the last two to three decades, in part in response to a series of dramatic public controversies (e.g. nuclear energy, BSE, genetically modified organisms (GMOs), and human embryonic stem cell research) (2011:583)

However, all these approaches to the missing public have understood the public as being in a relatively weak position, as the tail on the dog. However, increasingly the public is being more assertive that this and actively engages with the system through favoured charities. With serious money comes the power to drive the STI system. This is not lost on the C&Fs and because of the very perception of being on the receiving end of others’ priorities many C&Fs are formed to explicitly influence the direction of research (the strategies are discussed below in section 4).

The rise of patient groups and disease/conditions C&Fs

It would be valuable to have data and studies on a wide spectrum of C&Fs acting in the research system so that taxonomies could be presented and analysed, but unfortunately there are large gaps in our knowledge. The exception to this is that there is a significant body of research on so called 'patient groups'. Epstein (2009) positions this topic within the broader research on interest groups and social movements which is massive. Nevertheless in STS the research on patient groups covers an expansive range of topics. We are focussed on the engagement of patient groups with the research system but as this is not the sole or even prime focus of the STS material some of the context will be discussed here.

To make the case that C&Fs are strong enough to engage with traditional STI systems players, it is worthwhile showing that patient groups have been influential in the very identity and definition of diseases and conditions. It seems strange to think that diagnoses and treatments may vary between OECD countries but this is the case. One interesting example that highlights the role and strength of patient groups and their associated organisations and research funding is that of Tourette syndrome. 'Gilles de la Tourette syndrome is a disorder in which the affected person display a sudden array of rapid, recurrent, non-rhythmic, and stereotyped motor and vocal tics' (Kushner 2004: 72). The condition is called a syndrome because there is not yet a clinical etiology (cause/origin) and therefore its diagnoses relies upon doctors comparing a list of defined characteristics against a patient and determining whether a particular patient has enough evidence of the syndrome to warrant diagnoses.

Prior to the 1970s the condition was almost universally attributed to psychogenic causes (in the mind) but in the USA starting in the 1960s a patient group emerged that pushed for and funded research that sought evidence of a biological cause. Today in the USA and Britain (and by implication other anglo countries) the diagnoses of Tourette is not uncommon. The range is from around 0.04% to 5% of the population; with boys 4 times more likely than girls to be diagnosed with the condition (Kushner 2004:72). In these countries the etiology is thought to be based in genetic, biochemical or infections. However, in France there is virtually never a diagnosis of Tourette syndrome because the physicians there are convinced of the view of psychogenic origins (behaviours – bad habits, psychoanalytic – early childhood conflicts etc [Kushner 2004:76]). There has never been a strong patient group emerge in France.

So here is a case of a patient group emerging onto a national scene (the USA first) that was intimately involved in the actual definition of a condition through activism and research funding. Thus patient groups can help shape the very trajectory of research and what is the predominantly accepted view in a particular country and the lack of a patient group also shapes national medical culture. The medical establishment in France unchallenged continues in the view it had before the changes elsewhere in the world. We make no observation here as to which view of the condition is correct.

While many specific C&Fs may not have long histories, patient groups for a large range of conditions have existed for decades – dating back to at least the 1950s and 1960s. Why then was there such a rise in their profile and money raising abilities of them during the 1990s, such as there was (see Section 3 below). There is no apparent single cause, but three important events seem to have coincided. Callon (2003) brings together two of them. The 'Cold War institutional Configuration', as he calls it, dominated the public model of political discourse until the late 1980s. As the fear of a devastating war diminished, the public became more emboldened to get other issues on national agendas. Secondly, the activism of the AIDS movement that formed in the 1980s seems to have been instructive to other groups and taught them lessons for interacting

with institutional players and publics (see also Epstein 2009). The third factor is that of cut backs in government services in the USA (perhaps elsewhere as well) and the push to make the public more self-reliant (Eikenberry (2006); occurring as this did in the 1980s it was concurrent with the evolution of the other two factors.

Although, these appear to be the fertile soil for change it was the breast cancer movement in the USA that appears to have revolutionised C&F strategies. Many articles (see e.g. King 2006) document the rise of the breast cancer movement from a relatively weak group (Halebsky 2003) to one that resonated with the public (Kolker 2004) and moved the condition from ‘a stigmatized disease best dealt with privately and in isolation, to a neglected epidemic worthy of public debate and political organizing, to an enriching and affirming experience during which women with the disease are rarely ‘patients’ and mostly ‘survivors.’ (King 2004). In this journey key organisations have created ‘causerism’ as most visible through the pink ribbon campaigns (Ponte and Richey 2011).

Despite, this vast body of work, the organisational strategies and their role in the mainstream science funding system is opaque. The STS literature being based in the sociological disciplines has taken only a small interest in the strategic operations of the patient movement organisations. The focus has been much more on the socio-political causes and consequences of the particular orientation of a particular organisation in a particular country.

Even in obvious opportunities to articulate the importance of charities and patient groups in the STI system the articles miss their mark. Take for example Callon (2003), in a book about research funding his chapter dealt with the patient movements in a way that focuses on small obscure examples rather than communicating clearly on the overall scale and strategic activities of patient groups and C&Fs. Rabeharisoa and Callon (2002) describe in some detail the history of the Association française contre les Myopathies (French muscular dystrophy association) and also detail the complexities of its interactions with the Centre National de la Recherches Scientifiques (CNRS) but details on the importance of funding are absent. More recently Callon and Rabeharisoa use actor network theory to articulate some of the strategies of the Association française contre les Myopathies but do not generalise them to a wider perspective on the interactions between charities and the STI system. None of the studies that do address the role of the patient organisations indicate the scale of national funding or its direction.

Thus, the STS literature does not address itself to engagement with the STI system and the STI literature ignores the rise of the charities. Our first goal then in this paper is to establish a map to the role charities play in the science and research system.

3. Data Analysis: How important is the C&F sector

Before delving into the data it is important to discuss the technical details of R&D data collections. The OECD “Frascati Manual”, originally developed in 1963, defines how most developed economies collect data on R&D activities. When the structure was developed for the manual there were vastly fewer organisations involved in the science and innovation system so the statistical system that emerged focussed on surveying organisations that **perform** research. These organisations can then be asked to identify from whom funds to conduct the research and development came from, allowing the data to be simplified as own funds (intramural) or extramural from any of business, government, universities, overseas or private non-profits. For

the most part this approach has worked quite well over the decades (for details see OECD 2002). Nevertheless, the system does have weaknesses, revealed by when an organisation is established to provide funds for R&D but whose funds may be channelled through other agencies before they get to those doing the research, such as the case with charities and foundations. Statistics Canada, as one example, collects data from the C&Fs directly, but because this is a survey of the C&Fs that are suspected of spending money on research results should in general be considered a low estimate.

As a source of funds, this sector covers R&D financed by [not-for-profit institutions] NPIs serving households (NPSH). These provide individual or collective services to households either without charge or at prices that are not economically significant. Such NPIs may be created by associations of persons to provide goods, or more often services, primarily for the benefit of members themselves or for general philanthropic purposes. Their activities may be financed by regular membership subscriptions or dues or by donations in cash or in kind from the general public, corporations or government. They include NPIs such as professional or learned societies, charities, relief or aid agencies, trades unions, consumers' associations, etc. By convention, this sector includes any funds contributed directly to R&D by households.

As a sector of performance, PNP includes non-market units controlled and mainly financed by NPIs serving households, notably professional and learned societies and charities, other than those providing higher education services or administered by higher education institutions. However, R&D foundations managed by NPSH but having more than 50% of their running costs covered by a block grant from government should be included in the government sector.

...

The following types of PNP organisations should be excluded from this sector:

- Those mainly rendering services to enterprises.
- Those primarily serving government.
- Those entirely or mainly financed and controlled by government.
- Those offering higher education services or controlled by institutions of higher education (OECD 2002:65-66)

This definition needs to be understood with care. In Canada at least a number of large government funded organisations both at the federal and provincial levels, for administrative reasons have been established as legal non-profit entities. If the statistics are processed accurately while these are non-profits they should not appear as PNPs in research funding data.

Table 1 provides PNP data on OECD countries for 10 year intervals starting in 1981.

Table 1: PNP funding as a percentage of GERD – OECD countries

Countries	1981	1991	2001	201X [‡]
Australia	2.03	3.77	1.71	1.81
Austria	0.42	0.28	0.31	0.43
Canada	2.20	2.48	2.32	3.32
Denmark	2.03	4.60	2.62	2.70

Finland	1.14	0.88	1.04	1.15
France	0.45	0.41	0.86	1.05
Germany	0.40	0.52	0.43	0.31
Hungary		0.09	0.43	0.69
Ireland	0.99	1.23	0.51	0.48
Italy				2.77
Japan	0.70	0.66	0.71	0.69
Korea			0.39	0.34
Mexico			0.78	0.13
Netherlands	1.10	1.59	1.16	3.58
New Zealand		1.95	1.88	3.69
Norway	1.04	1.00	0.95	0.95
Poland			0.37	0.26
Portugal		5.17	1.60	1.65
Spain	0.08	0.62	0.83	0.55
Sweden	1.15	1.76	2.48	2.55
Switzerland		1.33	1.36	0.69
UK	1.74	2.77	4.86	4.93
USA	1.33	1.77	2.61	3.02

Source: OECD 2010.

Notes: † Latest available year – generally 2007.

In five OECD countries, the PNP sector of funding accounts for more than three percent of GERD. However, at three percent of GERD, perhaps the lack of attention is warranted. This is a small share of the overall effort of countries in creating new knowledge and thus, though interesting, relatively low in importance. If we look more closely at some of these examples we can examine the dollar amount increases (Table 2). Australia has been included here as its data is very accessible and it should be noted that there is a discrepancy between the national data and the OECD tables.

Table 2: Funding of Private Non-Profit Sector (national currency, current dollars)

Country	1990s	2000s	% Increase	Latest % GERD
Australia	\$ 101m (1992-93)	\$ 606m (06-07)	600 %	3.2 (2006-07)
Canada	\$ 272m (1992)	\$ 835m (07)	306 %	2.9 (2007)
UK	£ 336m (1990)	£ 1,154m (07)	343 %	5% (2007)
USA	\$ 2,589m (1990)	\$ 10,593m (07)	409 %	2.8% (2007)

Sources: Australia: Australian Bureau of Statistics (2008), Canada: Secretariat for Science and Technology Review (1994) and Industry Canada (2009), UK <http://www.dius.gov.uk/~media/publications/I/Internet-version-SET-Statistics-Nov-2009-v2> accessed 11 Feb 2010, USA - National Science Board (2010) appendix table 4-3.

These dollar amounts, given that they were raised from the public reveals a dramatic rise. But it is when we focus on university research funding that we find something totally surprising (Table 3).

Table 3: Comparison Business v PNP funding of HERD – OECD countries

	1981	1990	2000	2007	2008	2009	2010
Australia Business	1.44	2.24	4.88		5.86		
Australia PNP	2.65	5.51	3.38		2.03		
Austria Business	1.02			5.74			
Austria PNP	0.32			1.03			
Canada Business	4.08	4.98	9.55	8.54	8.55	8.54	
Canada PNP	6.63	6.13	7.22	8.74	8.73	8.73	
Denmark Business	0.67	1.57	2.03	2.13		4.44	
Denmark PNP	1.58	4.60	4.75	10.88		7.72	
Finland Business	2.13		5.57	7.00	7.21	6.39	
Finland PNP	2.11		1.17	2.47	3.45	3.35	
France Business	1.33	4.86	2.70	1.63	2.15		
France PNP	0.12	0.08	0.29	0.38	0.75		
Germany Business	1.77	7.89	11.63	15.46	15.14		
Germany PNP							
Hungary Business		22.66	5.47	13.70	14.65	15.52	
Hungary PNP			1.02	1.81	1.88	2.38	
Ireland Business	7.14	10.23	5.33	2.27	3.05	3.50	
Ireland PNP	2.64	1.37	2.65	6.06	5.31	1.57	
Italy Business	2.69	2.38		1.35	1.13	1.03	
Italy PNP				1.08	1.10	1.50	
Japan Business	0.98	2.32	2.50	3.03	2.99		
Japan PNP	0.05	0.11	0.16	1.02	1.09		
Korea Business			15.89	14.15	12.02		
Korea PNP			0.65	0.98	1.02		
Mexico Business			2.03	1.34			
Mexico PNP			0.21	0.03			
Netherlands B	0.26	0.87	7.03	7.47			
Netherlands PNP	2.34	2.19	7.69	9.00			
New Zealand B		4.60		3.11			
New Zealand PNP		6.09		3.42			
Norway Business	2.87			4.03			
Norway PNP	2.00			2.69			
Poland Business			7.85	11.34	3.85	3.32	
Poland PNP			0.69	0.42	0.27	0.18	
Portugal Business		0.70	0.99	1.39	0.92		
Portugal PNP		0.82	2.20	0.76	0.71		
Spain Business	0.00	8.94	6.91	9.01	8.82		
Spain PNP	0.00	0.52	0.98	1.16	0.95		
Sweden Business	2.28			4.92		4.47	
Sweden PNP	3.55			9.20		9.40	
Switzerland Business	9.52		5.12		6.85		

Switzerland PNP			2.25		0.25		
UK Business	2.80	7.58	7.10	4.54	4.60	4.60	4.60
UK PNP	4.92	9.56	16.39	13.50	13.93	13.93	13.93
USA Business	4.43	6.88	7.08	5.61	5.68		
USA PNP	6.53	7.37	7.58	7.55	7.87		

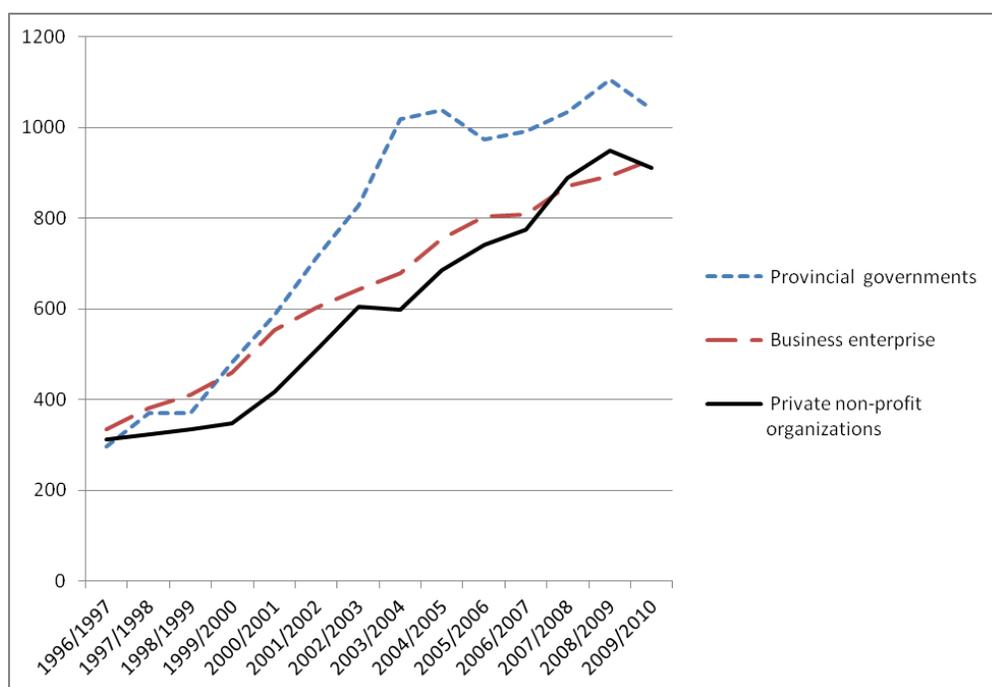
Source: OECD 2010.

Notes –Germany - From 1991 the data for the Private Non-Profit sector have been included in the Government sector

- funding calculated as percentage of total HERD funding

In eight OECD countries PNPs fund more research in the university system than business. If we follow the trend for a single country (Canada) we can see just how much the spending power of the PNPs has risen through the 1990s and 2000s.

Figure 2: Canadian higher education research funding 1996-2010 (excl Fed funds) – Current \$



Data source Statistics Canada 2011.

Using detailed Australian data we can calculate where the funding is directed. The Australian Bureau of Statistics (ABS) has published detailed fields of research data from which we see strengths both in the biological sciences and health sciences. More intriguing is the expenditure on social sciences, is that for health related as well, the data cannot tell us.

Table 4: Private Non-Profit Funding of Research Fields: Australia 2007

Research field	2000–01 \$'000	2002–03 \$'000	2004–05 \$'000	2006–07 \$'000
Mathematical sciences				443
Physical sciences	617		0	99
Chemical sciences	2,800	4,045		
Earth sciences	0	0		0
Biological sciences	77,942	104,560	92,230	97,695
Information, computing & communication sciences	3,105	4,844	1,730	929
Engineering & technology	410	1,465		1,866
Agricultural, veterinary & environmental sciences		2,087		2,230
Architecture, urban environment & building	0		0	0
Medical & health sciences	185,393	220,796	346,063	457,888
Education	14,241			
Economics	131	101		255
Commerce, management, tourism & services		53	103	219
Policy & political science	287	632		1,584
Studies in human society	671	1,206	2,096	2,087
Behavioural & cognitive sciences	474	933	1,516	3,353
Law, justice & law enforcement			0	
Journalism, librarianship etc	0	0	0	0
The arts		0	0	
Language & culture	0	0	0	
History & archaeology	0	0	22	0
Philosophy & religion	66	129	240	206
Total	289,038	359,548	478,861	606,337

Source Australian Bureau of Statistics (2008)

Remembering this probably underestimates nationally, it also ignores the increasing potential for large cross border flows from foundations such as the Wellcome Trust and the Bill and Melinda Gates Foundation, for which we have little data². We clearly need more data on this important sector.

One dimension that is clearly missing is the ability to classify funding by diseases and conditions so that funding could be compared with rates of conditions in the population. Epstein notes that there is likely a correspondence between conditions and the emergence of a patient group but the association is unclear:

the rapid rise of the social response to an emerging illness may depend on a range of factors, including the epidemiological significance of the condition, the availability of an

² However, existing data suggests it is still small (Statistics Canada 2010).

unequivocal diagnostic test, the social class of the sufferers, the degree of activism, and the extent of media coverage (2009: 516).

There are other important questions regarding the data. Importantly, there are no estimates of leverage. Because much of the funding of the C&Fs are channelled through the existing institutional system through partnerships with the granting councils and directed towards basic science in universities the perceived role of the C&Fs is obscured. It is impossible to measure the + factor here. Obviously, the overall amount of government funding remains the same but what role does the strength of particular charities play in pushing money in one direction or another. This then goes to the heart of strategizing in this environment which we cover in the next section.

4. STI system re-configuration – the SO-ANT framework

This project is aimed at exploring the role of PNPs in the reconfiguring the overall structure STI system. Our research approach has thus been to accumulate evidence of examples which appear in the existing literature, websites and media in order to build a framework for further more comprehensive research on the intermidate role charities are playing in funding and mobilising research. That methodology will need to incorporate the strategies of PNPs other than medical (patient group) based charities but for now the most comprehensive evidence exists there.

Conventional strategy research is not easily summarised but Hoskisson et al. (1999) emphasise that research has swung between accentuating the internal aspects of the organisation (leadership, organisational structure and more recently the resource based view), external factors (industry structure, environmental fit etc) and the space in between (transaction costs especially firm and market boundaries etc). There is no doubt that this research can be applied to non-profit organisations (see Moore 2000). However, we take the view that this literature is difficult to use for our purpose. Specific sub-fields of strategy (see e.g. Mintzberg et al. 1998), environmental fit (Dess and Beard), resource based view (Barney 1991), and dynamic capabilities (Teece 2007) do not capture the dynamics we want to emphasise.

The strategy literature takes as its core starting points either the success of individual firms within an industry or the industry itself. **Primarily, we are not interested in the success dynamics of individual charities as they compete against one another. We are interested in how charities and foundations generically have succeeded in changing the science funding ‘market’.** This accords most nearly to the growing ‘industry architecture’ literature (Jacobidies et al. 2006), yet there is no standardised approach to mapping such ‘architectures’.

Secondly in this study the structure of science funding markets are understood as relatively rigid, similar across many countries and do not change quickly. This provides very special conditions. Therefore we focussed on the changing structure of the funding market. Further, as we increasingly understand that economies and organisations are usefully represented as complex networks (Kilduff and Bass 2010) we wish to capture these issues. Lastly, the STS literature in already adopting a framework based on a constructivist network premise in its analyses of the histories of patient groups it is harder to ‘fit’ the data and evidence into a conventional strategic management mould.

The study of patient groups takes an interest in what social forces bring people together and how organisations can solidify that into action. One particular branch of STS that has developed a useful language for this process is Actor Network Theory (ANT) which is obscure to many academics and not without critics even within STS. For those that use ANT its benefits and

disadvantages simultaneously come from its rich sociological and communications theory ideas and concepts and the myriad of terms – sometimes duplicating and overlapping even within itself. From the ambiguities comes its strengths. For its critics those very same characteristics are its problems. Despite all this, the ideas emerged simply enough from the study of behaviours in a science lab in the 1970s (Latour and Woolgar 1986) and has generally been used in detailed case study contexts. Problematically, contained within ANT is an elegant language that describes the behaviours and strategies of players within environments that require complex networks to be developed before economic activity can be commenced. Although the originators of the ANT field object to its use for describing strategy there is a growing number who are using it in this way (see Neyland 2000).

With this background, we think it is worth adopting what we want to call the Strategic-Organisation variant of ANT (SO-ANT) which stripped down to bare essentials of the main core concepts can be applied in the current contexts. In this we are extending on a number of articles in the organisational studies and strategy fields and indeed even from within STS (see Neyland 2000, Manning 2002, Sarker et.al. 2006 Steen et.al. 2006, Woolgar et.al.2009 etc etc.). Within our study we can align the key concepts of ANT with components of the system. Our abridged SO-ANT structure emphasises the following concepts:

Network construction terms - organisations

- **System Builder:** In order to account for the heterogeneous activities of the people behind technological systems, Hughes employs this term to account for the management and interconnectedness of the entrepreneurial, financial, promotional, inventive, and lobbying efforts needed to build socio-technical systems. Like all other actors, system builders are constituted in the course of technology construction and the interaction with other actors. See Hughes 1979, 1983,1988; Law 1988;
 - In our analysis the charities are system builders – constructing networks that benefit their donors.
- **Obligatory Passage Point (OPP):** A product or effect of successful translation. Taken from military terminology, the location through which all enrolled actors must pass through. Understood in terms of power, forcing actors along certain paths and channels and barring access to others. See Callon 1986b; Law 1986b; Latour 1987, 1988b, 1992;
 - In our analysis the charities are attempting to build systems that make them obligatory passage points for particular conditions.
- **Local/Global Network:** Within ANT, an effect of negotiation strategies and processes between system builders and other actors in the (global) actor-network. The local actor network corresponds to the space where system builders have been granted relative autonomy. See Law & Callon 1988; Feenberg 1999;
 - The charities and foundations take on the role as a system builder – organising events, corporate sponsorship on the one side and research system as best it can on the other. There is strong competition for donations and each charity is trying to establish itself as the ‘go to’ organisation not just globally for your dollar but also in promoting a particular disease group. There can be competition between, by way of example, the Canadian Cancer Society which

covers many cancers, the Canadian Breast Cancer Foundation and the Breast Cancer Society of Canada. Charities need to operate at all levels from grassroots social networks to collect donation through to national 'global' networks negotiating funding agreements with large corporations and research partnering agreements with national funding councils.

Network construction – aligning actor interests

- Problematisation: the construction of the belief in society that certain problems are more important than others (see Callon, Law, and Rip 1986; Callon 1981);
 - The promotion that a particular disease and the current funding is a problem to be fixed.
- Enrolment: A strategy by which actors, their roles, and their interests are defined through translation. An attempt to durably situate and fix actors in a sociotechnical network. Understood as a contingent process where success is never guaranteed. See Callon 1986b; Callon & Law 1982; Callon, Law & Rip 1986.;
- Mobilisation: The attempts of system builders to oblige heterogeneous elements to *enact roles and positions in the system builder's sociotechnical scenario*. See also sociotechnical scenario; translation; enrolment; juxtaposition. See Callon 1986b; Law 1988;
 - The point of problematisation is to mobilise a group of people to become activists organising, collecting money, lobbying government.;

Strategy making

- Margin of Manoeuvre: An ambiguous potential inherent in the implementation of a dominant technical code. Corresponds to the potential actions and tactics of those charged with this implementation, that is, the actions and tactics unaccounted for by the system builders. See also translation; technical code; local/global network; program/anti-program symmetry. See Callon 1986b; Feenberg 1999, 2002.
 - The more crowded the space the charity dollar the harder it is for new organisations to grow. Unlike more conventional markets, it is not about new technologies it is about communicating that a particular cause has been underappreciated or under-funded.

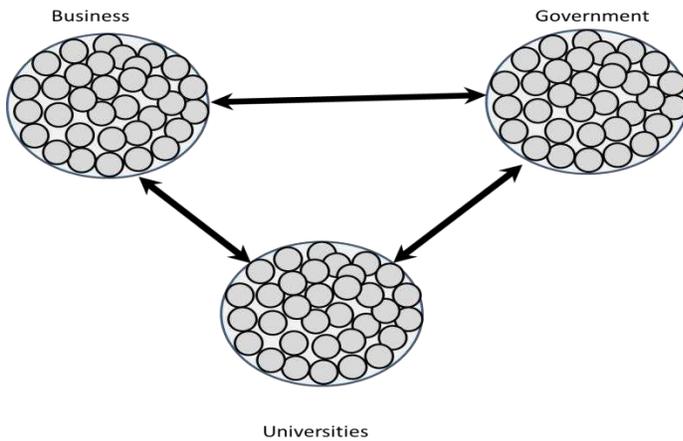
Italicised text is quoted from Cressman and Felczak 2009, various pages.

We can then use each of these concepts to illustrate the processes observed in the way C&Fs have reconfigured the STI system. There are different steps and time lines through which these stages may occur for individual C&Fs, We have attempted to simplify the ideas to their core elements and a generalised version of the timeline. But, to reiterate our focus is the strategy of the medical *charities' engagement with the main science, technology and innovation system* not how successful they are or their science impact; that must be left for a different paper.

The public sphere – from terra nullius to crowded space

In the triple helix model as discussed earlier in this paper there is little or no discussion of the public's priorities. It is the priorities of researchers, governments and business/markets that matter most. This is simplified into the view of Fig 3 which highlights the structuralist perspective as well as the fact that individuals or groups or individual make up these structures.

Figure 3: Triple Helix Model

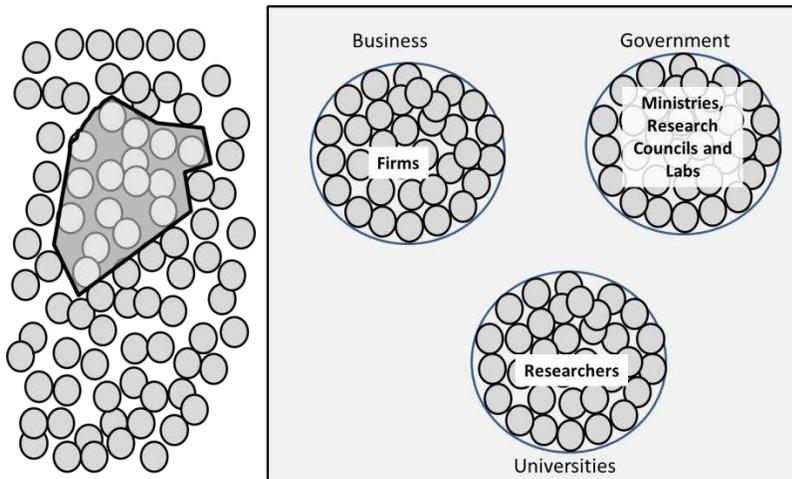


The public in this model is nowhere – it is an empty domain.

Problematisation

In the newly emerging charities the public may appear to be organised by a formal institutional legal entity from the start but always it seems the process appears to commence small. A particular public comes to a realisation that its interests are not captured by the researcher or business oriented model and it wants those interests to be understood (Fig 4). This public realises that coalescing around its special interests of a particular diseases or conditions can be influential. This ‘problematisation’ process is twofold with the second part quite overt as can be understood from the significance that almost every large research charity in America, Australia, Canada and probably in most countries promote a version of the slogan – ‘research for a cure’³.

Figure 4: A patient group forms



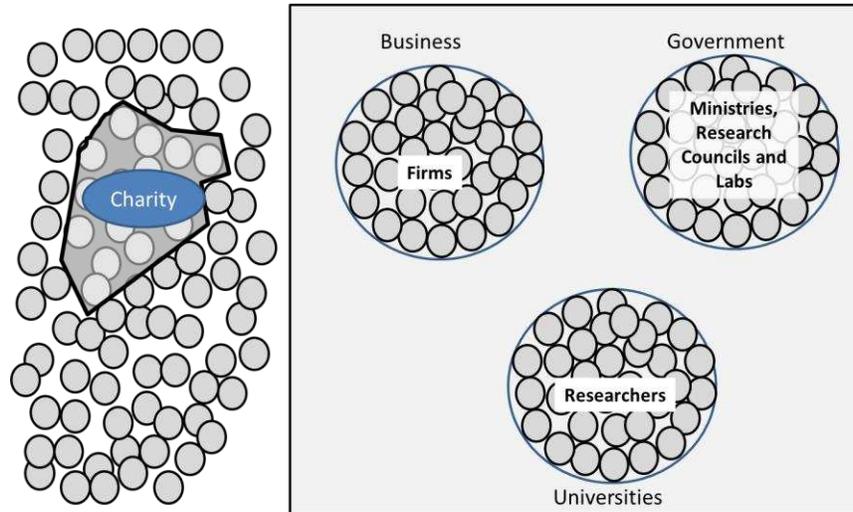
However, the only way research system prioritisation can be changed is through cash, and that only happens on a large scale through the emergence of a lead organisation.

³ So prominent has the word cure become that the Milken Institute – a American non-profit think tank runs an annual event called “Partnering for Cures”.

System builder emerges

The administrative hub for a cause takes on the task of organising networks across multiple levels of society. Social networks must be built with the community and media and more formal links with business, government and the science establishment.

Figure 5: System builder emerges



Funding enrolment and mobilisation

Large charities today do not only seek support of the community members across a country through word of mouth only, they run mass advertising campaigns such as that conducted for the Heart and Stroke Foundation of Canada (2012⁴). This campaign with the tag line ‘Death loves women. Make death wait’ is simultaneously an endeavour at problematising the status quo with the assumption that breast cancer is the main killer of women and also enrolling more people to its cause. Alternatively, the charities can reach for corporate sponsorship or celebrity endorsement (causerism - see King 2006 and Ponte and Riche 2011). For example the Canadian Breast Cancer event has a corporate brand attached.

Figure 6: Branding of Charity events



Source: Canadian Breast Cancer Foundation (2012)

Researcher enrolment and mobilisation

Not only do C&Fs seek to build a financial base through community support, that part of the community which suffers from a particular disease or condition forms a valuable resource of key stakeholders for researchers. Not only are they valuable as a group for influencing priority setting but they also provide for a pre-organised basis for clinical trials – thus cutting down the costs and time for patient recruitment.

⁴ “Death Loves Women” commercial can be seen here <http://vimeo.com/31387801> accessed 5 Feb 2013.

The National Organization for Rare Diseases (NORD [USA]) clearly reveals this part of the C&F approach to the research system. NORD with its fragmented base of rare conditions could never hope to garner the research dollars of a ‘breast cancer’ but it can lobby government, provide money for patient assistance programs and start-up money for research. An organisation in the same space has taken a different strategy; RARE has created a data registry platform:

The RARE Project is encouraging all families with RARE diseases to register with the ORP and to contribute their medical history and ongoing/daily medical experiences for the benefit of other families (including you!) and researchers. Every time you enter a piece of data into the ORP you will get a piece of information back – usually in the form of a comparison of how your data compares to others with the same disease, symptoms, or therapies (RARE 2012).

This growing database of patient information is of benefit to sufferers and in time will be invaluable to the research community. Self-organising communities around self-interest are aligned to promote research by making their data easier to access. The more accessible the data, the more likely the number of researchers in universities and companies will expand.

C&Fs can also choose, if they are large enough to fund research directly or leverage the system through partnering with national granting councils. In 2010 we collected 10 examples of calls for research proposals in their own right issued by the charities to university researchers. In the cases of co-funding (see e.g. CIHR 2012) calls do not make clear the respective financial contributions⁵ of different charities, government funded ‘non-profits’⁶ and the Canadian Institutes of Health Research (CIHR is the federal granting council for health and medical research). All of the processes are less than clear but partnerships are the least clear of all. Alternatively, C&Fs can also go directly to the business community. The Michael J Fox Foundation (MJFF) for research into Parkinson’s Disease based in the USA exemplifies this approach. Mumford (2011) states that in 11 years MJFF has spent US\$265m in research of which \$70m has gone to industry. Further, MJFF benefits with licencing revenues if the research continues.

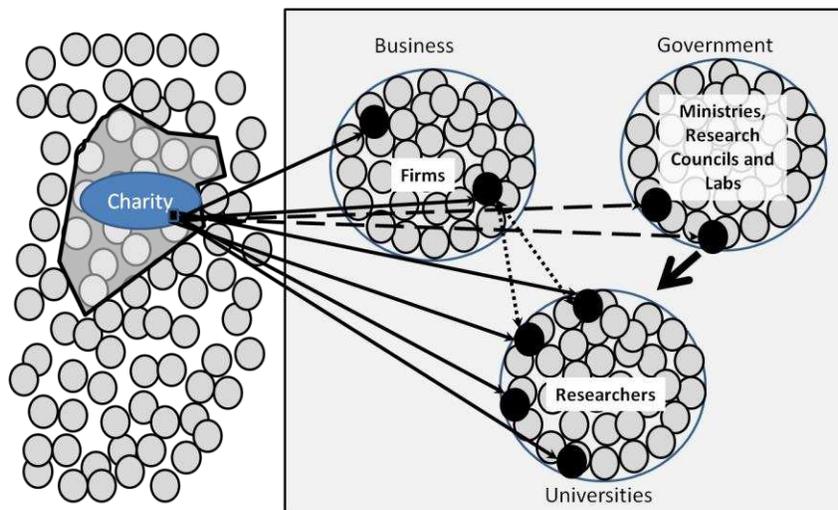
Finally, the entire research system can be leveraged if there is political engagement. King (2006 xv-xviii) provides the example of when President George Bush Sr decided not to support the transfer of \$210m to breast cancer research, the issue became political with breast cancer groups campaigning for Bill Clinton. The National Cancer Institute budget rose from \$155m in 1992 to \$400m in 1993 – with a significant amount of that increase dedicated to breast cancer.

Thus the new system begins to look something like Fig 7.

⁵ The CIHR Institute of Infection and Immunity in partnership with the CIHR Institute of Circulatory and Respiratory Health, the CIHR Institute of Nutrition, Metabolism and Diabetes, The Kidney Foundation of Canada, Cystic Fibrosis Canada, Canadian Blood Services, and Genome British Columbia.

⁶ For administrative reasons governments frequently create separate organisations to administer certain programs or near commercial activities. Often in Canada these are registered as non-profits although the majority of their funding is through government distribution. Based on the OECD Frascati Manual such organisations should not appear in the PNP statistics. Statistics Canada 2011 states, regarding PNPs.: Charitable foundations, voluntary health organizations, scientific and professional societies, and other organizations not established to earn profits comprise this sector. Private non-profit institutions primarily serving or controlled by another sector should be included in that sector (e.g., the Pulp and Paper Research Institute is in Canadian business enterprises).

Figure 7: Charity funding model



Manoeuvring in a crowded system

While the C&F sphere is now a crowded space there are two in-determinates in the systems – the total amount the public is willing to spend and the ability of new organisations to open up new niches. The most obvious example of a new cause is that of prostate cancer. In recent years organisations modelling themselves explicitly on those in breast cancer have emerged (King 2006 and Halebsky 2003). The most successful appears to have been Movember which commenced in 2003 in Australia with no money raised and 20 participants. In 2010 the global organisation raised \$72m AUD, while in 2011 it raised \$124 million AUD from Australia, Belgium, Canada, Czech Republic, Denmark, Finland, Ireland, Netherlands, New Zealand, Norway, South Africa, Spain, UK and USA, with 854,288 ‘Mo Bros & Mo Sistas’ participating in activities (Movember 2012); previously 1.1mill people had been involved cumulatively between 2003 and 2010 (Movember 2011). Clearly, the Movember campaign has found a place to grow.

STI research system reconfiguration

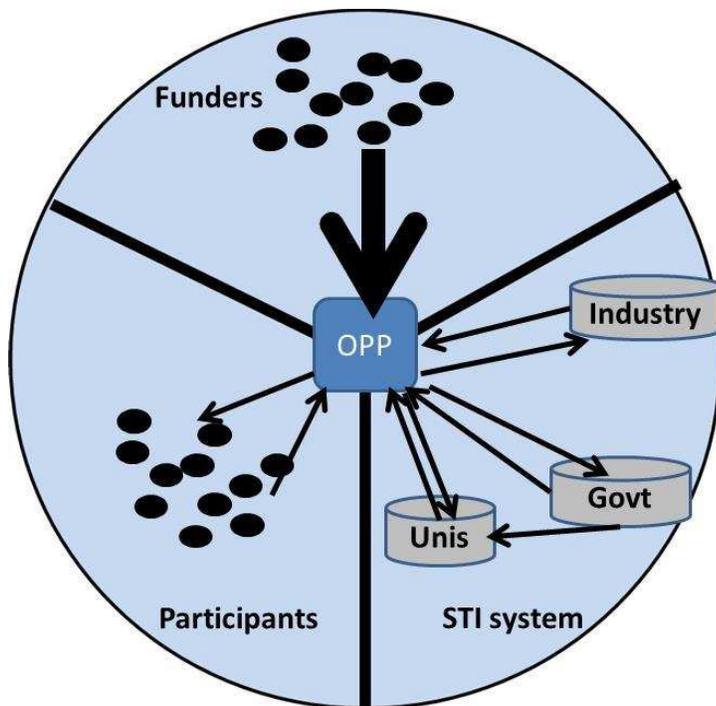
The charity and foundations as we have shown can exert influence on the STI systems as they gather public, corporate and philanthropic support. The goal of achieving this is not hidden. As one example the Muscular Dystrophy Canada’s website⁷ states:

Neuromuscular research was a driving reason for the formation of our organization in 1954. At that time little research was being done in Canada or elsewhere in the world. Our founder, Dr. David Green believed research was absolutely essential to our charitable mission..... Today, our research program is based on partnerships with other organizations and individuals. Partnering allows Muscular Dystrophy Canada to leverage higher investments in research than we could afford acting independently.

⁷ <http://www.muscle.ca/nc/national/research.html> accessed 1 March 2010.

For a huge variety of diseases and conditions there is now a new system to understand, a network of funding that co-organised by medical C&Fs, granting councils and business. The network stretches from individuals through to corporates to get funding and then funding is channelled through them to selected companies, government granting councils, academics and non-profit research labs. Many investigating the STI system have not understood this change in structure. There have always been obligatory passage points – typically granting councils and these still exist and are important for the majority of the research system. However, in a limited number of cases it can be argued that the structure is shifting.

Figure 8: The new system in special cases: charities as obligatory passage points (OPP)



Despite this picture it is interesting to note that the charities themselves appear to feel left out⁸ of the dialogues on the STI system both at an academic and in high policy discussions.

5. Discussion and Conclusions

We started looking seriously at this topic when we began to understand role of environmental complexity in network performance (Wixted and Holbrook 2012) and the role that charities potentially play in reducing that complexity for particular fields of research. Our focus in this paper has been to highlight the fact that charities and foundations (C&Fs) have been consistently ignored in the main literature on the science, technology and innovation (STI) systems and further to make clear that their funding is significant. Lastly, our emphasis is on the strategy of

⁸ Private conversations.. They have formed a peak association the Health Charities Coalition of Canada <http://www.healthcharities.ca/> accessed 05-02-2013 which itself has become part of a larger lobbying effort Research 7 <http://www.acaho.org/?document&id=339> accessed 05-02-2013.

the medical C&Fs' engagement with the STI systems not how successful they have been or their science impact.

Governments increasingly feel the need to justify research expenditures through research evaluation and impact assessments but this work remains disconnected from engaging with the public's interests. The public not only pays taxes for research but in many countries engages in direct democracy voting through cash in the hand for research of its own choosing. This form of science prioritisation is little explored and under appreciated. Part of the challenge to understanding the system better lies in the fact that the data framework is outdated.

In this paper we have shown that in a number of OECD countries charities are a bigger funder of research in universities than businesses yet the literature is devoted to the relationships between business, government and universities. The public has clearly felt that its interests have been ignored and have developed new pathways to researchers and influencing priorities. In this paper we have also attempted to show how C&Fs are able to form complex networks of mass participation, university researchers, corporate and government interests. The SO-ANT framework employed here we believe is useful for highlighting key activities of the medical C&Fs. While there has been an analytical turn in the social sciences towards 'networks' (Borgartti et.al. 2009), there is little room for the actor in such structural analysis (see Kilduff and Bass). There is room therefore for an actor centric approach to network construction and the SO-ANT approach is an early attempt at filling this need.

Yet, the questions which remain are huge. At the national level; how can policy makers in government and universities more openly discuss the 'science funding market'? Does the SO-ANT framework work for non-medical PNPs in the research system? We do not have a useful taxonomy of PNP organisations and their expenditure. We do not have data on medical research by medical conditions so that a comparison of disease likelihood and funding is simple and accessible. The accounts of charities while public are not systematically reviewed. Science policy, communications theory and organisational strategy are all part of understanding the complex world of the PNPs in the broader science and technology system. C&Fs employ sophisticated communication practices, using the most recent developments in new media such as social networking, and new communication technologies. These campaigns reach a completely new generation of potential donors. No longer, it seems, are most donors economically successful individuals who have large funds they can donate, but, now, the vast majority of fund-raising campaigns focus on raising funds through small donations from the largest possible number of citizens. The process has become mass-marketed and 'democratized'. This is a brave new world for the research establishment, who to date, have never really had to worry about public opinion.

Finally, while medical research is the major recipient of the funding from PNPs what impact does this have on the rest of the research system? Business in general may lobby on behalf of some of the natural sciences, including health but what voice is there then for the environment and social sciences research?

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