

**Shaping the Landscape of Biomedical Research: Are Patients Groups
*Influential*¹?**

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Introduction

It is well acknowledged that publicly conducted and produced knowledge plays a key role in the stimulating and directing downstream research developments². Empirical observations of interest to this paper are the higher level dependence of the pharmaceutical industry (in comparison to other sectors) on academic research and the closer interactions between academic and private researchers within this industry (e.g. Mansfield, 1991; 1995; Levin et al., 1989). Similar conclusions are drawn from research which focuses on the institutional location of the authors of scientific papers cited in patents (cf. Narin et al., 1997; McMillan et al., 2001). Not only is the proportion of the scientific papers authored by publicly located scientists high (73%), but also the dependence is strikingly for ‘most basic science’ (64%).

It is within this literature that an interesting question arises: are the widely noted sectoral variations in industry’s dependence on public science replicated at lower levels of techno-economic aggregation? If yes, than how does this influence the activities of ‘little science’ funding agencies that tend to selectively support public science within a well-defined area?

Ironically, the literature has tended to focus exclusively on federal funding, with little on either the nature of public-private interactions at lower levels of techno-economic disaggregation or the activities of ‘little science’ funding agencies³. It is in this respect that patient groups provide a useful social category for analysis⁴. Importantly, patient groups as collectives of individuals sharing a common condition could potentially be significant forums for ‘user involvement’ in knowledge production and public assessment of biomedical

² Much of the discussion here emphasises the role of public science in encouraging and stimulating private sector research. The interactions are definitely more complex and it is often the case that clinical practice advances beyond the frontiers of existing basic science. No doubt, the relationship between ‘science’ and ‘technology’ is complex and interactive, rather than unidirectional as might be suggested by the discussion here.

³ This is true with the exception of French scholarship that has examined the evolution of techno-economic networks in a specific disease area, i.e. Alzheimer’s (Penan, 1996) and the role of patient groups in funding biomedical research (see, Callon, dt.; Rabeharisoa and Callon, dt.; *Sciences Sociales et Sante*, 1998).

⁴ Defining patient groups is a hazardous task. We define a ‘patient group’ as a formally-constituted not-for-profit organization devoted to a single disease area or group of diseases. Patients may lead the running of such groups or the groups may be organized and managed by others acting on their behalf.

developments⁵. Moreover, given that patient groups, particularly those formed around chronic conditions, possess an intimate knowledge of the needs/priorities of sufferers and carers, the possibility of generating a portfolio of selective and focussed research is potentially high⁶. This is particularly relevant as evidence exists of R&D allocation mismatches in public funding of biomedical research⁷. As such, patient groups could bring the needs and priorities of its membership and the relevant healthcare professionals to bear on R&D decision-making process so as to influence the landscape of biomedical research. These issues form the core of the paper, where they are examined through a case study of the Multiple Sclerosis Society (MSS).

The paper is structured as follows. The next section briefly brings together diverse contributions that make a singular point: patient groups have emerged as powerful actors on the landscape of health care systems. This is followed by a summary presentation of MSS's research grants portfolio for 1981-2000. Thereafter, analysis of the bibliometric presence of MSS relative to other leading funding agencies is presented. A final section discusses the empirical observations presented in the paper. The discussion draws upon two bodies of literature: the evolutionary economics literature on innovation studies and the social studies of science/technology literature on the social shaping of technology systems.

⁵ This research effort in line with historiographies of technologies that draw attention to the interplay between innovation and diffusion, thus demonstrating the importance of users in socially shaping the direction and outcome of technical change (Pinch & Bijker, 1989; Williams & Edge, 1996). Importantly, this paper advances a few critical steps deeper into the knowledge domain supporting technical change to study the activities of users in influencing the landscape of biomedical research.

⁶ Outside the economic literature on physician prescribing behaviour where patients are characterised as passive agents, the nuanced and deep knowledge of patients, particularly those with chronic conditions, is acknowledged (see Wyatt, 2000). Interestingly, the Department of Health heralds this 'expert patient' and aims at promoting self-assessment of symptoms and management of well being (DoH, 2000).

⁷ Evidence exists in terms of research agenda mismatches between priorities set by public sector funding bodies and public needs (e.g. proxied by disease burden) (Gross et al., 1999). Similar evidence within a disease area concludes that "discrepancy exists between the treatment investigated by researchers and those preferred and prioritised by consumers [i.e. patients, GPs and clinicians]" (Tallon et al., 2000).

The Emergence of Patient Groups

There has been an explosion in the number of patient groups in the US and the UK – both exhibiting strikingly similar historical trends (Wood, 2000: 35-50). As table 1 demonstrates, 54% of British groups and 62% of American groups were established after 1980, leading Wood (2000: 39) to christen 1980 as the genesis of a ‘new patient movement’. Patient groups tend to be dedicated to a specific disease. However, often enough, there are alliances across medical conditions leading to the formation of umbrella groups like the Long Term Medical Conditions Alliance and the Genetics Interest Group, both UK-based.

Table 1
Number of Patient Groups, 1997

Year	Number of Groups	
	USA	UK
Pre-1939	8	10
1940-59	19	14
1960-69	13	12
1970-79	57	54
1980-89	122	82
Since 1990	37	25
Total	256	197

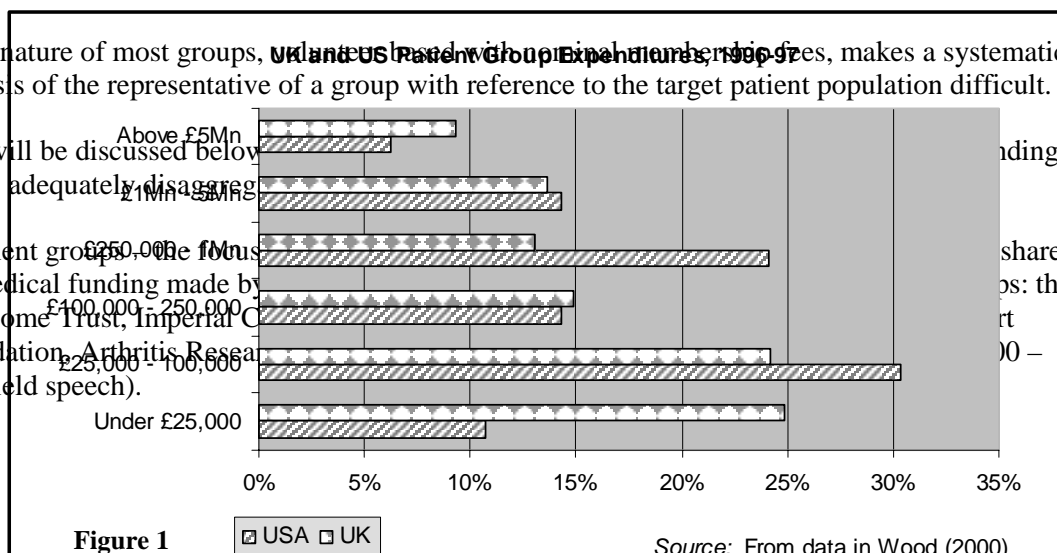
Source: Wood, 2000
Note: Number of groups by year of establishment

Increases in the number of groups have been accompanied by an expansion of the membership bases of most groups and growth in the financial size of groups⁸. Data reported in Wood (2000) shows that in 1996-97, 20% of American groups and 23% of British groups reported expenditures in excess of £1 million – with a small percentage having expenditures in excess of £5 million (cf. figure 1). Importantly, some of these groups provide funding for biomedical research. In the UK, according to a Wellcome Trust publication, the reduction in real funding for (public domain) biomedical research by the government during 1988-95 was proportionally matched by increases in real spending by the industry and the non-profit private sector (Dawson et al., 1998)⁹. In 1994-95, charities¹⁰ and foundations organised under the umbrella of the Association of Medical Research Charities (UK) reported biomedical funding of about £361 million. This accounted for 22% of the total UK-wide allocation for (public domain) biomedical research – ahead of the pharmaceutical industry that accounted

⁸ The nature of most groups, and the US have with group expenditures, makes a systematic analysis of the representative of a group with reference to the target patient population difficult.

⁹ As will be discussed below, that is adequately disaggregated.

¹⁰ Patient groups that fund biomedical research made by Wellcome Trust, Imperial C Foundation, Arthritis Research Sheffield speech).



for 12% (£192 million) of this total¹¹. These factors – disease-specific remit, their membership and financial base – endow patient groups with political resources with which they can potentially influence policy, resource allocation and treatment delivery.

The increasing formation of patient groups around single diseases strongly suggests the presence of disease constituencies (reference). Rabeharisoa and Callon (2002) conceptually differentiate patient-based associations into two types based on the dynamics of research funding made and the group's relationship with research institutions: the auxiliary association is one that remains dependent upon external sources of knowledge/information in determining research agenda; the partner association as one where patients as 'experts in experience' dissolves knowledge hierarchies to enable partnerships between patients and medical professionals. Their on-going research provides compelling evidence of the active participation by patients through the French Muscular Dystrophy Association (*Association Française contre les Myopathies*) in the production of knowledge and strategic supervision of researchers and practitioners; in effect enabling patients wrest control and leadership over research agenda.

The *effectiveness* and *influence* of patient groups can be gauged through socio-historical and political accounts of research projects. In the case of AIDS research in the US, Epstein's (1995, 1996) account demonstrates how 'disease victims' transformed themselves into 'activists-experts'. Beyond exercising political muscle, AIDS activists expended efforts to accumulate expertise so as to present "themselves as credible *within* the arena of credentialed expertise" (Epstein, 1995: 409, emphasis in original). There is little doubt as to the contested struggle involved in reconfiguring deeply embedded knowledge hierarchies. Consequently, "some of the negotiated trials were dirty and ill-disciplined as a result" (Anon., 2001: 1721).

Accounts of patient-carer based movements in breast cancer provide comparable evidence of the reflexive capabilities of laypeople in participating in scientific debates (Anglin, 1997; Klawiter, 1999). Interestingly, the evidence points towards the use of rhetorical devices that articulate personal experiences as instruments to influence research institutions, the legislature and local healthcare providers. For example, Anglin (ibid.) narrates how the efforts of women

¹¹ The industry's research expenditures are based on an assumption that 10% of the total R&D budgets are devoted to public domain research (Dawson et al., 1998: Appendix 4).

with breast cancer resulted in the passage of the bill for improved informed consent procedures in breast cancer trials in 18 US states.

Similar strategies are evident in the UK in the submissions made by patient groups during the cost-effectiveness review of new health interventions by the National Institute of Clinical Excellence. For example, the Alzheimer's Society succeeded in identifying methodological deficiencies with the traditional approach of evaluating the cost effectiveness by drawing attention to patient experiences that fail to be considered as outcomes within clinical trials (Alzheimer's Society, 2000). For example, the Society raised methodological questions on how emotional state of the patient could be evaluated alongside other easily reducible indicators like mobility:

The Society is keen to know how these changes, for example in mood, will be evaluated along side more quantitative measures. How will a two point improvement on an ADAS (Cog) scale be evaluated along side the response from one man with Alzheimer's, aged 55 years, who, when asked how the drugs have helped, said, '*I can play snooker again – I can identify the colour of the balls*' ... These changes may seem like minor achievements in the face of life-threatening illness, but they are the benefits that people with Alzheimer's and their carers value and which restores their quality of life" (Alzheimer's Society, 2000: 17).

MSS also adopted a similar strategy of reporting patient stories in their appeal of the NICE's recommendation against NHS inclusion of beta interferon (reference). Of relevance here are efforts at documenting patient experiences and making them available through use of information technologies. Andrew Herxheimer's *dipex* (database of individual patient experience project) is a notable exercise (Herxheimer et al., 2000). In the UK, the NHS has made efforts to widen and routinise patient involvement/participation in its research programme through the establishment of a 'Consumers in NHS R&D' group (reference). In the US, patient participation in assessing clinical protocols has become a regular feature, leading scientists to think "more broadly about the impact of their research" (Anon., 2001: 1721). The enhanced credibility and political presence of patient groups make them an "obligatory passage point" (cf. Latour, 1987)¹² in the health system between researchers and patients.

¹² Quoted in Epstein (1995).

MSS Research Grants Activity

In total MSS awarded 581 grants over the 1981-2000 period, which totalled £48,708,655. The value of an individual grant and the frequency of grant-giving fluctuated across the period of study. The number of grants awarded increased from about 25 per annum in the early 1980s to about 40 per annum in the late 1980s, eventually peaking at 47 per annum in 1992¹³. Consequently, in 1992 the Society allocated over £5 million for biomedical research.

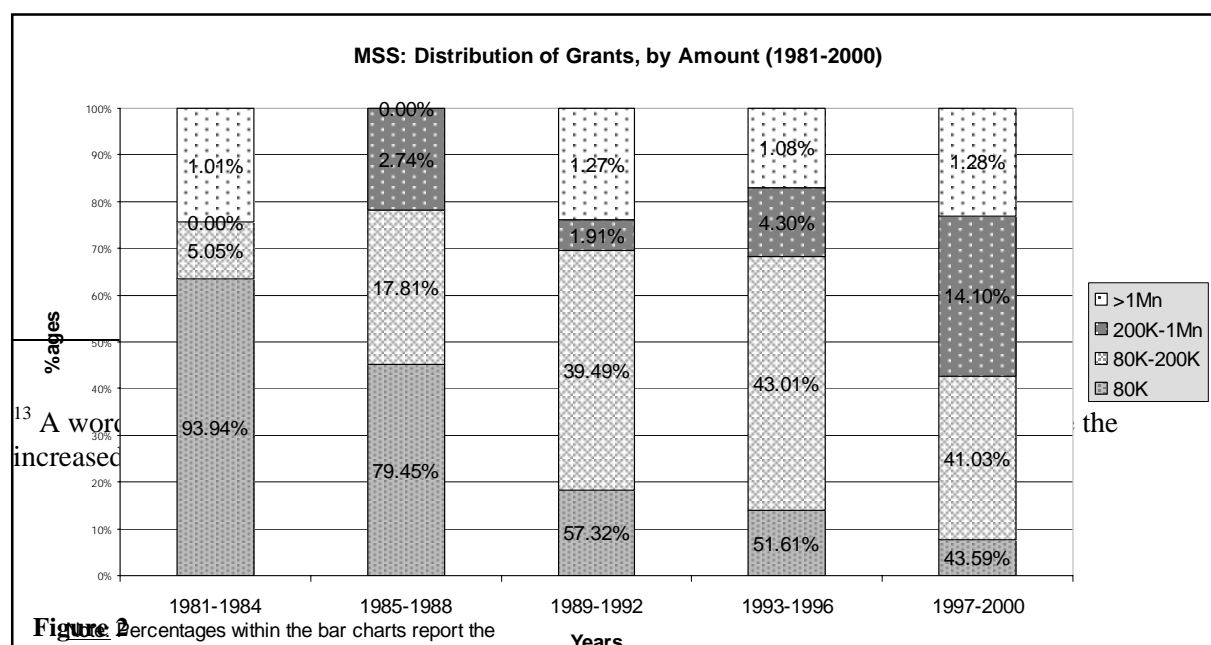
Table 2

MSS Grants (1981-2000): Basic Indicators					
	1981-84	1985-88	1989-92	1993-96	1997-2000
Number of Grants	99	146	157	93	78
Value of Grants	£4,374,428.00	£8,151,161.01	£14,238,648.66	£10,442,827.92	£10,833,028.00
Summary Statistics					
Average Grant	£44,186.14	£55,829.87	£90,692.03	£112,288.47	£138,884.97
Maximum Grant	£1,066,119.00	£837,661.00	£1,887,983.00	£1,767,865.00	£2,511,110.00
Minimum Grant	£500.00	£1,254.00	£1,984.00	£4,000.00	£3,100.00

Source: Author's calculations from Patient Group Biomedical Funding Database

The largest grant awarded by the Society was in 1998 and totalled £2.5 million. The Society is a regular and sizeable funder of biomedical research. Summary statistics of the research grants awarded by MSS is reported in the accompanying table 2.

Evident from table 2 is the fact that the Society's resource allocation has undergone change. Examination of the distribution of grants across different class intervals shed useful insights



into the society's grant giving behaviour¹⁴: in 1981-84 only 1% of the total grants allocated were greater than £200K, whereas in 1997-2000 more than 15% of the grants were of this size (cf. figure 2). Consequently, less than 25% of the total amount allocated was accounted for by large grants in 1981-84. Whereas, in 1997-2000, over 55% of the amount allocated was on account of large grants. In parallel fashion, small grants (i.e. ≤ £80K) have diminished in significance. In 1981-84, almost 95% of the grants awarded were of this size and they collectively accounted for 64% of the total amount allocated. In contrast, in 1997-2000, less than 44% of the grants were of this size and these grants accounted for less than 8% of the amount allocated. Clearly, the Society exhibits a tendency towards awarding larger grants in recent years.

MSS's biomedical funding may be considered nominal in comparison to the research budgets of pharmaceutical companies or the total allocations awarded by public sector funding agencies (e.g. the Medical Research Council). Moreover, when compared to the estimated cost of developing a new drug (recently estimated at US\$800Mn) these outlays appear limited. However, these comparisons are not appropriate. What is at issue are relative research allocations devoted to a specific disease area – research on multiple sclerosis. Consequently, to make any statement about the relative presence of MSS in UK biomedical research directed at multiple sclerosis, we need to have comparable data for other funding sources for (public domain) biomedical research that is disaggregated to provide disease specific funding allocations. Unfortunately neither is this data publicly available nor is access easy or affordable.

A methodological alternative adopted in the literature is to use indicators of the 'outcome' of research funding, such as publication counts in peer-reviewed journals, as a proxy measure¹⁵. There are a number of reasons supporting this approach. For example, the relevant data is available through the Institute of Scientific Information as recorded in the Science Citation Index and the Social Science Citation Index. A fair degree of standards and norms have

¹⁴ Four class intervals are used for the analysis: 80K (grants up to £80,000), 80-200K (grants greater than £80,000 and less than or equal to £200,000), 200K-1Mn (grants greater than £200,000 and less than or equal to £1,000,000), and >1Mn (grants greater than £1,000,000). All numbers are nominal.

¹⁵ Studies by funding agencies (e.g. The Wellcome Trust, UK and the National Science Foundation, USA), governments (US and Australia) and inter-governmental bodies (EC and OECD) have used this alternative.

evolved to provide a reasonable level of methodological uniformity between practitioners. Moreover, it is possible to demarcate biomedicine into specific subfields through the use of filters¹⁶. Most importantly, it is possible to link a specific publication to its source of funding through the acknowledgements stated in the article. This approach is considered more reliable as funding agencies do not possess comprehensive and time series data on the performance/use of their grants (Dawson et al., 1998, p19).

The research reported here uses The Research Outputs Database (ROD) – a database initially developed at the Wellcome Trust, which supplements the information recorded in the Science Citation Index with the information about authors and their funding sources and also disaggregates the data into biomedical subfields.

The Bibliometric Presence of MSS

To suggest that patient group biomedical funding ‘influences’ the research agenda requires the following empirical analysis:

- ❖ What is the patient group’s relative contribution to biomedical research funding in the relevant sub-field in comparison to other funding sources?
- ❖ What is the relative performance of the patient group’s funding allocation in comparison to other funding agencies?

The task is to establish the relative size and qualitative performance of MSS in comparison to other funding sources/agencies within the multiple sclerosis biomedical subfield. This requires the development of a filter to pull out papers from the *Science Citation Index* that pertains to research in multiple sclerosis¹⁷. The second task is to collect the funding acknowledgements for every paper within the data set and collate these acknowledgements across each funding agency. The above exercise led to the creation of a unique dataset of 1376

¹⁶ The term biomedical refers to clinical medicine, basic biology (excluding botany and ecology) and biochemistry (Dawson et al., 1998). As such, eight scientific disciplines are popularly used to examine research output, viz. clinical medicine, biomedical research, biology, chemistry, physics, earth and space science, engineering and technology and mathematics. It is within the category of ‘biomedical research’ that subfields like multiple sclerosis are subsequently identified using key words.

¹⁷ The sub-field is developed by the use of a filter (i.e. a set of keywords) working on paper titles in an iterative process. This was conducted by the Bibliometric Research Unit at City University.

papers with 2644 distinct funding acknowledgements, involving about 450 different funding agencies (cf. table 3).

Importantly, it is clear that MSS is the most frequently acknowledged funding agency for research in the MS sub-field, accounting for 18% of the total acknowledgements (cf. table 3). The Medical Research Council (13%) and the Wellcome Trust (11%) come second and third respectively. A side note to this distribution of funding acknowledgements is the observation that charities and foundations are largest institutional supporters of biomedical research in this subfield, accounting for 54% of the acknowledgements. In contrast, government funding bodies together account for 30% of the acknowledgements and industry-based agencies account for only 9% of the acknowledgements.

Table 3
Top Five Most Frequently Acknowledged Funding Agencies

	1988- 90	1991- 93	1994- 96	1997- 99	Total Acknowledgements	
					No.	%age Share
Multiple Sclerosis Society	104	124	121	134	483	18.27%
Medical Research Council	67	73	85	126	351	13.28%
Wellcome Trust	34	63	100	105	302	11.42%
Institute of Neurology	0	16	39	2	57	2.16%
Commission of European Communities	0	4	14	34	52	1.97%
Acknowledgements (No)	392	583	730	939	2644	100.00%
Papers (No.)	247	305	339	485	1376	

Source: Author's calculations from Research Outputs Database

The issue of 'influence' requires closer analysis of the quality of publications resulting from the funding agency's grant allocations and the impact of the publications within the 'world of science'. The impact of publications on a biomedical sub-field can be assessed in a number of different ways: research publications might improve medical training; clinical care might be enhanced through comparative examination of evidence-based practices; new techniques, methods of diagnosis or drugs might result from the research.

Unfortunately, it is difficult to systematically and objectively investigate any of the above potential indicators. An alternative is to assess impact through proxy quality indicators like citation scores, or surrogate measures of research quality like 'journal impact level' and 'research level' (see below) (Dawson et al., 1998), or through citation rates in patents (Narin

et al., 1997; McMillan et al., 2000). The research here uses surrogate measures of research quality (see Dawson, op. cit.):

- *Journal Impact Levels (W)*: Each journal is assigned a score based on the citation rates (within the relevant subject area) of the peer-reviewed publications in the journal. A score of 4 is assigned to journals that are ranked within the top 10% based on citation rates. Journals ranked within the bottom 40% are awarded a score of 1. A score of 3 is awarded to journals within the second and third deciles, while 2 is awarded to journals ranked within the 4th and 6th deciles.
- *Research Levels (RL)*: Journals are characterised by assessing the dominant characteristics of the papers it publishes. Following a methodology developed by the US-based CHI Research Inc., four categories of research have been identified – basic research (RL=4), clinical investigation (RL=3), clinical mix (RL=2) and clinical observation (RL=1)¹⁸.

Table 4
Comparing Funding Agencies – Journal Impact Scores

MRC (13%)	3.10
WT (11%)	2.67
MSS (18%)	2.75

Note: i) Journal impact scores are mean scores for the entire time period. ii) Percentages in brackets report the share of total funding acknowledgements accruing to the funding agency

Source: Author’s calculations from Research Outputs Database

¹⁸ We agree that the research occurs across a continuum, making it difficult to differentiate either research or publications into separable research levels. However, there is an analytical usefulness in classifying journals based on the dominant characteristics of the research material published. Basic research denotes fundamental scientific research, clinical investigation refers to research that is more applied in character, clinical mix refers to research that integrates applied research and aspects of clinical observation, and clinical observation corresponds to research that is pure applied and/or technical in nature. The use of numbers to refer to the research levels does not suggest ordinal ranking or hierarchy between different research types.

The influence of peer-reviewed publications is examined through citation rates, which we represent through a proxy indicator – ‘journal impact score’. MRC has the highest mean score (cf. table 4). However, MSS performs well in that its mean scores compare is above that of Wellcome Trust and indicates that peer-reviewed papers funded by the patient groups are (on average) published in journals ranked within the 2nd and 3rd deciles in terms of citation rates. It is also useful to keep in mind that journal impact scores tend to be higher for journals that are characterised as ‘basic research’ journals. Consequently, the higher score registered by MRC – and by extension the relatively lower score by MSS – could partly be accounted by the composition of research funded by the agency (cf. figure 3). The mean scores are not adjusted by an appropriate weight, such as the relative share of funding acknowledgements¹⁹. It is conceivable that the ranking of funding agencies would change with the use of an appropriate weight, particularly since MSS accounts for largest share of acknowledgements.

Interestingly, with different levels of emphasis, all funding agencies tend to have a low level

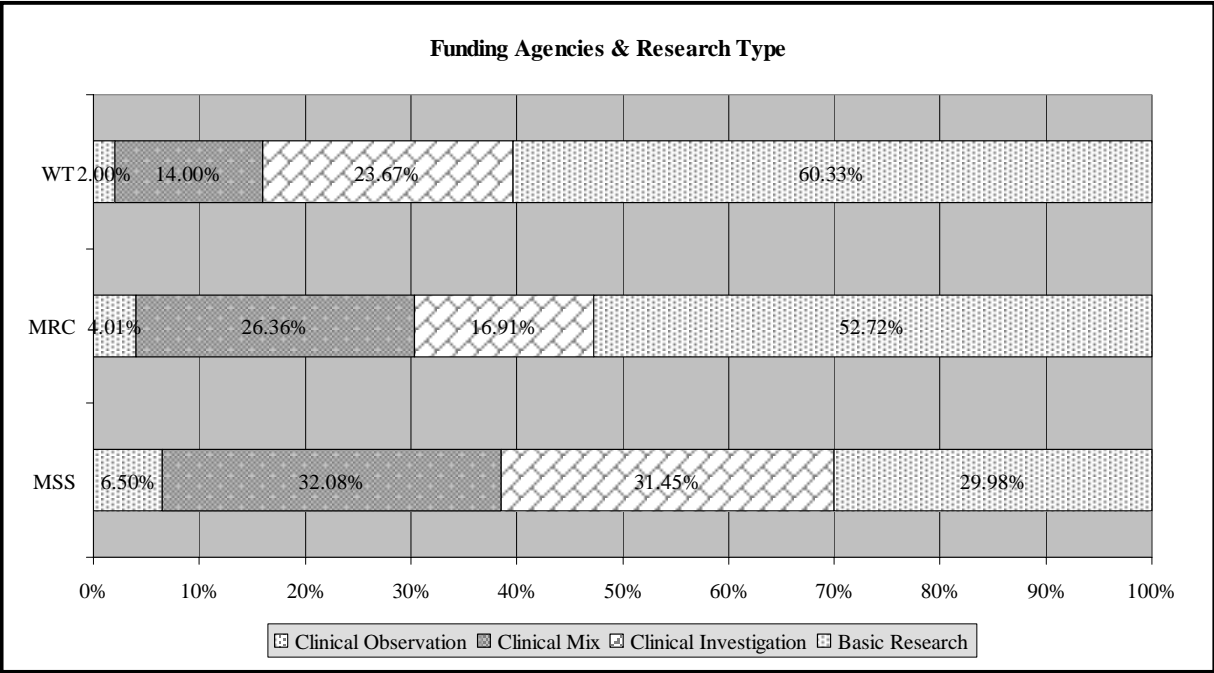


Figure 3

of funding acknowledgements in research characterised as ‘clinical observation’. Yet, there are differences in the distribution of funding across research types supported by each of the

¹⁹ Limitations with the explanatory use of indicators of journal impact scores have been recognised in the literature (e.g. Seglen, 1997).

funding agencies. MSS funded papers are evenly distributed across basic research, clinical investigation and clinical mix. In comparison, both MRC and WT exhibit a significantly stronger commitment to basic research with 53% and 60% of papers acknowledging their funding classified in this category. This suggests that MSS tends to prefer a broader spectrum of research activity – more importantly, the greater share of acknowledgements within research classified as ‘clinical investigation’ and ‘clinical mix’ suggests an effort to move basic research into clinical practice.

Discussion

To analyse the empirical evidence and assess it in terms of the issue at hand – patient group influence on biomedical funding – we first reiterate our key empirical observations:

- ❖ MSS is a regular and stable source of funding for biomedical research in multiple sclerosis. The Society has tended to award fewer, but larger grants in recent years.
- ❖ Using funding acknowledgements in peer-reviewed publications as a proxy for relative contributions to a defined biomedical subfield, we identify MSS as the leading funding agency. MSS is the most frequently acknowledged funding agency ahead of either MRC or WT.
- ❖ Analysis of bibliometric performance indicators demonstrates that MSS funded research perform well in comparison to the other key agencies (MRC and WT). Of importance are differences in the distribution of acknowledgements across research types exhibited by MSS in comparison to MRC and WT.

Two bodies of literature are relevant to other discussion of the above empirical observations: (a) evolutionary economics, where the spillover effects of publicly accessible basic research and the stimulating effects resulting from the formation of ‘scientific communities’ have been noted, and (b) social studies of science and technology, where sociologists and anthropologists have focussed on the role and influence of patient associations on the orientation, management and direction of biomedical and clinical research.

A classic rationale for the public funding of research was the incomplete appropriability of the returns to investments in research (Nelson, 1959; Arrow, 1962). However, recent theorising emphasises the distinction between information and knowledge to suggest that firms require

‘in-house capacity’ to recognise, assimilate and exploit publicly available knowledge (e.g. Cohen and Levinthal, 1989, 1990; Pavitt, 1991; Rosenberg, 1990)²⁰. Stated differently, this research concludes that knowledge is only a local, contingent public good – neither is it entirely codified into information nor are knowledge transfers free of costs²¹. Consequently, firms undertake in-house R&D as a means to develop and maintain absorptive capacity, i.e. the ability to assimilate and exploit externally generated knowledge. From this conceptual base it is argued that changes in the knowledge base²² through publicly conducted research generate techno-economic opportunities that stimulate and influence downstream developmental research (Stephan, 1996; Pavitt, 2000; Salter and Martin, 2001).

The second theme from evolutionary economics draws attention to the formation of loose and semi-formal ‘scientific communities’ through research funding. Apart from shared subject interest, entry into these ‘loose organisations’ requires a ‘credible’ contribution, i.e. demonstration of high-quality research, testified by publication in peer-reviewed journals (Hicks, 1995). The need to gain access to the ‘community’ is mainly warranted by the fact that publications are incomplete disclosures of the knowledge domain. Informal links and associations are key mechanisms for accessing the undisclosed and tacit components of knowledge. Moreover, by establishing links to leading scientific communities, external agents are able to participate in and influence the construction of public sector research agendas. Thus, in the interest of being ‘connected’²³ to the relevant scientific community, external agents will seek to build credibility by conducting research and publishing in high-quality peer-reviewed journals (see Cockburn, 1998).

²⁰ Much of the discussion here emphasises the role of public science in encouraging and stimulating private sector research. The interactions are definitely more complex and it is often the case that clinical practices advance beyond the frontiers of existing basic science. No doubt, the relationship between ‘science’ and ‘technology’ is complex and interactive, rather than unidirectional as might be suggested by the discussion here.

²¹ The fact that research results of a public project are *freely* available does not mean that a firm aiming to use and exploit these results can do so *freely*, without incurring costs.

²² Changes in knowledge base occur through a wide variety of routes: increases in peer-reviewed biomedical publications, human capital and skill development, articulation of new codified rules, and development of new clinical methods and practices.

²³ The growing linkage between public-private sciences is most apparent in the case of biotechnology. High citation rates of publicly conducted research in patents is a compelling indicator of the

Using the above theoretical principles, we note that MSS is a leading funding agency, both in pure financial terms where it exhibits a regular and sizeable resource allocation and in terms of our proxy indicator of funding acknowledgements. In addition, the positive performance of MSS in quality indicators suggests that the Society generates significant spillovers that would stimulate downstream developmental research. Further, MSS is seen to be acknowledged in different research categories, suggesting an effort to pursue and develop basic research findings. Interestingly, drawing on the second theme, research funding from MSS is almost entirely allocated to researchers in higher education institutes, which suggests the formation of loose scientific networks.

From the social studies of science/technology literature we draw upon recent conceptualisation of the emergence of patient groups on the landscape of biomedical research as ‘researchers in the wild’ (Callon, dt). Here it is suggested that the growing socio-political presence of ‘disease constituencies’, which heralds patient groups as ‘obligatory passage points’, is manifested in network proliferation and modification of institutional landscapes. With specific reference to biomedical research, Callon (op. cit.) identifies three key movements within the patient group: problem formulation, collaborative research and transposition of clinical results.

We tentatively suggest that MSS manifests some of the above characteristics. For example, the Society is a regular source of biomedical funding and demonstrates active involvement in ‘problem formulation’. Of relevance here is the Society’s use of patient stories in its submission to NICE on the beta interferon case. Equally pertinent is the role played by the Society in ‘setting the agenda’ in clinical trials to assess the efficacy of cannabinoids in the use of treating spasticity. The spread of research supported by MSS, in particular its greater presence in research characterised as ‘clinical investigation’ and ‘clinical mix’, allows us to infer that the Society actively seeks to take basic research results forward into clinical practice. However, at this stage of our research, it is difficult to make a stronger conclusion.

A number of issues and questions remain unanswered. For example, there are troubling questions of causality: ‘who initiates and directs the grant-giving process?’ ‘how is the process organised, and do patients actually participate in the process?’ ‘what role do scientists

‘connectedness’ between the two domains – and of the impact of public science on private research activities (Narin et al., 1995, 1998).

play through the Medical Advisory Panel?’ In addition, the question of ‘influencing the research agenda’ is itself highly problematic. These questions are part of the on-going research project.

Yet, the paper makes useful and important contributions to the study of ‘technology and the public’. It contributes to the growing focus on patient groups as actors in transforming the health care system. Methodologically the paper attempts to bring together two interconnected literatures: the evolutionary economics literature and the social studies of science/technology literature.

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References

- Available on request, and will be included with the next revision of the paper