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Reflexive Governance in the Public Interest

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Reflexive Governance as Social Learning in Non-Governmental Organisations: Two Case Studies of the Genetic Approach

by Caroline Mullen and Peter Vincent-Jones

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Reflexive Governance as Social Learning in Non-Governmental Organisations: Two Case Studies of the Genetic Approach[1]

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Introduction

Non-Governmental Organisations (NGOs) have a longstanding and prominent role in British society.[2] Among these NGOs are charities who have responded to particular social needs by seeking to represent the interests of various patient groups and carers (the charities' beneficiaries). Broadly, such organisations aim to represent their beneficiaries' interests by combinations of direct service provision and engagement in activities and debate designed to influence decisions on commissioning in health and social care services, government policy, and wider social attitudes. More specifically, these NGOs face questions of what activities they should undertake, and how they should approach these activities, in order effectively to promote the interests of their beneficiaries. They need also constantly to consider whether and how their activities and approaches might adapt in the face of changing political, economic and social conditions coupled with developments in science and research on health and social care.

This study considers two charitable NGOs working in the field of health and social care in England.[3] The activities of these organisations are analysed with reference to the hypothesis of reflexive governance as social learning developed in the REFGOV project. On this hypothesis, the ability of actors such as NGOs to realise the interests of those they represent will depend on their engaging in processes of reflexive social learning, in particular on their ability if necessary, to transform their collective identity by reframing the way in which they represent their interests.[4] The research has been conducted through interviews with the organisations, the findings and analysis being based on the organisations' own perceptions of their aims and work. This report of the two case studies begins by outlining our interpretation of the REFGOV theory of reflexive governance as social learning (section I). We then set out our empirical research questions (section II), explaining why NGOs have been chosen as a study of reflexive governance, and how we approached the investigation of reflexive social learning in this context. An account is then given in section III of the changes to the policy environment for NGOs in England since the arrival of the New Labour government in 1997, highlighting both the increasing opportunities for NGOs to influence policy and provide publicly funded services, and the problems posed for NGOs' independence. We then present the two case studies in sections IV and V. In each case we begin with a description of the organisation's aims and work derived from interviews with staff of the respective organisations. Drawing on the theory of reflexive governance we present our analysis of the organisation's activities and developments.

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2   See for instance, House of Commons Public Administration Select Committee, '*Public Services and the Third Sector: Rhetoric and Reality', Eleventh Report of Session 2007–08,* Volume I HC 112–I, (2008)', 9.

3   The NGOs' work is not restricted to England. However the study considers the NGO's activities in the context of the particular policy environment that they work within. This policy environment is different in each of the UK countries.

4   Lenoble, J and Maesschalck, M., *Democracy, Law and Governance* (Aldershot, Ashgate) (forthcoming 2010), part II chapter 6; Lenoble J. and Maesschalck M., 'Renewing the Theory of Public Interest: The Quest for a Reflexive and Learning-based Approach to Governance', in de Schutter and Lenoble, eds., 2010, 3-23.

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I. Reflexive governance as social learning

The motivation for the REFGOV account of reflexive governance as social learning stems from failures of both bureaucratic hierarchy, and market approaches to governance (in our case, governance of health and social care).[5] According to the REFGOV account, reflexive governance implies decision making that is responsive to the opinions and interests of those affected by the decisions in question. Within this conception, the public interest is defined with reference to the normative expectations of those to whom the governance applies: in other words the public interest is not objectively or authoritatively determined, but neither is it held to be a purely subjective matter.[6] The authors of this report suggest that the phrase 'normative expectations of the members of a collective action' can be understood in terms either of what the members believe *should be done or gained*, or of *the manner in which* (or *how*) the interests with which they are primarily concerned should be met.[7]

On the REFGOV theory, if governance is to be capable of 'maximising the satisfaction of normative expectations'[8] of actors, then that governance must enable decisions to result from processes of social learning by the actors. Four approaches to social learning are identified: these approaches are not considered to be mutually exclusive, but instead each expands the account of the conditions of learning required if actors are to be able to 'provide for the best possible fulfilment of …their normative expectations.'[9] The first approach is neo-institutionalism. In this approach the rules governing activity are designed to create incentives or disincentives so that people act in ways that conform to the general or public interest. That is:

> Neo-institutionalists recognise the role of institutions in shaping expectations and in solving coordination problems; and they seek to alert us to the need to conceive of 'choice' between different options as having to be guided.[10]

However if (as in the REFGOV theory) the public interest is defined with reference to the normative expectations of those to whom governance applies, then there is an objection to reliance on the neo-institutionalist approach, since neo-institutionalism assumes an "'externalist' concept of learning, in which the public interest is defined

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[5]　de Schutter and Lenoble, *Introduction* in de Schutter and Lenoble, eds., 2010, xv-xvi

[6]　See Lenoble J. and Maesschalck M., 'Beyond Neo-institutionalist and pragmatist approaches to governance, *Working Paper Series: REFGOV-SGI/TNU-1*, Centre de Philosophie du Droit, UCLouvain (2006). Lenoble and Maesschalck suggest the idea that 'spontaneous convergence occurs between and private interests and public interests' has been rejected, but that this rejection 'often leads to a skeptical and constructivist position, according to which it is necessary to abandon any claim to a theoretical position about the public interest and by implication any theoretical investigation of the conditions for its satisfaction.' They want to avoid this sceptism, but also to deny that 'research into the public interest is equivalent to research into normative criteria for defining the public interest.' Therefore they 'define the problem of conditions for satisfaction of the requirements of the public interest or the common good as conditions that must be respected in order for a (collective) action *to maximise satisfaction of the normative expectations of its members*. Such a definition internalises the possible gap between the general expectation of rationalization and the way in which the actors themselves conceive of the interests to be satisfied. This internalisation yields the benefit of avoiding the presumption of a possible a priori definition of such expectations.' *ibid* 5.

[7]　 If there is reframing then it may also refer to their understanding of what interests they are primarily concerned with. So 'expectations' are not solely self-interested (as private interests are expected to be, e.g. in accounts of the market).

[8]　*Ibid*

[9]　Lenoble and Maesschalck, in de Schutter and Lenoble, eds., 2010, 4.

[10]　de Schutter and Lenoble, in de Schutter and Lenoble, 2010, xvii

from above, outside the actors concerned, defining the boundaries which the actors are prohibited from crossing."[11] In other words, a neo-institutionalist approach will set out and influence choices available to those actors subject to the governance, however it will not provide for those actors themselves to engage in decision-making (such as decision-making on the choices that should be available) and in solving governance problems.

In contrast to neo-institutionalism, the three further approaches within the REFGOV theory 'internalise' the conditions of social learning, so that it is the actors themselves who engage in decision-making involving social learning.[12] The first of these, the deliberative or collaborative/relational approach, is concerned with the actors' capacities to engage in deliberative processes of decision-making and problem solving. On one interpretation, the ideal here is that through discussion and debate, people seek decisions capable of being justified 'to all affected' by the decision.[13] In seeking agreement (or 'justifications'), people need to engage in 'public reasoning' and to 'go beyond the self-interests typical in preference aggregation and orient themselves to the common good.'[14] While deliberation may aim at agreement, there is (probably unsurprisingly) no guarantee of consensus. Nevertheless, through deliberation it may be possible for actors to engage in a learning process and so to increase confidence that resulting decisions would be justifiable to those affected. Arguably this process of decision-making (and learning) would involve actors presenting their opinions and arguments, which would be either accepted by others, or would be challenged on the basis that there are reasons for rejecting or doubting them. Progress towards agreement would depend on participants in deliberation being willing to accept such challenges to their own opinions and positions, or to provide further reasons for rejecting the challenges (and these further reasons would in turn be subject to challenge). Ultimately however people can have conflicting positions, each of which are supported by sound argument, and thus it is possible that actors in deliberation may arrive at a point where disagreement cannot be resolved through further discussion.[15]

Such conflicting opinion is one potential limitation of the collaborative/relational approach to social learning, addressed in part by the third (pragmatist) and fourth (genetic) approaches to governance identified in the REFGOV project. These approaches identify and respond also to other limitations of deliberation which stem from the way in which 'knowledge is provisional and radically contextualised.'[16] In particular, changes to, or uncertainty about circumstances and conditions may mean that information available to actors in deliberation is partial, and so decisions reached on the basis of that knowledge tend to

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[11]   de Schutter and Lenoble, in de Schutter and Lenoble, 2010, xxix. This objection is explained further: 'Neo-institutionalists …assert that the common will must be restored and rehabilitated, and given a central place in directing the evolution of society. However, they fail to define who is to define this common will, and in the name of which privileged access to what is in the general interest it should be recognised primacy', de Schutter and Lenoble, in de Schutter and Lenoble, 2010, xvii -xviii

[12]   Lenoble and Maesschalck, in de Schutter and Lenoble, 2010, 13.

[13]   Chambers points to the common idea across conceptions of deliberative democracy, that the legitimacy of decisions depends on 'justification to all affected' – Chambers, S. 'Deliberative Democratic Theory', *Annual Review of Political Science* 6, 2003, 309.

[14]   Bohman, J. 'The Coming of Age of Deliberative Democracy', *The Journal of Political Philosophy,* 6, 4, (1998), 402.

[15]   See Vincent-Jones and Mullen, in O. de Schutter and J. Lenoble 2010, 156-158; Mullen, C 'Representation or Reason: Consulting the Public on the Ethics of Health Policy' 16(4) *Health Care Analysis* (2008) 397–409.

[16]   de Schutter and Lenoble, in de Schutter and Lenoble, 2010, xviii

be liable to challenge.[17] The third approach identified by the REFGOV theory is described as pragmatist, and consists of two distinct strands. Firstly, democratic experimentalism (described as 'best represented in the work of Charles Sabel'[18]) responds to the limits of deliberation by maintaining that:

> it is necessary that actors be engaged in a process of joint inquiry in order to 'allow themselves' to be taught by the results of an experimental encounter between existing solutions and new problems requiring solution[19]

Lenoble and Maesschalck[20] describe how the second strand of the pragmatist approach (developed by Donald Schön, Chris Argyris and Martin Rein[21]) considers actors' capacities to represent their interests in different contexts or circumstances.[22] That is, it is concerned with:

> the operation by which one adopts an identity – that is, by which we 'represent' ourselves, we represent our 'interests' in a given context of action, and we 'present ourselves as actors' capable of interacting with other actors in order to advance our own interests[23]

This approach maintains that unless actors are capable of reframing the way in which they represent their interests in the face of changing conditions or circumstances, then they may face difficulties in reaching decisions through collaborative/deliberative or democratic experimentalist processes. Further, it is argued that actors have a tendency to use 'defensive strategies' in order to avoid reframing the representation of their interests. According to Lenoble and Maesschalck, this approach recognises that actors will not 'spontaneously' alter the frame by which they determine their ''interests' in a given context of action', and instead actors need to give particular attention to this reframing. Such reframing, "or true learning or 'double loop' learning in the vocabulary of Argyris and Schön, must be distinguished from mere adaptation of policies to changing environments, without questioning our background assumptions or mental maps."[24] However, the problem with this notion remains that:

> the mere incentive to the development of this generative attention is presented as automatically producing the attitudes and competencies required for a capacity to transform one's 'frames'… Thus the assumption is that, in some manner or another, there exist pre-given rules and capacities that are already available.[25]

The fourth (genetic) approach avoids the assumption about such 'pre-given rules' enabling actors to undergo a process of reframing. This approach maintains that such reframing involves the organisation of a 'specific "pragmatic operation", designed to lead the actor to construct the representation she or he has formed of the new identity that the change in context requires'.[26] This operation has two parts: the first is a

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[17]   Such uncertainty is raised by Gilson, RJ, Sabel, CF and Scott, RE 'Contracting for Innovation: Vertical Disintegration and Interfirm Collaboration' 109 *Columbia Law Review* (2009) 431–502.
[18]   de Schutter and Lenoble, in de Schutter and Lenoble, 2010, xviii
[19]   Lenoble and Maesschalck, in de Schutter and Lenoble, 2010, 16.
[20]   Lenoble and Maesschalck, in de Schutter and Lenoble, 2010, 16-18.
[21]   See de Schutter and Lenoble, in de Schutter and Lenoble, 2010, xviii
[22]   What the actors conceive as their interests, and how they explain or justify those interests.
[23]   Lenoble and Maesschalck, in de Schutter and Lenoble, 2010, 17
[24]   de Schutter and Lenoble, in de Schutter and Lenoble, 2010 xix, citing Argyris, C. and Schön, D., *Organizational Learning: A Theory of Action Perspective* ((1978; Reading, Mass, Addison Wesley), 2-3.
[25]   *Ibid*
[26]   *Ibid,* 19

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'dimension of *reflectibility'* described as the 'first dimension of *the installation of the capacity to be an actor* (i.e., the operation of self-capacitation)'[27] in which:

> The collective actor must experience itself through its capacity to represent itself, that is, to form an identity whose substantive representation can vary and adjust according to transformations occurring in the contexts for action.[28]

In other words, the actor needs to realise both *that* it has an identity and frame by which it determines how to represent its interests in different contexts and circumstances, and that this identity can be altered. The second part of the operation is a 'dimension of '*destinability'* (the 'second dimension' of 'the operation of self-capacitation'), and 'concerns the relationship with the future'.[29] This involves the actor considering *how* it should alter its identity frame; that is examining *how* it should change the way in which it represents its interests so as 'to ensure the fulfilment of this [identity] form in a new context for its application.'[30]

II.   Research questions: NGOs and reflexive social learning

NGOs were chosen for this case study as they potentially provide an illuminating site for investigation of the 'internal' approaches to reflexive social learning. One reason for this stems from the rationale of NGOs that exist to address some social or environmental need.[31] In the case of NGOs concerned with health and social care, their rationale is to further interests of particular groups of patients or carers, and this involves promoting ideas, such as opinions of how policy should develop, or how services can be provided. NGOs may not view these interests as being satisfied within either bureaucratic, or market-based, or even neo-institutional forms of governance, since all of these methods provide little opportunity for the NGOs to bring their ideas to processes of decision-making in policy or design and provision of services. So NGOs may seek to engage in deliberative (collaborative/relational), and democratic experimentalist processes, both of which provide some scope for the NGOs to participate in decision-making which enables them to express and debate their ideas. NGOs working in health and social care in England may also have reasons to reframe the representation of their interests given significant changes to the policy environment in which they operate, coupled with developments in research relevant to their work. If there is any such reframing, then we can consider whether it may be understood with reference either to Schön and Argyris' pragmatism, or the genetic approach.

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27   *Ibid,* 20
28   *Ibid*
29   *Ibid*
30   *Ibid*
31   Non-governmental organisations making up the 'third sector' are described as 'value-driven and which principally reinvest their surpluses to further social, environmental or cultural objectives … …the sector includes voluntary and community organisations, charities, social enterprises, cooperatives, commercial and private donors and mutuals.' http://www.esrcsocietytoday.ac.uk/ESRCInfoCentre/Images/ESRC%20Third%20Sector%20Engageme nt%20Strategy_tcm6-25071.pdf. Note that voluntary and community organisations are referred to as 'VCOs.' For further discussion of the definition of the third sector see: Kelly, J., 'Reforming Public Services in the UK: Bringing in the Third Sector', *Public Administration* 85, 4 (2007), 1004-1008; Carmel, E. and Harlock, J., 'Instituting the 'third sector' as a governable terrain: partnership, procurement and performance in the UK', *Policy & Politics* 36, 2 (2008), 155-71.

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The case studies consider two NGOs operating in differing areas of health and social care. We examine the work of each in seeking to influence government policy and commissioning in these fields, and in developing and providing services, in the context of a rapidly changing policy environment. The studies examine whether or how these activities of the NGOs can be understood according to the REFGOV hypothesis on the conditions of social learning which enable actors to maximise satisfaction of their normative expectations.[32] The studies focus specifically on the actors' engagement in 'internalised' learning processes (i.e. involving the deliberative or collaborative/relational approach, the democratic experimentalist approach, the pragmatist approach of Schön and Argyris, and the genetic approach), with particular attention to any transformation of their collective identity for action involving reflectibility and destinability. We should emphasise that these are qualitative studies of social learning involving the two NGOs, and that the empirical research has considered only the perspective of the two separate organisations. Consequently while we are able to comment on the organisations' views of their own success in meeting the normative expectations of their beneficiaries, we cannot make a judgement as to whether processes of social learning have contributed to the public interest (such an account would require examination of the range of actors involved in the relevant area of health and social care).

First, in relation to the NGOs' development and provision of services, the studies consider whether any organisational changes can be understood as transformation of collective identity 'in a context for action', and if so, how these transformations impact on the NGOs' ability to develop and provide services in a way that meets the normative expectations of their beneficiaries. We investigate these questions by studying changes and developments in how the NGOs: (a) perform contract bidding and service providing functions; (b) involve patients and the public in service specification and management; and (c) engage in research and evaluation, including any experimentalist and collaborative practices such as joint inquiry, peer review, and benchmarking in developing expertise.[33]

Secondly, in relation to influencing health and social care policy, we again consider whether changes in the NGOs' representation of their interests can be understood as transformation of collective identity for action, and examine how this transformation impacts on the NGOs' ability to fulfill the normative expectations of their beneficiaries to the greatest extent possible. These questions are addressed by studying developments and changes in: (a) choices made by each NGO of issues on which to focus (involving examination of why these issues have been selected rather than others, what are the 'public interest' grounds for the selection, and whether the interests are sectional or general within the group); (b) the degree of receptiveness of policy makers to inputs from NGOs (including the nature of any subsequent deliberation or dialogue); (c) the analysis of the issues by NGOs following the government's response or lack of response to their input, including whether the government response is considered reasonable; (d) the government's position, including any evidence of increased receptiveness to NGO input following the initial exchange; and (e) the strategy on the part of NGOs (including changes in the way in which they advance their argument, or their priorities).

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[32]   Lenoble J. and Maesschalck M., 'Beyond Neo-institutionalist and pragmatist approaches to governance , *Working Paper Series: REFGOV-SGI/TNU-1*, Centre de Philosophie du Droit, UCLouvain (2006), 5

[33]   Joint inquiry, peer review and benenchmarking are aspects of democratic experimentalism, particularly experimentalism presented by Sabel –see See Sabel, C. F. 'Learning by Monitoring. The Institutions of Economic Development' in NJ Smelser and R Swedberg (eds), *The Handbook of Economic Sociology* (1994; Princeton, Princeton UP and Russell Sage Foundation) 137–65; Vincent-Jones and Mullen, in O. de Schutter and J. Lenoble 2010, 158

III.   Changing policy environment for NGOs

The policy environment for NGOs changed substantially under the New Labour administration which began in 1997. The Government's enthusiasm for engaging the energies of NGOs (as part of the 'third sector'[34]) created significant opportunities for those organisations to raise their profile as actors within health and social care networks, by influencing policy making at national level, by engaging in decision-making on commissioning of public services,[35] and bidding for and winning social care and health service contracts.[36] However, such opportunities have been accompanied by novel challenges. Closer ties with government in the making and development of policy have posed new problems for NGOs in how to promote 'general interests' while continuing to serve the needs of the particular patient and carer groups they represent. Furthermore, the extension of the role of these bodies to include the delivery of services under contract with government has led to tensions with their traditionally independent public service mission.[37] Craig, Taylor and Parkes suggest that: 'as these organizations gain access to the policy-making process, they face difficult strategic decisions in balancing the opportunity to gain influence with the need to maintain their independence and autonomy.'[38] Carmel and Harlock argue similarly that organisations have found themselves 'under pressure to change their organisational forms and even goals in response their involvement in public service delivery.'[39]

1.   <u>NGOs and health and social care services</u>

NGOs (and the wider 'third sector') have been seen by the Government 'as being neither market nor state',[40] with a particular capacity for innovation:

> The key dimensions of this apparent distinctiveness were and are that it is
> independent, not hidebound by bureaucracy like the state, and therefore able to be

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[34]   The term 'third sector' refers to 'non-governmental organisations which are value-driven and which principally reinvest their surpluses to further social, environmental or cultural objectives … as such the sector includes voluntary and community organisations, charities, social enterprises, cooperatives, commercial and private donors and mutuals.' http://www.esrcsocietytoday.ac.uk/ESRCInfoCentre/Images/ESRC%20Third%20Sector%20Engageme nt%20Strategy_tcm6-25071.pdf. Note that voluntary and community organisations are referred to as 'VCOs.' Further discussion of definitions of the third sector may be found in: Kelly, J., 'Reforming Public Services in the UK: Bringing in the Third Sector', *Public Administration* 85, 4 (2007), 1004-1008; Carmel, E. and Harlock, J., 'Instituting the 'third sector' as a governable terrain: partnership, procurement and performance in the UK', *Policy & Politics* 36, 2 (2008), 155-71.
[35]   See Cabinet Office of the Third Sector, and the Improvement and Development Agency (I&DeA), Shared Intelligence, *Evaluation of the National Programme for Third Sector Commissioning Baseline Report*. (2008) I&DeA
[36]   While NGOs have historically provided publicly funded services to client groups, this has tended to be on the basis of government grants – see for instance, Public Administration Select Committee 2008, para 17.
[37]   Craig, G., Taylor, M. and Parkes, T., 'Protest or Partnership? The Voluntary and Community Sectors in the Policy Process'*, Social Policy & Administration* 38, 3 (2004), 221-239, 221.
[38]   *Ibid.*
[39]   Carmel and Harlock 2008, 155 (Carmel and Harlock cite Barnes, J. 'From charity to "not-for-profit": changes in the role and structure of voluntary social service agencies', in M. Fenger and P. Henman (eds) *Administering welfare reform*, (Bristol: The Policy Press, 2006)).
[40]   Carmel and Harlock 2008, 158. In support of this assertion, Carmel and Harlock cite: Home Office *Compact on relations between government and the voluntary and community sector in England*, London: The Stationery Office (1998).

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innovative. It is close to users, and thus especially able to respond to their needs, generating trust from 'hard-to-reach' social groups. [41]

The closeness of third sector bodies to the community, and their ability to promote voluntary work within the particular communities they serve, are considered to have the further benefit of increasing social cohesion.[42] However in addition to this claim that the third sector can offer a distinctive benefit in delivery of services, the Government has maintained that 'the sector deserves parity of treatment with other sectors.'[43]

The changes in government attitude described above have been accompanied by a new emphasis on 'partnership' with the voluntary sector:

> Partnership can be directly contrasted with the competitive contracting policy that dominated UK–voluntary sector relations up to the late 1990s. From 1998, the role of VCOs in UK public service delivery, and their relationship with the state, were considered to be governed by the 'Compact' with government. This Compact outlines positions of mutual respect, and recognition of the independence of VCOs vis-à-vis the state (although it is without legal status).[44]

However, the government's enthusiasm for the third sector and the opportunities for NGOs to which this has given rise, both in the direct provision of publicly funded services and in influencing national policy, have led also to problems and tensions in reconciling different dimensions of their role. The representation of the third sector as having 'apparently *shared v*alues with the Labour government'[45] has resulted in the perception of its conflation with the 'statutory sector as *generic service providers* (HM Treasury, 2002: 5).'[46] The problem is that '[t]he discourse of partnership [with the third sector]…presents an 'illusory unity' (Newman, 2001) of public and VCO services, disguising important disparities between them, while simultaneously lauding VCOs' distinctiveness and independence.'[47]

This account is not intended to imply denial by government of the independence of third sector organisations. It does, however, reflect a certain re-presentation and re-definition of the role of voluntary bodies in government discourse, which fails to take sufficient account of the diversity of aims and underlying values of the many bodies that comprise the third sector.[48] The more these bodies are treated as

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[41]   Carmel and Harlock 2008, 158-159.

[42]   Kelly 2007, 1009.

[43]   Public Administration Select Committee 2008, para 7. The committee noted the complexity of the government's aim of achieving parity for the sector, coupled with its view that the third sector provides a particular benefit.

[44]   Carmel and Harlock 2008, 158. However 'TS organizations continue to formally contract for the delivery of specific services with central government departments and local authorities; although both government and the sector anticipate the new relationship will release added public value to the shaping, commissioning and delivery of public services more generally (Kelly *et al.* 2002; Blackmore 2004)' Kelly 2007, 1012; William Plowden, 'The Compact: Attempts to Regulate Relationships Between Government and the Voluntary Sector in England', *Nonprofit and Voluntary Sector Quarterly*, 32, 3, (2003), 415-438. . See also Cabinet Office of the Third Sector, *Overview of the Compact Codes*, www.thecompact.org.uk/information/100022/101508/overviewofthecompactcodes/

[45]   Carmel and Harlock 2008, 159

[46]   *Ibid*, citing HM Treasury, The role of the voluntary and community sector in service delivery: Across-cutting review (2002: London: The Stationery Office). 5.

[47]   *Ibid*, 159-160, citing Newman, J. *Modernising governance* (2001: London: Sage Publications).

[48]   It creates an 'unstable fiction of the unity and similarity of purpose, organisation and structure of the multitude of organisations that comprise it' *ibid*, 160. Carmel and Harlock further maintain that '[t]hrough the formal dimension of partnership and the operational dimension of procurement and performance, VCOs are to be drawn into and made subject to processes of state governing' *ibid*, 167.

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'*generic service providers*,'[49] the more difficult it will become for them to provide public services in ways that they hold to be most appropriate to the particular needs of their client groups.[50] This appears to conflict with the government's view that third sector organisations should be supported precisely because they are independent, innovative and close to users, and thus especially able to respond to their needs.[51]

2.   NGOs influencing policy

New Labour has broken with past governments in recognizing the potential of NGOs to contribute to the development of national policy in their specialist areas. Craig, Taylor and Parkes have noted:

> Most of the organizations studied agreed that the New Labour governments elected in 1997 and 2001 were more open to influence than their immediate predecessors — some indeed described a "sea-change" in the policy environment…'[52]

> These changes appeared to have created a policy environment with more "permeable" boundaries between government and those who sought to influence it. Under New Labour, key individuals from the voluntary and community sector have been drawn into new policy units such as the Prime Minister's Policy Unit, the Social Exclusion Unit and its Policy Action Teams, and the Neighbourhood Renewal Unit, as well as sitting on national policy advisory groups.[53]

This account of the transformation in the policy environment of public services is reflected in the suggestion that 'New Labour has signalled that it hopes that the (third sector) would play both supplementary and complementary roles to government.'[54]

New Labour arguably provided NGOs with greater scope for working with government, however NGOs need to consider how they should orientate themselves in relation to government: that is, to what extent should they embrace opportunities to become involved in policy processes or provision of public services, or adopt a critical stance as 'outsiders'?[55] Craig, Taylor and Parkes found views among some organisations that an approach of remaining an 'outsider' better enabled their organisation to get their 'issues on to the policy agenda' and further to 'hold on to their own agenda.'[56] By contrast, in the case of organisations working closely with government, it was noted that: 'Government players tired of those groups that continued to press for what they considered to be "lost causes" instead of assisting

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49   Carmel and Harlock 2008, 159.

50   This concern is heightened by reports that some organisations face practical difficulties in working in ways required by contracts with government – See Ann Blackmore et. al. 'The reform of public services: the role of the voluntary sector', (NCVO, 2005?). www.ncvo-vol.org.uk/asp/uploads/uploadedfiles/1/635/reformpublicservicesjune2005.pdf
It has also been argued that there are tensions for third sector organisations in providing public services in the way that they hold to be most appropriate. Kelly has pointed to regulatory oversight as a factor constraining organisations in their delivery of services –see Kelly 2007, 1016. In this context it is worth noting that according to the NCVO *UK Civil Society Almanac 2009*, *'[t]*he statutory sector has seen a strong, comparative shift from grant funding to contract funding over recent years,' (Reported by John Plummer, *Almanac shows sector depends more on contracts* Third Sector Online, 18 February 2009)

51   Carmel and Harlock 2008, 158-159.

52   Details of the study are given at Craig, Taylor and Parkes 2004, 223-224.

53   *Ibid*, 224.

54   Kelly 2007, 1014

55   Craig, Taylor and Parkes 2004, describe the dilemma as one of organisations choosing to act as insiders or outsiders (although they maintain that any organisation may choose a combination of forms of the two approaches)'

56   *Ibid*, 227

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them in honing government objectives'.[57] Some organisations considered that a benefit of working closely with government was the increased potential for bringing 'their own evidence and research to bear on policy planning and development,' and presenting 'special knowledge or perspectives which could change the way issues were viewed by decision-makers.'[58] However, this study found that making a case on the basis of evidence and research was equally effective for organisations working as 'outsiders':

> One of the large environmental organizations—though often dismissed by government as oppositional—funded research that drew attention to flaws in the economic arguments underpinning the building of a new city bypass in the south-east of England, and this evidence was hugely influential in the final decision to abandon the road.[59]

Various other issues arise in the analysis of the attempt by NGOs to influence government policy. Third sector bodies that engage in the direct provision of publicly funded services under contract with public purchasing agencies may be inhibited from critically engaging with government on policy issues.[60] There are concerns also about the partiality of voluntary organisations, and a suspicion that the arguments they present for policy development are linked with corporate sponsorship.[61] Further difficulties for NGOs seeking to influence policy stem from the complex conditions within which health policy is developed. For example, the Patient's Forum noted that '[i]t is increasingly difficult to influence national policy as more decisions are devolved and it becomes harder to know how to influence change.'[62] In their study, Craig, Taylor and Parkes note that '[h]aving a good understanding of how policy and policy development worked was seen to be essential to making an impact.'[63] A major problem faced by NGOs attempting to influence policy stems from the large number and diversity of organisations that are likely to be engaged in processes of policy development, and the high degree of diffusion of the 'voice' of the third sector. Even where a number of NGOs share similar aims and positions, there are significant obstacles to presenting their case in a co-ordinated manner, limiting the impact on the

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[57]   *Ibid*, 228

[58]   *Ibid*, 226

[59]   *Ibid,* 229. However the study also noted that '[u]sing the media was a tactic many such organizations used alongside more *insider* strategies when it was felt to be necessary: "A few well-placed newspaper articles are going to have more effect than many tomes of detailed policy analysis and discussion in terms of why something should be changed; getting on the Today programme is the best way to get your views over to politicians"' ibid, 233.

[60]   Many organisations in Craig, Taylor and Parkes' study 'felt that funders might try to use funding as a lever with which to hold organizations to particular policy lines or to discourage criticism,' *ibid,* 225. This concern was also expressed in the Patients Forum Discussion Paper, which also notes that '[T]he Compact between the voluntary sector and the Government safeguards the independence of voluntary organisations to speak out of behalf of their members and users. An NCVO report indicates that many organisations do not have confidence in this Blackmore, A (2004) Standing apart, working together: a study of the myths and realities of voluntary and community sector independence. NCVO.'- Hogg, C., Loosemore-Reppen, G. and Rowan, K., *Discussion Paper: The Patients Forum; Options for the future* (2006), 6-7.

[61]   Hogg, Loosemore-Reppen, and Rowan 2006, 7; Weale, A. 'What is so good about citizens' involvement in healthcare?' in
E. Andersson, J. Tritter and R. Wilson (eds.), *Healthy Democracy: The future of involvement in health and social care,* London: Involve and NHS National Centre for Involvement (2006) 37-43, 41.

[62]   Hogg, Loosemore-Reppen, and Rowan 2006, 5.

[63]   Craig, Taylor and Parkes 2004, 228.

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policy making process. This problem has been part of the motivation for collaborative initiatives such as National Voices and the Patient's Forum.[64]

IV.   Case study: social learning within a mental health charity

1.   Description

In recent years the organisation (which we shall call MENTHEAL) has undergone significant changes in its approach to service development and capacity to provide services, and in its approach to policy and campaigning. The following paragraphs offer an interpretation of developments in the organisation's work, based on analysis of open format interviews (conducted in Summer 2009) with staff working in the areas of service development and design, and campaigning and policy development ('SD' and 'CP' respectively in the following).

a)   Service development and design

   i.   Organisational capacity for provision of public services

SD showed MENTHEAL's awareness of the necessity for substantial organisational change in adapting to a policy environment which had shifted from statutory grant funding to contract commissioning. Since contract tendering began in the 1990s, there has been increasing recognition of the benefits of competing for large scale contracts which treat *'whole populations of need'*. The decision to bid for such contracts was motivated also by the concern to avoid over-reliance on working in partnership with bigger organisations. This sort of partnership might be with an NHS Trust which, on winning the contract, could subcontract part of the service to a voluntary organisation. While NHS Trusts and local authorities have some incentive to form partnerships with charitable bodies in order to *'build a bridgehead'* with the voluntary sector, MENTHEAL believes that such arrangements may present a risk to the organisation's independence.

   SD suggested that MENTHEAL has recently reached several milestones in the organisational development needed to create the capacity to bid for large scale contracts. The potential difficulties of such development, including problems of practical positioning and of securing accountability for and reflection on the changes taking place, have been recognised. The problem of market positioning is illustrated by the example of therapy services which, until very recently, MENTHEAL had little experience of delivering. SD described how an unmet need for these services had been identified through patient surveys. This development work enabled the organisation to bid for and win contracts for these publicly funded services when the

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[64]   E. Taggart, on behalf of National Voices Working Group, *National Voices; A proposal to strengthen the voices of service users, patients and carers in national health and social care policy making* (2007), 3; Hogg, Loosemore-Reppen, and Rowan 2006, 6. National Voices is an attempt by groups to organise together in order to engage in policy development. They maintain that '[t]here is a need to enhance and amplify the influence of service user, patient and carer voices in national policy making and its implementation, and to create a route to influence to match that of the health professions' (Taggart 2007, 4). Their membership consists of voluntary organisations representing users and carers. It has been stated that National Voices is 'not an attempt to represent the views of voluntary sector organisations as contracted public service providers' (*ibid*, 6). National Voices is independent of government, however it hopes to receive funding from government (*ibid* 9). The Patients Forum was set up in 1989 as an umbrella group for national voluntary organisations to share and coordinate their views' (Hogg, Loosemore-Reppen, and Rowan 2006, 3).

opportunity arose. SD was aware of the potentially negative impact of tendering for large scale contracts on the organisation's rationale as a body representing the interests of people suffering mental illness and their carers. The risk for charitable bodies in this regard was that they might become '*redefined because of mission creep*', and become a '*casualty of contracting*'. There was recognition more generally of the dangers of '*unintended consequences of change*', and of the need to manage internal tensions within the organisation. SD indicated that mitigating these risks has involved reflection both on the environment that has prompted change, and on the mode of adaptation to that environment. Care is being taken to ensure that development and growth are consistent with MENTHEAL's mission, rather than simply following '*government prescription*'.

SD maintained that the successful management of change is dependent on both good charity governance and systematic business processes. Systems are required to help promote accountability and ensure that staff hold the organisation in trust, with different sections and departments (including regional offices) sharing a sense of ownership in the organisation and its development. *'Emotional intelligence'* can assume particular importance when changes are not implemented smoothly (for instance, if regional sections disagree with decisions made by the centre). SD explained that cooperation between different parts of the organisation could not simply be expected, so development processes included the use of methods by which internal issues and concerns could be raised and explored. Any development is subject ultimately to a test of whether it is consistent with, or can be grounded in, the organisation's charitable objects.

Even where changes are grounded in the ways described above, it was acknowledged that organisational development can have unforeseen effects on the relationship with beneficiaries and service users. SD reported a view that, although a charitable organisation may feel that it is retaining its independence, bidding for large contracts would inevitably affect service users' perceptions of the organisation. Voluntary bodies need therefore to strive to remain distinctive in the way in which they deliver services, and to set clear limits as to how far they will '*dance in tune*' with commissioners. Expansion of the organisation's role in service provision also affects the nature of relationships by changing the profile of the people to whom services are provided. While anyone receiving a service from MENTHEAL could be described as a beneficiary of the organisation, they are not all members of the organisation. The relationship or 'contract' with service users who are members will be different from that with non-member service users. SD maintained that care was needed to ensure that both types of service user are appropriately treated, and their relationship with the organisation protected. MENTHEAL seeks to achieve this by methods of self assessment and 'value audits'. Value audits are described as an internal audit involving a structured method of providing evidence (SD commented that the organisation had previously used an internal quality standard, but that this had been found to be unhelpful, especially in conjunction with other forms of accountability and reporting that were required of contract providers).

ii. Decisions on bidding for contracts and designing services

MENTHEAL recognises that as an independent charity, it is free to decide what public services to take on. SD maintained that the decision whether to bid for public service contracts should involve consideration of consistency of the proposed course of action with the organisation's mission, in the same way as decisions on organisational development. The scope for influencing a service was a key factor in deciding whether or not to bid for a contract to provide it. If there was considered to be little

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scope, MENTHEAL would not bid for that service. Such scope is limited, however, by the fact that NHS contracts apply the same inflexible rules for any potential provider (whether public, private or third sector). These rules are performance-related, involving particular quality indicators relating to volume, outcomes and clinical measures. In this respect, contracts differ from block grants. Despite this lack of flexibility, SD suggested that there is some potential for innovation, especially during the tendering processes in which there may be opportunities to shape the design of services. These potential increases where services put out to tender are supposed to be concerned with development and learning. MENTHEAL also uses other strategies to facilitate innovation in service design. One approach is to seek grant funding which, although requiring accountability to funders, imposes fewer restrictions than contracts. A further approach is to build margins into funding structures thus enabling innovative projects to be conducted (for example, the organisation prioritises such projects involving service-users).

SD estimated that since 50 per cent of their bids were successful, there was a need also to take account of the cost to the organisation of bids for contracts that might not be secured. The decision-making process here involves discussion among staff, and signing off by the organisation's board. SD emphasised that MENTHEAL seeks to enhance its decision-making in this context through conscious reflection on its previous mistakes.

b)   *Campaigning and influencing policy*

i.   Service user involvement and effective argument

CP indicated that MENTHEAL has a clear sense of its identity as a '*service user and carer-led*' organisation which exists for the benefit of mental health service users and their carers. This identity informs the organisation's approach in selecting issues on which to campaign and/or take up with policy-makers. Some campaigning issues have been initially identified through, for instance, focus groups involving the organisation's beneficiaries and service user testimonials. CP explained that policy initiatives by government would also have a direct influence in determining issues taken up in the organisation's campaigning and policy work. Decisions on such matters are made by the organisation's public affairs team and need to be approved by the board of trustees, with the involvement of service users in both cases.

CP explained how the role of service users and carers can go beyond simply suggesting issues on which the organisation might focus in its campaigning activities and attempts to influence policy. This extended role might include involvement in discussions as to how policy should develop and why it should develop in particular ways. One such example was the use of a 'policy proofing' panel examining criminal justice, commissioned by the Government, including the participation of people with direct experience of the criminal justice system. The panel heard policy proposals, gave their opinion of how they would work in practice, and offered views as to the form the policy should take. A further example concerned the organisation's involvement in an NHS programme of events in which service users and carers were asked how policy should develop. MENTHEAL is a member of the Programme Board organising these events, and is also tasked with drawing conclusions and making recommendations in light of discussion at them. Such examples indicate the emphasis that the organisation places on ensuring that service users and carers can engage proactively in policy development. However, at this stage in the research, questions remain about the processes by which different individuals' ideas and arguments are taken into account in the recommendations made following such debate. The issue here is not so much whether individuals are enabled to make their point (in this

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regard, CP highlighted the role of facilitators in drawing out each individual's positions and reasoning). Rather it concerns how the organisation develops recommendations from the ideas and discussion at the event (in other words, how are recommendations determined on the basis of the points and arguments made within the debate?).

CP indicated that the organisation, and service users and carers, have varying success in influencing policy development. MENTHEAL's engagement with politicians and policy-makers has undoubtedly created conditions which might help gain such influence. Building on ongoing relationships, the organisation has been able to persuade politicians and policy-makers to attend meetings, to secure commissions (such as running the criminal justice policy proofing panel), and to occupy positions such as involvement in the NHS programme described above. Through such activities the organisation has been able to raise concerns in areas where it considers that its views have not been adequately taken into account. More broadly, CP explained that a requirement of continued service user engagement is that this is not tokenistic, and that recognition of this point acts as an incentive for policy-makers to listen to opinions of service users and carers.

Successfully presenting a case to policy-makers can be, but is not necessarily, dependent on the capacity to make a good argument. Such an argument might be a result of reasoning combined with the presentation of evidence. One example of successful use of evidence involved the organisation demonstrating that while people being prescribed a particular drug should have been routinely tested for diabetes, these tests had not been occurring. MENTHEAL secured amendments to legislation which provided mechanisms to help ensure this routine testing took place. Nevertheless, the organisation has also experienced situations in which policy-makers have failed to take account of reasoned arguments, and discussion has resulted in stalemate.

ii. Developing awareness of civil rights

CP described how MENTHEAL is currently developing a 'civil rights approach' which will increasingly form the basis of the organisation's campaigning. In advocating and explaining this approach, the organisation draws expressly on the experiences of the civil rights movements in 1960s America, and of the Suffragettes in Britain. MENTHEAL considers that there remains substantial public misinformation about mental health illness, and that the current treatment of people suffering from such illness amounts to discrimination. This discrimination is reflected in social attitudes which are prejudiced against people with mental health problems. Discrimination also occurs when public services treat people with mental health illness as a patient group with multiple problems, rather than viewing the 'problem' as occurring when services fail to meet people needs. For the organisation, adopting the civil rights approach means developing campaigns which make the case for tackling discrimination against people suffering mental health illness.

The approach also aims to empower service users through training on how to deal with media and politicians, so that they can more effectively make their case directly. In this respect, individual empowerment through the civil rights approach may have a positive effect on people's recovery from mental illness. The reasoning is that developing the capacity of service users to articulate their experiences and opinions in debate with policy-makers and politicians will enhance their ability to '*use their direct experience as a powerful means of changing things*'. This in turn means that service users feel that they have made a contribution to influencing policy, and this will have a beneficial impact on their recovery. CP explained how the civil rights approach has affected the relationship with politicians more generally. The suggestion

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is that, since service users are held to be *'experts in the system'*, politicians view their involvement as a credible way of developing policy. However, there is evidence that politicians also support service user involvement in policy discussion because they find that service users' case studies can reinforce their own arguments and positions.

The adoption of the civil rights approach is consistent with the organisation's self-identity as existing in the interests of, and being led by, service users and carers. In particular, it seems consistent with MENTHEAL's emphasis on enabling service users and carers to put forward ideas, accounts and opinions. However, such an approach would not *necessarily* follow from a position of being a '*service user and carer-led*' organisation, so its adoption appears to have been the result of a deliberate decision.

2. Social learning in MENTHEAL

a) *Service provision*

i. Deliberation

It is plausible to maintain that MENTHEAL has been, and is still, undergoing significant change. The discussion on provision of public services showed how the organisation considers expansion of its capacity to take on large-scale contracts as necessary to retaining its independence. In this sense, it can be suggested that the organisation believes that such expansion is *a condition* it must fulfil in order to satisfy the normative expectations of its members and beneficiaries to the greatest extent possible. The organisation recognises potential difficulties that this expansion presents to its mission, and uses forms of reflection and deliberation in seeking to mitigate these difficulties. This can be seen in the account of internal debate over the potentially damaging effects of any proposed developments on the organisation's core purpose. There is no evidence here of identity transformation. Instead, deliberative processes appear to be concerned with how to manage change in a way that does not impact negatively on the organisation's collective identity in respect of its mission.

ii. Reflectibility?

MENTHEAL is aware that the expansion of capacity to provide services will have a significant impact on relationships with service users and beneficiaries. In this regard, the organisation recognises the need to transform its collective identity. The discussion with SD showed that attention is being given to the understanding of these relationships; the organisation acknowledges that there will be a change in the relationships, and also seeks to influence that change. This recognition of the possibility of varying the 'representation' of the relationship with beneficiaries and service users might indicate the dimension of *'reflectibility'* (the first operation in transforming collective identity, as discussed by Lenoble and Maesschalck[65]. However, from the findings so far, it is not certain *how* these relationships have changed, and furthermore, it is not clear whether the organisation has adapted to its expansion by altering the representation of the relationship with service users and beneficiaries. Consequently, it is not apparent from the findings that the organisation's identity for action is transformed through the expansion of its capacity to provide services.

b) *Civil rights approach*

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[65] Lenoble and Maesschalck. 2010, ch. 6. , and Lenoble, and Maesschalck in de Schutter and Lenoble, eds., 2010, ch. 1 part III C.

By contrast, the adoption of the civil rights approach does appear to indicate transformation of collective identity, although in a different sense to that just discussed. First, the decision to frame its campaigning in terms of anti-discrimination might tentatively be suggested to be a reframing of MENTHEAL's representation of the public interest it is aiming to promote; in other words, reframing its reason for action, and hence its collective identity for action. In explaining its campaign against discrimination, the organisation explicitly draws upon, and sets itself as part of, a history of campaigns against discrimination in differing forms. As noted earlier, this approach is in keeping with the organisation's established identity as existing in the interests of service users and carers. The approach involves reflection on the organisation's established identity, yet it consciously represents this identity in a particular way in terms of tackling discrimination and promoting civil rights. In doing this, MENTHEAL shows awareness that it can alter its representation of its purpose, and that it has considered the identity for action that it is constructing (thus indicating a 'dimension of "*destinability*"'[66]. One question that has not been answered by these initial findings is whether this appeal to anti-discrimination enables the organisation more effectively to make its case in seeking to influence policy and public attitudes (that is, whether anti-discrimination campaigning is effective in satisfying normative expectations of beneficiaries with respect to influencing policy and public attitudes).

Collective identity for action also appears to be altered by the adoption of the aspect of the civil rights approach involving training to enhance service users' ability to engage with politicians and the media. It could be suggested that such training should be understood solely at the collaborative/relational level, as developing the capacity of actors to engage in deliberation, given the organisation's emphasis on service user and carer involvement in campaigns and debate on policy. However, to focus just on this collaborative/relational dimension would be to miss significant features of the civil rights approach. The approach aims to enhance service users' ability to explain their experiences and present their arguments directly to politicians and policy-makers. Therefore it appears to seek to increase emphasis on the autonomy, or individual voice, of service users, and this indicates a development in the organisation's understanding of its relationship with service users and beneficiaries. As with the move to campaigning on anti-discrimination, therefore, the adoption of this aspect of the civil rights approach can be understood as involving both awareness that there can occur development of the organisation's identity as user and carer led, and deliberate adaptation of this identity suggesting a conception of destinability. As noted above, the civil rights approach is held to provide an effective means of engaging with politicians, and it may also help the recovery of people suffering mental health illness. In these respects, it has potential to increase satisfaction of normative expectations. However, a number of questions would need further consideration before a full account of any transformation in identity for action can be presented, for example concerning how MENTHEAL reached the decision to adopt the civil rights approach, and its experiences in developing the approach in practice.

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[66]   Lenoble, and Maesschalck 2010, part II chapter 6, and Lenoble, and Maesschalck in de Schutter and Lenoble, eds., 2010, ch. 1

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V.   Case study: social learning within a palliative care charity

1.   <u>Description</u>

This organisation (which we will call 'CANCARE' for this report) is a charity which has traditionally focused mainly on providing end of life care for cancer patients. The following discussion describes developments in the charity's work over the past decade, concentrating the services it provides directly to patients, and on the way that in recent years it has sought to shape and influence the wider health and social care sector. The discussion is based on open format interviews (conducted in Autumn 2009 and Spring 2010) with CANCARE staff working across the organisation, including in research and development, governance and communications, service design and provision, and policy. Each of the interviewees discussed a range of areas of the organisation's work.

a)   Service provision: beneficiaries, relationships and funding

   i.   Range of beneficiaries

While the majority of patients who receive care from CANCARE have a cancer diagnosis, and the organisation's memorandum of association and charitable objects mean that this will remain the case, in the past decade CANCARE has placed increasing emphasis on providing end of life care for patients regardless of their diagnosis. Interviewees suggested that this change in emphasis is significant given the organisation's established identity as concerned with provision of end of life cancer care. One reason for the shift has to do with considerations of equity or equality. Since cancer is cause of death for a minority of people, there is inequality in the services available to 'non-cancer' patients requiring end of life care. A further reason is that both CANCARE clinicians and business staff have realised that they must be responsive to NHS commissioners' planning decisions which do not differentiate according to patient's diagnosis. Such responsiveness has enabled the organisation to influence commissioners' views as to the significance of end of life care, and this in turn can have an influence on public policy. Nevertheless interviewees maintained that working with commissioners in this way would not preclude their also challenging commissioners where appropriate.

       Certain tensions and difficulties surround this move. Firstly, CANCARE is an organisation which is recognised by the public as primarily a cancer care charity. Interviewees were aware of the need to consider the effect on fundraising of CANCARE talking about their work in terms of assisting non-cancer as well as cancer patients. Secondly, the public's recognition of the organisation as primarily a cancer care charity, and a corresponding concern about misleading the public, was given as a reason for the charity retaining its commitment that a majority of its beneficiaries will be cancer patients. It might be thought that a further potential future tension would arise if it came to be that a majority of those seeking assistance from CANCARE did not have a cancer diagnosis. However interviewees indicated that the nature and trajectory of illness meant that end of life care would most commonly be possible and suitable for cancer patients. Further challenges associated with the shift in emphasis concern the capacity and knowledge required to provide end of life care to patients with a wider range of conditions. It was noted that CANCARE's clinical staff already have skills to care for patients with non-cancer diagnosis since this is something that the charity has always done to some extent. Nevertheless, as indicated above,

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interviewees noted that the trajectory of illness for cancer patients makes planning end of life care more straightforward than for other illnesses. Patients with different illnesses will have differing needs. Given this interviewees explained that CANCARE engaged in processes of learning which enable them to extend the services they provide.

ii. Partnership working with other voluntary organisations

CANCARE's understanding that patients will have specific needs according to their differing illness has prompted the organisation to become involved in collaborative working with other specialist groups, voluntary organisations and NHS bodies, to conduct research and investigations into service design and delivery.

Interviewees described a significant example of this type of collaborative working in the discussions that took place between CANCARE and another voluntary organisation, which resulted in realisation that although they ostensibly served different beneficiary groups, they actually had interests in common in the provision of end of life care. The two organisations, together with an NHS body, have embarked on a project to develop a model of palliative care for patients with differing needs. The interviewees emphasised that the project began from the standpoint that certain groups of patients might benefit from end of life care, but did not initially make assumptions about what this care should involve and how it should be delivered. Instead the process of collaboration was described as '*an iterative process'* and as involving '*action research.'* The intention is to develop new models of care and to test whether they produce better outcomes than their predecessors, and CANCARE emphasise the importance of remaining aware that the models may not result in improvements.

It was suggested that such collaborations with other voluntary organisations arise because of discussions at '*multi-levels fundamental to the third sector',* in which members of the respective organisations find '*common points'* which lead them to discuss how '*services can be developed.'*

iii. Public funds for service provision and relationship with the NHS

A substantial part of CANCARE's work is the provision of end of life nursing care, and in particular, care which enables patients to die at home if that is what they choose. NHS District nurses decide the point at which a CANCARE nurse is required, and CANCARE nurses are employed on a basis that means they can provide care at short notice when it is needed. A significant proportion of the funding for CANCARE nurses comes from local Primary Care Trusts on a contractual basis.

CANCARE argue that there is an unmet need for their nursing services for end of life care at home. One response to this involves their trying to increase the funding they gain from the NHS. There are several strands in the organisation's approach to seeking greater public funding for their nursing care. As well as attempting to persuade the government of the importance of meeting patients' and carers' needs at end of life, and seeking to secure additional funds for this either for itself or other organisations, CANCARE is taking a leading role in research on service design and provision, and on people's preferences on whether they would wish to receive such care at home. CANCARE maintain that the research has shown that end of life care delivered at home can be as cost effective as care provided in hospital. Therefore they argue that it should be possible for NHS funded services to be reconfigured to better

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meet demand for end of life care at home.[67] CANCARE is attempting to further their argument for such provision by providing the type of economic evidence (i.e. concerning quality of outcomes for patients and cost effectiveness[68]) that NHS bodies use in their decision-making on services. Nevertheless interviewees suggested that while this form of evidence does carry weight, it has only limited force in persuading NHS decision-makers to provide greater funds for this purpose. Also relevant is a developing consensus about how services can be provided away from hospital. Further, interviewees described how CANCARE staff might talk to NHS planners about the services they can offer, and that these discussions '*feed into commissioning*'. NHS commissioning decisions may also be affected by local factors, including the influence of local hospices (run by other organisations). In addition to the content of arguments made to government and NHS commissioners, interviewees emphasised their awareness of the importance of the manner in which CANCARE make their case. Traditionally clinical staff negotiated with local NHS commissioners for funding for CANCARE's nursing services. However in recent years CANCARE has decided there is a need to '*become more businesslike*' and employ staff who '*specialise in negotiating with commissioners.*' Reasons for this include the view that particular expertise is necessary to effectively negotiate, and that the NHS has itself adopted a more business-like approach (particularly in relation to the development of 'World Class Commissioning'[69]).

A further matter of concern to interviewees was the way in which patients are referred to CANCARE nurses, who '*provide a demand led service with the NHS as a gatekeeper*'. Interviewees noted that over the past few years the organisation has significantly increased the level of care that it delivers, and that this has created a greater awareness of the service among patients, which has led to requests specifically for the service. CANCARE have also run advertisements following concerns that some patients may remain unaware of the service. However the method of referral by NHS gatekeepers, coupled with the system of NHS funding for 50% of the cost of nursing care, means that the number of patients who can receive CANCARE nursing is limited. The particular concern is that in some cases PCTs '*refer patients up to budget, and then not refer any more after that*'. It was argued that there could be an improvement if it were possible to '*de-link commissioning from payment*'. The idea would be that CANCARE could receive block funding or a grant either nationally from the NHS or Department of Health, or locally from Primary Care Trusts, and that this would then be managed directly by the organisation according to their own resources. However, CANCARE would now seek to secure such grant funding only on the basis of specified quality of care outcomes, rather than input/output measures. It was acknowledged that on this suggestion, if care was delivered to more people, then CANCARE may provide more than the 50% funding that they currently cover.

The provision of NHS funding for at least part of CANCARE's nursing services raises further questions about the relationship between the organisations, in particular regarding CANCARE's identity as an independent body working alongside the NHS. Interviewees described the concern that 'CANCARE *does not exist to service the NHS*'

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[67]   Significantly CANCARE has sought to persuade government to provide greater funds for end of life care even if that care is not provided by CANCARE – this move to influence government is discussed in more detail in following sections.

[68]   It is worth highlighting that it is cost-effectiveness, rather than just cost which is at issue here. One interviewee noted that if the case for increasing funding for CANCARE's nurses was made purely on cost grounds, the CANCARE would not be able to secure the money. Instead, when NHS commissioners provide funding for CANCARE nurses, they are '*buying into end of life care*.'

[69]   See, for instance the Department of Health webpages on World Class Commissioning http://www.dh.gov.uk/en/Managingyourorganisation/Commissioning/Worldclasscommissioning/index.htm

and that they should '*make sure they do not lose voluntary funding, and make sure that* CANCARE *doesn't become part of the NHS.'* One aspect of this concern is that CANCARE should not be '*a dependent partner'*. Given the increase in available funding accompanying the growth in the NHS since 1997, CANCARE are conscious of the need to consider how far they reposition themselves to provide additional services. Moreover, CANCARE are aware of the need to undertake work that the organisation is good at, and to resist requests from commissioners '*who ask for more.*' More broadly interviewees argued that the organisation is '*not a service provider for the state but also using expertise to provide knowledge about how to improve services.'*

b)   Influencing the expansion of end of life care

   i.   Priorities: expanding availability of end of care at home

When asked about CANCARE's priorities, interviewees emphasised the aim of expanding and improving end of life care and the '*ability to achieve choice to die at home'* and to '*improve quality of life for people at end of life.'* The motivation for this emphasis was explained as having resulted from the development of a stronger focus on the interests of beneficiaries, and as a response to inequality in access to and provision of end of life services. There was awareness among those interviewed that there are '*questions about evidence of how you achieve'* this expansion and improvement, and more broadly that the methods of achieving these aims are open to consideration. The organisation's activities in pursuit of these aims are not limited to their own provision of services.[70] Interviewees described how CANCARE has moved from a '*perception…that they should provide care where they can'* to an approach of expanding provision of care by seeking to influence others to provide end of life care. This aim was described as '*trying to set agenda for care at end of life at place of choice.'*

   It was explained that this move to seeking to influence others has been prompted by the understanding that '*no matter how much* CANCARE *grows, it can never meet demand.'* There was some concern that the attempt to keep up with increasing demand might be difficult to reconcile with the fundamental commitment to high quality services, and that this might put the organisation's reputation at risk. Attempting to satisfy demand by expanding could also place the organisation at risk if, for instance, it invested in service infrastructure and then became subject to NHS cutbacks. Consequently part of the rationale for influencing others to provide services was that this would enable risks to be shared across organisations. Further, interviewees noted a view within the organisation that the government and NHS generally have a responsibility to provide end of life care.

   ii.   Engagement in public and political debate

CANCARE are concerned to talk about '*unmet need'*, and to '*support and facilitate public conversation on end of life care, death and dying'*. Interviewees noted that over the past seven or eight years CANCARE '*have been much more transparent about the service they provide – whereas 8 years ago, didn't talk about dying … now talk about dying.'* While this '*brings concerns about 'tone of voice''*, they have found that it has not harmed fundraising, including corporate fundraising. It was suggested that '*in talking to politicians and the public'* CANCARE '*find recognition of the scale and importance of the issue of end of life care.'* Interviewees indicated that they were

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[70]   It should be noted that in addition to the nursing care discussed above, CANCARE provide other services including although not limited to) hospices. They are also considering development of web-based services, for instance offering information and advice, and forums for carers.

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sometimes able effectively to make their case to politicians using evidence-based arguments and reasoning concerning the unmet need for such care, emphasising the *'NHS's obligations from birth to death.'*

iii. Campaigning

Approximately six years ago CANCARE undertook its first campaign aimed at persuading government of the importance of enabling people to exercise a choice to receive end of life care at home. A further aspect of the campaign was to increase public awareness of the organisation's work.[71] It was suggested that this campaign had some success since although it was *'difficult to get the government to listen',* the *'choice of place of death resonated with people in government',* and had an effect on the priority given end of life care in NHS policy. Further, CANCARE was considered to have used its independence effectively to make points to government. Interviewees also explained that at the time of their campaign – and co-incidentally – the House of Commons Select Committee held a session on palliative care.[72] It was suggested that now *'Government has realised that there is unmet need* [for end of life care services] *and that there is a need to do something about it.'* Despite this satisfaction with the results of the campaign and having learned from it, interviewees noted reservations about this role, stating that CANCARE are not really a campaigning organisation.

iv. Research and service development

While the campaign coupled with the Select Committee report on palliative care led to increased awareness, and government recognition, of the relevance of end of life care and the choice to die at home, CANCARE realised that *'services had not changed'.* Interviewees described how the organisation therefore *'moved to consider how services could be developed.'* As is noted above, CANCARE seeks to lead research related to palliative care. In particular, interviewees suggested that CANCARE aims to influence government and commissioners *'by transferring knowledge about how to provide the care.'* The potential to influence government in the current policy environment was recognised, with the *'voluntary sector having a voice that it did not have ten years ago'.* So it was noted that *'NHS bodies have been told that they must work with the voluntary sector – so there is scope to show how services can work',* and that the *'voluntary sector (has been) invited into Advisory groups',* and further that the *'sector is also involved at local level.'* There is a view that an *'effective way of influencing government is to provide evidence of how they can improve services.'*

One approach adopted by CANCARE is the facilitation of projects in different geographical areas which consider *'a whole systems approach'*, investigating *'what is needed to change to make these more seamless to enable people to choose to die at home.'* These projects *'started in areas where senior NHS providers are committed to getting the project accepted'.* The idea of the projects is to enable providers *'to appraise local services for end of life care in their area'* and to design *'new service specifications … for services for people who want to remain at home'.* Interviewees maintained that in being placed in different geographical areas these projects were capable of sensitivity to local circumstances. The idea is that CANCARE consider characteristics that any care system would require – such as seeking to ensure that

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[71]   Prior to the campaign there was a view that the public were uncertain about the type of work undertaken by CANCARE. This uncertainty was considered to be a result of CANCARE presenting a complicated view of itself encompassing all areas of its work.

[72]   House of Commons Health Committee *Palliative Care, Fourth Report of Session 2003–04*, Volume I, HC 454-I (2004)

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people are *'free from pain where possible or in familiar surroundings',* and can *'then tailor these characteristics for local services.'* This approach avoids problems of imposing a *'potentially inappropriate model on local areas.'*[73] Among the results of these projects to date has been the development of a number of initiatives including *'rapid response services, discharge liaison between services, and co-ordination of care.'* Once developed, these services are evaluated, and CANCARE is *'now using funds to transmit this information to other professionals'.* By developing and evaluating services in this way, CANCARE considers that it can contribute to influencing commissioners and providers by showing how services may be reconfigured. As is also noted above, interviewees commented on the importance of showing that *'services could be cost-neutral'* and be of high quality, along with the broader influence gained by disseminating results of projects which develop and evaluate services.

CANCARE directly funds three institutions undertaking palliative care research, and currently is adopting a greater role in setting the agenda for these institutions by providing grants so that the institutions have to set research plans which are then peer reviewed. CANCARE also undertakes evaluations of innovations by employees and volunteers, sometimes involving evaluation of small projects. Interviewees described CANCARE's understanding that *'there is a relationship between research and development and care,'* such that innovations and ideas by clinical staff may contribute to the development of services. CANCARE have realised that they are in a position to collect evidence from clinical staff, and are *'developing a bank of evidence'* along with mechanisms enabling staff members' ideas and innovations to be *'considered, evaluated and piloted.'* Interviewees noted that through publications in journals CANCARE's research, evaluation and development has an impact on commissioning.

CANCARE is emphasising its research, evaluation and development in palliative care, and has decided to withdraw from scientific research into causes of cancer that it was conducting. It was noted that this move away from scientific research has made possible the focus on palliative care research. However interviewees suggested that the reason for giving up scientific research *'was driven by factors in the external environment: which means that the science that was being done can no longer function within a single institution …instead, this sort of science is now global.'*

2. Social Learning in CANCARE

a) *Beneficiaries and service provision*

In one respect, CANCARE's move to improve satisfaction of their beneficiaries' normative expectations by increasing the volume of their (partially publicly-funded) nursing services, and by providing end of life care for patients in their own homes, may be understood as a response within the existing economic structure. That is, CANCARE promote their service in terms of its quality and cost-effectiveness, and in doing this it might be supposed that they are simply seeking to show that their service most appropriately fulfils the specification required by commissioners.[74] Considered

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[73]   It was suggested that policy makers and politicians have often sought *'system reform'* or the imposition of models, although it was also noted that *'policy makers and politicians they are moving more to local commissioning.'*

[74]   We might further suggest that CANCARE's decision to *'become more businesslike'* and employ staff who *'specialise in negotiating with commissioners'* can also be understood in terms of the organisation seeking to further their beneficiaries interests by operating within the given economic structure.

alone, these activities would not involve reflexive social learning either by CANCARE or by the commissioners since both are operating within existing economic arrangements.

    i. Collaboration/deliberation

However CANCARE do not rely on showing the cost-effectiveness of their services, and moreover they indicate that while important, emphasising cost-effectiveness is not sufficient to make the case for greater public funding. As is suggested in the discussion above, successfully increasing the volume of nursing services has depended on developments in the priorities and considerations shaping NHS commissioning. In other words, increasing the public funding for CANCARE's nursing services has depended on the NHS accepting that greater priority should be accorded palliative care and provision of end of life care at the place of the patient's choosing. These developments have been influenced by the emergence of a '*consensus about how services can be provided away from hospital*,' and by discussions between CANCARE staff and NHS planners on the services that CANCARE can offer. In this sense it can be argued that CANCARE is working collaboratively (or that it is engaged in deliberation) with decision-makers in the NHS to change the criteria by which decision-makers plan and commission services. So this collaborative approach appears to have contributed to the satisfaction of the organisation's normative expectations by increasing their volume of service provision. However, there is the suggestion that this collaboration has limited value as CANCARE might improve their ability to provide services if they could '*de-link commissioning from payment'* by receiving a grant for their services with which they could determine where services are required. Yet although interviewees identified this concern and its potential resolution, there remain questions about how, or whether, this resolution could be effected.

    ii. Changing collective identity for action

CANCARE arguably have had some success in collaborating with NHS decision-makers and persuading them of the case for increasing funding for the organisation's end of life nursing care. Nevertheless it is apparent that CANCARE itself has been influenced by the decision-makers within the NHS. Notably CANCARE has moved to place more focus than previously on providing care for patients regardless of whether they have a cancer diagnosis. According to the interviews with the organisation's staff, this move was prompted in part by realisation that commissioners do not distinguish between patient groups in commissioning end of life care. As such, seeking public funding for services, it would be an advantage to CANCARE if they limited the extent to which they differentiate between patient groups. As explained in the previous discussion, this move is significant for CANCARE which is an organisation known as a cancer care charity. In other words, this move can be understood as a development of their identity.

      The questions for us, however, are whether this development is more than an 'adaptation of policies to changing environments, without questioning … background assumptions,'[75] and whether we can identify processes of reflectibility and destinability in the development. While apparently a response to NHS commissioning practices, interviewees explained that the increased emphasis on provision of care for patients regardless their diagnosis is underpinned by concern for equality or equity (i.e. concern of 'inequality in the services available to 'non-cancer' patients'). So the

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[75]   de Schutter and Lenoble, *Introduction* in de Schutter and Lenoble, eds., 2010, xix

suggestion is that the move is motivated by more than strategic considerations, and that it involves CANCARE re-assessing its previous assumptions about being a cancer care organisation. Perhaps a further indication that this move can be understood as more than simply a strategy, is revealed by CANCARE's aim to influence others through research, evaluation and development along with its campaigning. As is shown in the discussion above, in this work the organisation has been concerned with palliative care and patients' choice over where they receive end of life care. Here CANCARE's representation of their interests focuses on palliative care and end of life care without an emphasis on the diagnosis of those potentially receiving the care. Therefore we can argue that in this sense, CANCARE's approach to increasing the satisfaction of its normative expectations has entailed a reframing of its identity for action. Moreover the interviews with CANCARE staff revealed that there was a dimension of reflectibility in this development. In particular, interviewees showed their explicit awareness that the move amounted to change in CANCARE's identity, and pointed to the organisation's reflection on this change.[76] As to destinability, it can be suggested that this dimension is shown both in the organisation's formal decision to allow an increased proportion of beneficiaries of its care who do not have a cancer diagnosis, and in its subsequent activities in providing more care than previously for such patients. A further indication of this dimension of destinability is evident in CANCARE's collaboration with organisations having other sorts of expertise in order better to provide care to patients with non-cancer diagnosis.[77] Such collaboration might be understood as an example of the conditions in which CANCARE can make its reframed identity 'effective in the context of the new constraints on action.'[78]

Nevertheless certain questions remain concerning this reframing. CANCARE are conscious of their public recognition as a cancer care charity, and consequently are aware of the need to give careful consideration to the way that they publicise their aims and work. CANCARE have decided that cancer patients will remain as the majority of their beneficiaries. It happens that this presents no immediate tension with a concern from equality for provision of care to patients regardless of their diagnosis. The reason for this stems from the possibility of providing end of life care for different illnesses. However, if this reason changed in future (perhaps as a result of medical advance, or research on palliative care) then it is possible that CANCARE's position might be more difficult to maintain.

b)   Influencing end of life care

CANCARE has the aim of setting the '*agenda for care at end of life at place of choice,*' and influencing other actors – including the government and NHS, public and other voluntary organisations – in order to increase the availability and the quality of end of life care. As discussed above, the means for achieving this aim (and thus maximising the satisfaction of their normative expectations) have included a campaign, and more

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[76]   That is, CANCARE has shown that it can 'experience itself through its capacity to represent itself, that is, to form an identity whose substantive representation can vary and adjust according to transformations occurring in the contexts for action' Lenoble and Maesschalck. 2010, ch. 6; Lenoble and Maesschalck in de Schutter and Lenoble, eds., 2010, 20.

[77]   For example, collaboration with bodies such as the British Heart Foundation has enabled CANCARE to benefit from specialist knowledge on coronary care. At the same time, the BHF has benefited from the collaboration in acquiring valuable knowledge on palliative care to which it did not previously have access.

[78]   *Ibid.* We might also note that as a result of CANCARE's reframing its identity and thus collaborating with other organisations, CANCARE may be engaging in some processes of democratic experimentalism. Interviewees described how this process of collaboration on the development of new services involved '*action research*' and an '*iterative process*'.

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recently an increasing emphasis on research, evaluation, and development in palliative care. This approach may be described as engagement in processes of deliberation and collaboration. Both in their campaign and in their research and development, CANCARE are seeking to further their cause by persuading other actors of the importance of end of life, and providing evidence and understanding of how that care can appropriately be provided.

However, while this analysis in terms of collaboration and deliberation is important to understanding the way in which CANCARE has influenced other actors, we need also to consider why CANCARE adopted this approach. Interviewees noted the organisation's previously held '*perception…that they should provide care where they can.*' There appears to be a transformation in CANCARE's identity for action in the change from this perception to the development of the present aim of seeking to '*set the agenda.*' This change seems to have involved CANCARE re-assessing its view of itself as a service provider (although providing services remains primary to the organisation's work), and moving to represent itself as primarily concerned that end of life services are improved and increased (although other organisations may provide those services). It is possible to indicate how dimensions of reflectibility and destinability have been a part of this change. There was a realisation that in spite of its concern to address unmet need for services, '*no matter how much* CANCARE *grows, it can never meet demand'*, and recognition of the risks associated with attempting to provide services that keep up with demand. The organisation's response to this was first to decide to shift towards influencing others through its campaign.[79] Once it was felt that the campaign had achieved what it could (and the government had accepted the case for palliative and end of life care), CANCARE moved to emphasise work in research, evaluation and development of palliative care. These developments suggest reflectibility as the organisation has formed 'an identity whose substantive representation can vary and adjust,'[80] and destinability in the changes from campaigning to a greater focus on research, evaluation and development.[81]

VI.   Conclusion

Both organisations involved in this study have engaged in deliberative and collaborative processes in seeking to maximise the satisfaction of their beneficiaries' normative expectations. Further, in recent years each organisation appears to have reframed their identity in the context of developments in their policy environments. That is, in each there has been development in the organisation's understanding of what it means to seek to maximise the satisfaction of the normative expectations of members of the collective action. As would be expected of two diverse organisations,

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[79]   We should keep in mind that this was the first campaign run by CANCARE

[80]   Lenoble and Maesschalck. 2010*,* ch. 6; Lenoble and Maesschalck in de Schutter and Lenoble, eds., 2010, 20.

[81]   CANCARE seems focussed on considering how its research, evaluation and development can most effectively contribute to its aims in influencing the agenda for end of life care. At present there may be little reason to alter this approach, since the case for palliative care has apparently been made (and accepted Department of Health and NHS). However possible tension could appear if the case for palliative care was somehow lost (for instance, moved down the NHS's priorities). If this occurred it could be seen as a reason for CANCARE to return to its campaign in order to increase the prominence of the arguments for palliative and for patient choice in where end of life care is provided. In this case the potential tension would centre on CANCARE's ambivalence about campaigning, and particularly on it's desire not to be viewed as a campaigning organisation.

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the nature of change in each is very different. However as the REFGOV hypothesis predicts, these changes have not been spontaneous,[82] and in both cases it is possible to identify how the change has involved reflectibility and destinability as elements in social learning.

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[82]   Lenoble and Maesschalck in de Schutter and Lenoble, eds., 2010, 6, 16