Public Policy Subsystems Dealing With Ethically Contested Medical-Technological Issues

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The questions tackled in this paper are: How do we deal with ethically contested medical innovations?, and Can we do better? First, I analyse how we deal with these problems by a division of labour and competitive boundary work between the medical R&D system’s research and technological imperative, the medical profession’s claim to self-regulation and health policy-makers’ claim to political primacy and an incrementalist style of policy making. Second, turning to the normative question, I propose that policy-makers shift to a primacy of problems. Different types of problems demand different types of policy-making systems and styles. Thus, policy-makers could commence designing a health policy-making system robust enough to adequately deal with non-incremental but ethically contested medical innovations. I argue for medical innovation which also takes ethical, social and legal issues into account. This may be achieved by turning political competition through venue shopping into meta-governance through deliberate venue choice. This requires deliberative and participatory design elements in procedures and spaces for health technology assessment.

Medical Technological Developments, Health Policy Innovation and Politics: A Complex Affair

Having your own biological child, even though you are an infertile couple, or single parent? Bearing your child irrespective of age? No more premature deaths due to shortages in donor organs? Celebrating your 100th birthday in good health and excellent spirits?

These are just some of the promises offered by innovations in medical science and technology. Biomedical technology, genetics, genomics, nano- and neuroscience have already led to and will continue to generate wide-ranging medical technological innovations. Because they are so tangible for most men and women as (potential) parents, this is especially true for technologies in human reproduction (Kirejczyk et al., 2001), pre-natal diagnostics and predictive medicine. Pre-implantation genetic diagnostics, therapeutic cloning (Swierstra, 2000) and preventive embryo selection are good examples.

Yet, is being informed about carrying a foetus infected by Down’s syndrome or neural tube defects (potentially leading to anencephaly or spina bifida) inherently desirable? Is being informed about your own genetic profile with its vulnerabilities to future (hereditary) diseases desirable or not? Is there a right not-to-know? How about the rights of relatives and loved ones to such knowledge? What is the use of such knowledge when no effective prevention and/or treatments are (yet) available? Are such ethical dilemmas to be solved on a personal basis, or is there a role for government regulation?

The development from genetics to genomics may even affect the entire health care system. Genetics is about rare hereditary diseases, whereas genomics is about the genetic profile leading to widespread common diseases. Genetics-based innovations still fit within a treatment-based system in which the security and privacy of the doctor–patient relation are paramount. Yet, genomics-based innovations become cost-effective only in a prevention-based public health care system where political and social pressure for healthy lifestyles may easily threaten personal responsibility.
and individual patient empowerment (Van Rijswoud et al., 2008).

How have we dealt with such ethically contested medical innovations so far? Can we do better? These are the questions tackled in this article on the admittedly limited basis of examples and illustrations from the Dutch health care system. First, I analyse how we reluctantly deal with these problems at present by a division of labour and competitive boundary work between the medical R&D system’s research and technological imperative, the medical profession’s claim to self-regulation and health policy-makers’ claim to political primacy and an incrementalist style of policy making. Second, turning to the normative question, I propose that policy-makers shift to a primacy of problems. Acknowledging that different types of problems demand different types of policy-making systems and styles, policy-makers could commence designing a health policy-making system robust enough to adequately deal with non-incremental but ethically contested medical innovation. I argue for more societally responsible medical innovation which, next to scientific and economic aspects, takes ethical, social and legal issues into account. This may be achieved by turning political competition through venue shopping into meta-governance through deliberate venue choice. This implies introducing deliberative and participatory design elements in procedures and spaces for health technology assessment.

Boundary Work and Policy Politics of Medical Technological Innovation

One way of looking at political systems is as ‘federations’ of policy sectors, or issue domains. These are components of the political system organized around stable, substantive policy problems. Health policy is one of the oldest policy sectors in any political system. Usually, too, policy domains develop their own style of policy politics. This is the specific mode or style of policy making among the set of players – politicians in parliaments or as ministers in executive positions, policy advisers in- or outside bureaucracy, interest groups or stakeholders, implementing agencies in the public or private sector, non-governmental organizations, target groups, media personalities and commentators – involved on a continuous basis in processing a particular policy issue. Again, health policy is no exception.

Its policy politics is a close but clumsy kind of ‘boundary work’ between players in the medical research and professional camp, and those directly engaged in health policy making. Boundary work is, like a living apart together relationship, simultaneously about keeping distance by demarcation of your own domain, and staying close enough to co-ordinate your activities (Jasanoff, 1990; Halffman, 2003). In the case of health care, the boundary involved is the institutional demarcation line between science and politics/administration; while co-ordination involves necessary transactions and resultant co-operative schemes between science-based experts and advisors and political executives and their policy-analytic staff. Currently, the professional medical players produce a constant stream of ethically sensitive and politically contestable and contested new medical technologies. The issue for the policy-making players – private, like health insurers, and public, like policy analysts in the Department of Health – is whether or not medical treatments using these technologies ought to be included in the set of medical treatments applied in clinics and other health services institutions; and whether or not such innovative treatments will be reimbursed to patients with health care cost insurance. For the policy-makers, the problem is exacerbated because, at present, the entire health care system is in transition. It is envisaged to change from a need- and professional- or producer-driven and state-financed health care regime to a new system of ‘managed competition’, which will be more demand- or health-consumer or patient-driven and market-financed.

In this system of boundary work, the medical research and professional camp is largely concerned about policy for medical science. This advocacy coalition is driven by the operational codes of the technological-cum-research imperative and professional self-regulation. The technological ‘imperative’ is the tendency to believe that once technologies exist, they ought to be used and most of the time actually will be used. The research ‘imperative’ is the conviction that research either for its own sake, or as a means to achieve individual or social ends, such as the possible prevention or relief of suffering, is obligatory. Both ‘imperatives’ imply that medical research and technology cease to be psychologically, morally and politically optional (Callahan, 2003, p. 3). Although technically distinct from the research-cum-technology imperative, it is reinforced by the principle of self regulation of

1 On the same page Callahan quotes Joshua Lederberg, a Nobel prize winner for work in genetics, as a particularly strong advocate of the research imperative: ‘The blood of those who will die if biomedical research is not pursued, will be upon the hands of those who don’t do it’.
an independent professional medical community at large. In the case of ethically contestable medical technological innovations, it means that ethical debate ought to be depoliticized by leaving it to professional peers.

The public and private policy-makers are mainly concerned about medical science for (public) health policy, i.e., with priority setting between society’s politically articulated health needs and cost control. Policy-makers also have their own operational codes. First, by far the most important operational code of public policy-makers is the rule of the primacy of politics. Applied to medical technological innovation it may be expressed in the maxim: ‘Politics on top, medical experts on tap’. It is clear that the primacy of politics may conflict with the research imperative and the principle of professional self-regulation – unless there is prudent and clever boundary work on both sides. The trick here is ‘acquired’ regulation (Evett, 2002) in the form of disguised self-regulation by the profession itself, but ‘in the shadow’ of state hierarchy (Scharpf, 1993): ‘Regulation is an object of professional concern and professional bodies are working to develop their own regulatory systems in order to prevent intervention by the state. The result is a form of externally required but internally devised and operated regulation which might be termed acquired regulation’ (Evett, 2002).

This acquired regulation usually is the result of consultation and bargaining between professional associations’ leaders and high-level state officials. The political constraints on professional self-regulation result from two other operational codes of policy-makers. For these players, health policy is a legacy, i.e., a path-dependent stream of commitments of resources (money, personnel, buildings, equipment, existing divisions of labour, regulatory regimes, etc.) by vested interests and known stakeholders. Hence, first, the constant pressure to weave medical innovations as new threads into an already laid out regulatory matrix. Hence, second, the incrementalist reflexes dominating the puzzling and powering in most policy formation. The status quo is the rock-like benchmark against which all proposals are measured as marginal improvements or deteriorations of stakeholder positions. Although incrementalism slows down policy reform and innovation, it is defended as one manifestation of a sort of precaution against political hubris or policy overreach (Popper, 1957; Lindblom, 1979, 1999; Scott, 1999): Deal prudently with (cognitive) uncertainty and (ethical) ambiguity by small experimental steps, avoiding irreversible collective tragedies. By taking only a few incremental and reversible steps at a time, politicians avoid the hubris of large-scale reforms and the irreversible damage they may cause for ordinary citizens.

Applied to (medical) technological innovations, incrementalism is particularly prone to the Collingridge dilemma (Collingridge, 1980). In the early stages of innovation, incrementalist prudence suggests government non-interference for the sake of experimental learning. In the later stages an innovation may already be so technically, economically and socially entrenched that an incrementalist regulatory approach is ‘too little, too late’. It should be clear that, in this way, the medical profession may exploit the Collingridge dilemma as a resource in boundary work. Professionals have much earlier and deeper knowledge of new medical technological developments than politicians and other policy-makers. Using this information asymmetry strategically, the profession may aim for ‘too little, too late’ regulation. This is one important reason why the boundary work is frequently more about demarcation than co-ordination. I will illuminate this through a brief analysis of venue shopping by some parties in the Dutch debate on the issue of pre-natal screening.

### Venue Shopping in Ethical Medical Issues, or the Art of Political Manipulation

Policy politics and boundary work are not without political manipulation for the sake of achieving one’s substantive policy goals. The art of political manipulation (Riker, 1986) consists mainly in combining three strategies: (1) agenda control through agenda shaping (Rochefort & Cobb, 1994) and agenda denial strategies (e.g. Cobb & Ross, 1997); (2) controlling the nature and number of policy alternatives; and (3) selection of (comparative) decision dimensions or criteria under active political consideration. Usually, these partial strategies jointly make up a venue2 shopping strategy.

2 Webster’s Dictionary defines a ‘venue’ juridically as ‘the locality in which a jury is drawn and a case tried’. By analogy, political and policy scientists use the term to mean the institutional and/or procedural landscapes in which an issue is up for political decision making: ‘Depending on the issue and how it is understood by those potentially involved it may be assigned to an agency of the federal government, to private market mechanism, to state or local authorities, to the family, or to any of a number of institutions. We term this the venue problem. Each venue carries with it a decisional bias, because both participants and decision-making routines differ’ (Baumgartner & Jones, 1991, p. 1047).
strategy, i.e., the deliberate political effort to find or create a decision arena or setting that offers the best prospects for achieving one’s policy preferences (Baumgartner & Jones, 1991, 1993). Venue shopping, however, is more than political strategy or tactics. It can be experimental, instead of instrumental and calculated; or it may serve organizational needs and identities, instead of best advancing substantive policy goals (Pralle, 2003).

The political strategy of venue shopping in medical-ethical issues may be illustrated by the example of the Dutch debate on pre-natal screening. Given the players and their operational codes in the policy domain, there appear to be three major venues for decision making on innovative but ethically contested medical technology: (1) let the politicians decide; (2) let the doctors decide; and (3) let the citizens decide. The boundary work practice of acquired regulation described above is, in fact, a venue shopping strategy of modulation and compromise between politicians and medical professionals. Still, this long-term strategy is not a manifestation of peaceful and prudential consensus, but comes about as a result of continuous political strife.

Christian-Democratic MPs and politicians, recently supported (and surpassed in ethical zeal) by their new coalition partner, the Christian Union, oppose many new medical technologies on ethical and religious grounds. Instead of a previous Cabinet’s policy of generously introducing and making available new medical technologies, Christian politicians tacitly endorse and implement a policy of restraint, if not stand-still. For a time, they have opted for a political strategy of deliberate debate avoidance. Says Kees Klop, Christian-Democrat politician and the party’s former think-tank director (quoted in Trappenburg, 2005:19): ‘It is deliberate that Christian Democrats do not make lots of noise about the shift in policy. That is clever when you know that the greater part of the population disagrees with cabinet decision making on pre-natal screening. One should not start a national political debate on the issue’. The Christian-Democrats’ political strategy, in fact, leaves medical-ethical issues arising from medical innovations to spontaneous and chaotic processes of opinion formation in civil society and the news industry, hoping that ‘political silence is policy gold’.

This low-cost agenda denial strategy (Cobb & Ross, 1997) of a politics of silence and debate avoidance is challenged by the Rathenau Institute, a knowledge institute and advisory body which informs and advises the Dutch parliament on societal and ethical impacts of technological developments in general. On the basis of previous studies on ethical discourse about medical technologies they concluded that political debate usually reflects orthodox, academically fashionable, and ‘rational’ ethical paradigms, but disregards the ‘life ethics’ found to be used among sizable parts of ordinary citizens and patients (Kirejczyk et al., 2001). Concluding that ethical debate was insufficiently pluralistic to capture a major strand in public beliefs and discourse on issues of human reproduction and pre-natal screening, the Rathenau Institute advocates a more citizen-oriented participatory approach to medical ethical decision making. In medical technology assessment, the voice of patients and citizens should be strengthened relative to the chorus of the ‘usual suspects’, such as the medical professions and health insurers in the public health policy networks.

Representatives of the Labour Party, finally, prefer to keep the system of medical provision on medical indication intact; and generally stress equality or solidarity between younger and older, and poor and rich patients, as a value in health care. For them this implies that clinics and other health services organizations should not have the discretion to vary access and treatment regimes on the basis of ideological or religious world views or ‘patient-as-client’ willingness to pay. Hence, they advocate more stress in health policy making on ‘consent on the level of the medical profession’, as a ‘third way’ between debate avoidance and debate stimulation through interactive and participatory exercises in medical technology assessment. Defending this option, they explicitly state that the plausible outcome of public debate would be undermining the medical provision on medical indication model. They fear that public debate would reveal a consensus among citizens for more patient self-management, more diversified demand and more diversified supply at individual cost. Hence, the Labour Party defends the status quo, leaving decision making on the acceptability of new medical innovations, ethically contestable or not, largely in the hands of the medical profession.

Towards the Primacy of Problems

One implication of the primacy of politics is venue shopping as described in the previous section: politicians ought to think about the possible course and potential outcomes for political decision making of debating issues.
for particular audiences in particular institutional settings. If, for example, the potential outcomes of deliberative and participatory policy making on ethically contestable medical-technical issues involving ordinary citizens are perceived as threats to your preferred party-political preferences, you look for other modes of regulation. Although debate and argumentation is said to be at the heart of democratic governance, this type of political manipulation may lead politicians to debate avoidance, and bans on certain topics for policy analysis.

However, the political and political science ‘truth’ that party politics determines the content of debate and the substance of policy is not self-evident. One may substitute the primacy of politics maxim for a primacy of problems principle. In this view, the nature of the policy problem determines the properties of the political and policy-making process in and through which the problem is addressed: ‘perceived attributes of the policy determine the attributes of the political process that makes the policy’ (McCool, 1995, p. 175). From a social-constructivist and discursive view of politics and policy, the meanings people attribute to policy proposals are inherently multi-vocal, ambiguous, and thus politically contested. Therefore, politics is the verbal and symbolic struggle over the frames and key terminology used in the definition of the meaning of policies (Hoppe, 1993; Stone, 1997).

From this perspective Hoppe (1989) and Hisschemöller and Hoppe (1996, 2001) developed a typology of possible problem types and their concomitant political and policy-making processes. The starting point is that in judging a particular situation as problematic, people distinguish between ‘facts’ and ‘norms and values’, if only for pragmatic reasons. Every problem is socially constructed as a claim about ‘facts’ deviating from a ‘norm’ or ‘standard’ or ‘ideal’; a deviation which ought not to exist. In the case of political or policy problems, addressing the problem is not an individual concern, but a matter of public, collective action; where usually government is claimed to have an initiating and leading role.

In claims making about policy problems, policy actors and public authorities face different kinds of situations. Regarding moral or ethical standards, they may differentiate between problem claims whose standards, norms and values carry more or less consent. Similarly, concerning the perception of ‘facts’ about present and future conditions, and the conversion of the former into the latter, they may differentiate between problems in which there is more or less certainty about available and usable knowledge. Using these two dimensions – degree of agreement on normative claims at stake, and degree of certainty on relevant and available knowledge – one may construct the following typology of the politico-cognitive status of problems for policy-makers (see Figure 1). These four policy problem types may also be interpreted as different task fields. In individual cognition and problem processing, different task environments require different methods and heuristics for successful problem solving. Similarly, in addressing public policy problems, the different politico-cognitive status of

Figure 1. Types of Policy Problems and Concomitant Policy-Making Styles (Hoppe, 1989; Hisschemöller & Hoppe, 1996)
problems generates its concomitant variable styles of policy making.

Structured and Unstructured, ‘Wicked’ Problems

When we are very close to full agreement on values and norms, and if we are close to certainty on knowledge instrumental for achieving our concrete objectives, we are in the top-left quadrant of fully structured problems. A structured problem is like a puzzle. However complex, the pieces of the puzzle are given, and for every puzzle there is a configuration of pieces representing an adequate solution (Mason & Mitroff, 1981; Dery, 1984). It is the type of problem politicians and civil servants like and desire to create and maintain – at least, in principle, and as long as it delivers satisfactory results (Hisschemöller & Hoppe, 1996). For structured problems may be delegated to professional experts – a kind of ‘invited’ technocracy. Cost control and some re-allocation of resources is the only administrative task left for non-expert administrators. Bureaucratic managers and professionals rule in closed professional communities. Through (scientific) learning by analysis-cum-instruction, policy regulation may gradually avoid errors, qualitatively improve or become more efficient.

The history of the eventual political acceptance of pre-natal screening for Down’s syndrome and neural tube defects provides a good example (Meijer, 2008). For a long time, politicians resisted the expansion of pre-natal screening to women under the age of 36. In 1996, the deputy minister of health ruled that if pre-natal screening was to be offered to all women (and reimbursed), screening centres would need official permits under the Bill on Medical Population Screening (Wet Bevolking-sonderzoek). Technological improvements in probability-based screening methods enabled the Health Council in 2001 to advise the conditional introduction of screening for all. Good quality control and good counselling in order to realize informed consent and rational patient choice were two of the strictest requirements. In 2004 the cabinet resolved the issue. Screening was offered to all women irrespective of age, but reimbursement was limited to women of 36 and over. Immediately, implementation was delegated to a small professional community of relevant (para)medical professionals, coordinated by the National Institute for Public Health (and the Environment – RIVM).

The situation causing unease among most politicians, and nervousness among their civil service staff, is thoroughly unstructured, or messy or wicked problems (in the lower, right-hand quadrant). Policy-makers perceive persistent high uncertainty about relevant knowledge claims, and high preference volatility in mass and elite opinions; or strong and divisive, even community- or regime-threatening discord and conflict over values at stake. Also, they have no fixed and reliable set of ‘partners in governance’. Unstructured or ‘wicked’ problems frequently come in issue networks in flux, open to many different social groups next to the ‘usual suspects’ of bureaucrats, politicians and representatives of vested interests. Unstructured problems are difficult to disentangle ‘webs’ of interrelated problems; they resist decomposition in (quasi)independent, separately solvable problem clusters or parts. There is dissent and conflict over which pieces belong to the ‘puzzle’, and over which arrangement of the pieces means ‘solving’ the puzzle.

Sometimes the negative side effects of entrenched technologies cause a U-turn from structured to unstructured problem, like the car mobility problem. Sometimes, as in the case of medical science and technology as argued above, it is the unbridled research and innovation drive that leads to new, unstructured problems. Contrary to structured problems that are almost politically uninteresting, unstructured problems occasionally are in the political spotlight, and may even generate sustained, intractable political controversies (Schön & Rein, 1994).

Part of the predicament for policy-makers is that even the recognized experts and scientists continue to quarrel over problem causes

4 Pellizoni (2003, p. 330) speaks of this traditional model of the politics of expertise as enacting a tacit co-operative scheme: ‘This scheme assumes that an essentially technical definition of policy issues is possible, so that they can be settled by relying on specialized knowledge. ... In this scheme, lay citizens are disabled because they lack the ability to speak pertinently and appropriately. ... Moreover, a co-operative scheme focused on specialized knowledge implies the tendency to narrow the definition of the relevant abilities involved in a policy issue, i.e., to increase the specialization of usable expertise’.

5 Since the beginning of the 20th century it has been known that the probability of having a baby with Down’s syndrome increases with age.

6 This Bill regulates medical screening among people who are in principle free of complaints for cancer and other diseases for which no prevention and/or treatment methods are (yet) available.
and future perfectability of technologies. However, this does not mean that learning about unstructured problems is impossible. Rather, the orderly forms of analysis-cum-instruction learning have to give way to ‘wilder’, more destructive (Schumpeter), but sometimes more creative modes of innovation through variety-cum-selection learning. These learning modes are characteristic for (quasi-)markets or ad-hoc experimental policy making, and for the kind of society-wide debates triggered by participatory and deliberative technology assessments such as advocated and sometimes staged by the Rathenau Institute (Van Eijndhoven & Van Est, 2000; Hoppe & Grin, 2000).

### Two Types of Moderately Structured Problems

Moving away from unstructured problems is only possible by generating a transition to moderately structured problems in scientific, social, media and political debates. One possibility is that instrumental knowledge is increasing over time, and the problematic situation moves from unstructured to moderately structured, with means consensus (lower, left-hand quadrant). This problem type occurs when relevant and required knowledge tends to high levels of certainty, but there is ongoing dissent on the normative claims at stake. The key characteristic of this type of policy problem is not knowledge certainty, but the valutative ambiguity, and frequently the contested and divisive nature of the ethics of the problem.

Under such conditions, some policy actors may decide to bring together a new network of a selected, restricted number of policy-makers, some of them as representatives of groups outside normal venues of policy making. Contrary to open issue networks’ spontaneous processes of garbage cans and variety/selection learning, institutional design is the catchword here. The design is for building of discourse coalitions between stakeholders with different, sometimes diametrically opposed belief systems. The design is for interactive learning aiming for synthesis, or some other means for turning divergent views and mutual criticism into opportunities for policy change (Roe, 1994; Van Eeten, 1999). Or, in case synthesis and real change are a ‘bridge too far’, design of other means for deliberative and procedural accommodation of conflicting values, principles and goals; finding means for credible conflict management and pacification; gaining time to avoid solving the problem immediately, without losing trust and legitimacy among citizens. Clearly, designed networks for discourse coalition formation need strong network management, both in their creation and maintenance.

The Dutch debate on abortion provides an excellent example. When the issue arrived at the political agenda, a new, fully safe abortion technique had recently been introduced. The early debate focused on the moral permissibility of abortion in principle; later phases concentrated on the conditions under which abortion might be permissible; and on alternative procedures of consultation for establishing such conditions (Outshoorn, 1986). A very recent case involves embryo selection after in vitro fertilization. Until 2008 embryo selection was allowed only for defective genes leading to lethal diseases such as Huntington’s. The deputy minister for health announced a ‘technical’ expansion to serious forms of hereditary breast and intestinal cancer. However, she was temporarily opposed by the Christian Union, a coalition partner in the present cabinet. This political party feared a ‘slippery slope’ if the list of diseases for allowed embryo selection was politically determined. The resulting compromise was to allow screening for such genetic defects and embryo selection for IVF patients on a case-by-case basis, after approval in a specially created ethical commission.

Another possible scenario is the move to moderately structured problems, with goal consensus (upper, right-hand quadrant). In this type of case, the policy-making arena usually consists of a number of advocacy coalitions in well-delineated (Sabatier & Weible, 2007) or institutionalized policy sub-systems, like health policy. Coalitions come about because policy actors are aware of basic congruencies in their policy belief systems and policy core values; and on this basis decide to pool resources and co-ordinate strategic policy influence. Advocacy coalitions attempt to influence the goals, instruments, budgets and personnel for government policy making in their own direction. Usually there is one advocacy coalition which dominates the others, sometimes for considerable periods of time. Given this dominance, policy-makers observe a great deal of agreement on the norms, principles, ends and goals of defining a desirable future state; but simultaneously considerable levels of uncertainty about the relevance and/or reliability of knowledge claims about how to bring it about. This kind of problem typically leads to disputes of what kind of research might deliver more certain knowledge for solving the problem. Given uncertain knowledge, and thus uncertain effectiveness and efficiency of interventions, this problem type also frequently raises issues of bargaining...
about who will be responsible for expenditures in financing or otherwise enabling certain interventions; and for risks in case of ineffectiveness or negative side effects. Players in and around the national advisory systems and implementation agencies in health care policy act in this way when they decide on the long list of treatments that belong to ‘medically required care’, or negotiate hospital budget allocations. Also an issue like tackling obesity seems a good example (Council for Public Health and Health Care – Raad voor de Volksgezondheid en Zorg [RVGZ], 2002).

**Primacy of Problems Applied to Health Care**

The big issue facing players in the health policy sub-system for quite some time to come is whether or not, and to what extent, medical treatments using innovative but ethically contestable technologies ought to be included in the set of medical treatments routinely applied in clinics and reimbursed to patients with health care cost insurance, but partly also from the government budget. So far, government and health insurance companies rely on a system of medical provision on medical indication. Decision making seeks consent on the cost-effectiveness of the technology and treatment methods derived from it. This is the task of a rather closed, corporatist policy sub-system of stakeholders and medical professionals. On the one hand, there are the medical professional groups, such as specialists, general practitioners, medical researchers, the many types of paramedical professionals, the pharmaceutical and biotechnology researchers and engineers in their industrial laboratory complexes. Their views count especially to establish sufficient certainty on the laboratory, clinical and real-life effectiveness of standardized medical treatments. On the other hand, there are stakeholders, such as health insurance companies, hospital and other health care institution managers, representatives of the medical-pharmaceutical-biotechnological commercial complex, trade unions of health care workers and patient organizations. They are supposed to discuss matters of resource efficiency, implementation feasibility, patient acceptability, etc.

In fact, the policy-making system is a hybrid between professional self-regulation and corporatist interest articulation. The historical core of the system is shaped by defining the problem of medical technology and its impact on health policy as a moderately structured problem with knowledge certainty. Medical peer review took care of the knowledge dimension; the ethical dimension was left to politics. Politicians would have the role of linesmen: doctors should not mix up medical treatment with implicit, but constraining conditions that implicitly or explicitly reflect religious, ethical and political judgements on ‘good parenting’, or on the role of medical technology in a ‘good society’.

Once new technologies were admitted, the system shifted to a rule-mode fit for structured problems, where everything was left to the medical profession. Owing to strong consensus on the goals for health policy – equal access to equal medical treatment for all Dutch citizens at reasonable costs – the health sector was allowed to grow and grow, seemingly under medical self-regulation. But the ever increasing macro-economic importance of health-related technological, industrial and service activities gradually led to more deliberate efforts at cost control. This took the shape, in essence, of bargaining about health care costs in an ‘iron triangle’ between medical professionals, insurance companies and the state.

In order to curb and complement the interests of the medical professionals, in the 1980s and 1990s, politicians facilitated the interests of patient groups as a kind of countervailing public power. It is a clear case of policy sub-system restructuring. Politicians feared that the existing ‘iron triangle’ network, without a representative ‘voice’ for patient interests, threatened effective policy deliberation and the legitimacy of decisions on far-reaching reforms for managed competition in health care. In order to widen the deliberative capacity and save the legitimacy of political decision making, they recognized patient groups as legitimate ‘players’, and used public funding of patient interest groups and organizations to expand the composition of the network. Hence, the problem definition shifted to moderately structured problems with considerable goal consent; and the policy sub-system acquired the corresponding traits of a neocorporatist sub-system for stakeholder interest articulation – but as an overlay on top, not as a substitute for the older institutional arrangements.

However, next to the transition to managed competition, this hybrid, opaque and difficult to steer policy sub-system is also challenged by ethically contested new medical technologies. These innovations breed unstructured problems, because frequently neither their cost-effectiveness, nor their ethical dimensions have crystallized into clear, publicly defensible, and dominant policy views or beliefs. The contemporary policy system evolved from efforts to cope with both forms of moderately structured and fully structured problems. Yet,
now it appears to have serious difficulties in dealing with the new type of unstructured problems. Thus, one may speak of a potential structural mismatch: a policy network, designed to cope with structured and moderately structured problems is now ‘bombarded’ with ‘un-processable’ unstructured problems as a result of rapid technological developments. The system was capable of relatively harmonious ‘gear shifts’ between accommodation, negotiation and rule as modes of problem coping. But, in spite of the presence of patient organizations and forums as a modest shift to a more pluralist, participatory and deliberative style of policy making, the system is straining to add a learning style of coping with unstructured problems to its repertoire.

This is reflected in the political responses to the problematic situation. They typically show how different players differ in their political judgements on the nature of the ‘same’ problem. They also clearly demonstrate that politicians consider it their task to initiate or suppress and avoid political and public debate, depending on their political judgement on the course and potential outcome of such debates. They keep seeing patients and patient interest organizations only as counter-vailing power in the new bargaining system for managed competition in health care; and probably the patient organizations have come to share this definition of their identity and role. This is a regularly occurring co-operative scheme in network restructuring towards more ‘participatory’ modes:

These often seek to reveal a ‘public opinion’ on an issue by throwing light on opinions and ideas, principles and values, and by comparing to the ‘facts’ provided by experts . . . However, the abilities attributed to citizens [in this case, patients] are carefully circumscribed. They . . . have an ethical competence, they can discuss what is to be inferred by looking at facts from their own principled viewpoint, but they do not have a say on the facts themselves – how they are constructed, selected and presented (Pellizoni, 2003, pp. 335–6).

**Societally Responsible Innovation through Meta-governance**

It looks like competitive venue shopping is an inevitable part of normal politics. Yet, sometimes venue choice is shaped by policy learning. Far-sighted policy intellectuals and policy entrepreneurs may arrive at a new understanding of the nature of the policy problem (Pralle, 2003, pp. 242–4). This may cause them to choose different venues, and sometimes even to create new venues that did not exist before. In other words, they may redesign the boundaries, composition of players (adding patient organizations is a case in point), rules and policy-making styles of the existing policy sub-system – or even create new ones.

In health care, the social, legal and ethical aspects of medical technological innovations ought to be as intelligently and seriously debated as the more common scientific, technical and economic aspects. On the basis of the principle of the primacy or good governance of policy problems, the health policy system ought to be sufficiently robust and flexible to accommodate all policy-making styles for all types of problems. In the previous section, I showed this not to be the case; the system is less able to deal with unstructured problems. In the present system of health care politics, such ‘wicked’ problems are supposed to gradually acquire more structured formats in unpredictable or erratic processes of mass communication and opinion formation. If this is considered unsatisfactory, politicians and policy-makers should create more opportunities or ‘spaces’ for more disciplined deliberation and debate among all involved stakeholders (e.g. Funtowicz et al., 2000). What would be necessary, then, is to find institutional resources to inject more participant and substantive pluralism in more seriously and creatively dealing with unstructured problems through more public spaces for participation, deliberation and learning. How is this to be achieved?

The short answer to this question is by gently nudging the policy politics of the health policy network to more deliberation and/or participation through meta-governance. Meta-governance means letting the primacy of politics be influenced by the primacy of problems. It constitutes the endeavour by politicians, policy intellectuals or some other policy entrepreneurs to influence the discourse, the composition and participation modes of players, the rules of the game, and the interdependencies between players in governance networks (Sorensen & Torfing, 2005, pp. 202–5) so that they are continuously aligned to the problem type involved. Frankly, it would be difficult to draw the line between meta-governance and political tinkering or *bricolage*. The health system is simply too complex and self-controlled to be amenable to meta-governance as top-down steering from a central control unit. The only way to ‘steer’ such complex systems is by using the forces and drivers already effective in it; to ‘interpolate’ small doses of change in such ways that the balance of forces is changed in the desired direction.
(Dunsire, 1986; Hood, 1986). One would have to fine-tune the relative weight of the different, partially opposing governance modes (rule, negotiation, accommodation, learning) present in the overall constellation.

In health care, some developments go in this direction already. Under managed competition, the role of (potential) patients as clients will gain in weight and influence in policy implementation as health service delivery. Patient self-management, case management, more choice in health service delivery, patient and user rankings of health service organizations will all become more important. Yet, bolder steps are required in dealing prudently with ethically contestable medical innovation. Under present conditions, patient organizations and platforms function as interest groups. Valuable as this may be, they have become part of the ‘usual suspects’. The voices (in the plural) of ordinary people and citizens as potential patients, and as relatives, friends or care-takers of patients, are only faintly audible through the normal modes of political participation in representative democracy. To really inject more pluralism in creatively dealing with and collectively learning about unstructured problems of medical technological innovations, a good start would be to introduce more participatory and deliberative design elements in health technology assessments (Van der Wilt, 1995; Grin, 2004; Reuzel, 2004; Moret-Hartman, 2008).

References


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