

REFGOV

Reflexive Governance in the Public Interest

Services of General Interest

REFGOV CASE STUDY

**Patient and Public Involvement in Healthcare Governance –
England and Wales**

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Patient and Public Involvement in Healthcare Governance – England and Wales

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Introduction

This Report begins by introducing the UK healthcare case studies on patient and public involvement (PPI), explaining differences in the coverage of the subject-matter in England and Wales. The second section outlines the statutory framework for the NHS in England and Wales following devolution of power to the Welsh Assembly in 1999. Part 3 sketches the main features of the first wave of modern PPI reforms in England in the period 2000-2006. Part 4 highlights the deficiencies of this PPI system as reflected in Government reviews and Parliamentary scrutiny, and in academic policy analysis. Part 5 describes the ‘new regulatory landscape’ of further reforms introduced in England by legislation in 2007 and 2008. Parts 6 and 7 discuss respectively the divergent policies on PPI followed in Wales and some limitations of the Welsh approach. Part 8 considers the prospects offered by the PPI systems in England and Wales for improved healthcare governance from a social learning perspective. The conclusion suggests that, while PPI policies tend to be justified in terms of increasing both democratic legitimacy and the responsiveness of public services to local needs, there is a further rationale in terms of the building of capacities for social learning.

1. PPI case studies – background and theoretical framework

PPI provides an obvious focus for the study of reflexive governance. Health services are necessarily co-produced by medical professionals and patients, who arguably also have

an important part to play in the effective organization and management of healthcare. The involvement of patients and other stakeholders is clearly amenable to analysis in terms of the theory of social learning set out in the Synthesis Reports.¹ Furthermore, while policy initiatives aimed at increasing participation have been a feature of UK healthcare policy for many years, the contrasting implementation of PPI in England and Wales offers scope for rich comparison. PPI has acquired a fresh impetus in England through radical organizational reforms under the Local Government and Public Involvement in Health Act 2007, while Wales is adopting an incremental approach to reform building on more traditional structures.²

Our analysis in the two countries is conditioned by such differences. In England we consider how the PPI system implemented after 2000 will be reformed under the 2007 Act. The main sources for this part of the research are government policy documents (Green and White Papers), parliamentary committee reports, and the legislation itself. The principal aim here is to provide a critique of the new governance framework, focusing on its potential to facilitate (or impede) the development of institutions and processes for the involvement of patients and other stakeholders that are necessary pre-conditions of effective social learning. In Wales, where autonomy from Westminster following devolution has resulted in a more moderate approach to reform and a greater degree of continuity in healthcare policy, the emphasis is more on policy implementation and the practical operation of relatively stable governance arrangements in securing such conditions.

Before proceeding further, we summarise the REFGOV theoretical perspective outlined in the second synthesis report, and indicate how this framework will be adapted in the analysis of our particular case study of healthcare governance. In REFGOV terms, PPI initiatives in England and Wales must be evaluated with reference to the potential of the different PPI governance arrangements to facilitate the development of institutions and processes that are conducive to more effective social learning.³ The basic criterion of the adequacy of governance is the degree of reflexivity in the organisation of conditions of social learning in collective actions to resolve problems in the general interest. Reflexive governance (here equated with ‘maximisation of fulfilment of normative expectations held by participants in a collective action’⁴) cannot result spontaneously from the expression of individual preferences, as assumed by neo-classical economics, but requires instead the creation and maintenance of specific institutional conditions.

¹ J. Lenoble and M. Maesschalck, ‘Beyond Neo-institutional and Pragmatist Approaches to Governance’, Working Paper Series: REFGOV-SGI/TNU-1, Centre de Philosophie du Droit, UCLouvain 2006; ‘Reflexive Governance: Some Clarifications and an Extension and Deepening of the Fourth (Genetic) Approach’, Working Paper Series: REFGOV-SGI/TNU-2, Centre de Philosophie du Droit, UCLouvain 2007.

² D. Hughes and P. Vincent-Jones, ‘Schisms in the Church: NHS Systems and Institutional Divergence in England and Wales,’ 49 *Journal of Health and Social Behaviour* (forthcoming, December 2008).

³ In section 4 below, we point to the limitations of an evaluative approach conducted in terms of the imbalance of power between bureaucrats/professionals on the one hand and patients/citizens on the other hand, as is typical of much academic and policy analysis. It should be clear that the focus on social learning does not deny the importance of power relations, or of ‘empowerment’ in the sense of capacitation.

⁴ J. Lenoble and M. Maesschalck, ‘Reflexive Governance: Some Clarifications and an Extension and Deepening of the Fourth (Genetic) Approach’, Working Paper Series: REFGOV-SGI/TNU-2, Centre de Philosophie du Droit, UCLouvain 2007.

Such conditions vary according to the particular analytical level (economic institutionalist, collaborative/relational, pragmatic, or genetic) at which the evaluation of reflexivity of learning operations is conducted. The four approaches and their associated conditions are supplementary rather than mutually exclusive – each adding value in building our understanding of the role of reflexivity in social learning, rather than displacing or simply superseding the less developed approach.

(1) The first conception of social learning, implicit in the new institutional economics, emphasizes the need for external ordering or coordination of economic interaction through institutions designed to improve efficiency by altering incentives and representations among local economic actors. In section 8 below, we analyze this aspect of healthcare governance in healthcare in England and Wales under the heading: *economic coordination*.

(2) At the second level of analysis (referred to variously as deliberative, collaborative/relational, and dialogic) the focus is on the development and aggregation of communicative competencies, through the design of specific fora of representation and negotiation combined with ‘capacitation’ strategies directed at strengthening argumentative capabilities and increasing opportunities for dissent and counter-argument in dialogic processes. We discuss this dimension under the heading: *capacitation and communicative competence*.

(3) The third, pragmatist approach specifies two further sets of conditions of success of learning operations: (i) Democratic experimentalism builds on the deliberative conditions established at the second level by emphasizing the ‘experimentalist’ forms of joint inquiry and investigation in which social actors must engage in order to achieve effective social learning, involving specific techniques of benchmarking, co-design, and learning by monitoring. Here we use the sub-heading: *experimentalism and joint inquiry*. (ii) The Schönian strand of pragmatism re-focuses attention on the issue of capacitation of social actors, with reference to cognitive processes of representation and re-representation, the adjustment of frames and reframing, and governance techniques capable of overcoming ‘defensive strategies’ and of challenging preconceptions and hitherto entrenched positions of social actors and stakeholders in the healthcare environment. We consider this aspect in terms of *capacitation and cognitive reframing*.

(4) The fourth, genetic approach to social learning specifies conditions of collective identity-making and reframing going beyond the simple substitution or replacement of one representation by another, as is claimed to occur under the second pragmatist strand. Fully reflexive governance in the learning operation depends on the presence of a ‘third element’, or ‘terceisation’. In the case study described in the synthesis report, the ‘third element’ responsible for changing collective representations and ultimately repositioning key actors in relation to issues of environmental sustainability and energy regulation is the role of the ‘citizen-consumer’. In our PPI case study, by contrast, the citizen-patient cannot be part of such a *solution*, but is rather the *governance problem* to be investigated and explained. Analysis in terms of the genetic approach is beyond the scope of this overview, and will be developed separately in a case study of implementation of PPI in one English region.⁵

⁵ C. Mullen and P. Vincent-Jones, ‘Indications of Prospects for Social Learning in Leeds LINK’.

The analysis in both countries will ultimately draw on empirical research currently being conducted in five local health economies in England and Wales in a project linked to but separate from REFGOV, funded by the UK Department of Health.⁶ The PPI case studies will explore three overlapping aspects of healthcare governance: patient and public involvement in the commissioning of secondary care; the role of bodies representing the patient and public interest; and the regulation of involvement.

(a) *Patient and public involvement in commissioning*

The introduction of the NHS internal market in 1991 replaced centralized planning with a commissioning system in which health authorities purchased care on behalf of patients from semi-autonomous NHS Trusts on the basis of negotiated contracts.⁷ In both England and Wales, PPI initiatives may be understood as part of the attempt to counter the tendency of the contractual process to exclude the interests of stakeholders who are not party to the principal exchange by enabling citizens to be ‘connected’ with commissioning and other aspects of healthcare governance through the operation of mechanisms of voice and/or choice.⁸

In England, Primary Care Trusts (PCTs) choose among competing providers in the public and independent sectors in purchasing secondary care services on behalf of patient populations. Contracts with NHS Foundation Trusts are legally binding in the same way as contracts with private and non-profit providers. Prices are fixed nationally, so competition is restricted to quality. Remuneration ‘follows the patient’ through a system of ‘Payment by Results’, according to tariffs based on health resource groups (HRGs). In addition to choice exercised by the PCT, patients may be directly involved in the selection process through a computerised ‘Choose and Book’ scheme which, when fully implemented, will allow choice among at least four providers of hospital operations.⁹ The choice (made in consultation with a general practitioner) cannot, at least in theory, be blocked by the PCT. The encouragement of choice has an explicit economic purpose, intended to influence the pattern of commissioning by enhancing quasi-market competition and incentives on service providers. However, patient involvement in commissioning is not just about choice. Patient *voice* is presented in

⁶ Department of Health Service Delivery Organisation, ‘Contractual Governance in a System with Mixed Modes of Regulation.’ Refer to Patient Choice empirical research here also?

⁷ An alternative form of economic organization, also combining an element of public control with market incentives, involves *integration* of purchaser and provider functions in Health Management Organisations, with competition between them – see C. Ham, *Commissioning in the English NHS: The Case for Integration* (London: The Nuffield Trust, 2007).

⁸ PPI includes policies encouraging involvement in economic as well as political processes – see A. Thompson, ‘The Meaning of Patient Involvement and Participation in Healthcare Consultation: A Taxonomy’ (2007) 64 *Social Science and Medicine* 1297 (distinguishing the ‘consumerist’ model of involvement espousing individual choice and the power of ‘exit’ when dissatisfied, from the ‘democratic’ model espousing collective freedom and emphasizing ‘voice’ as a direct mechanism for exerting change).

⁹ The fourth principle of public sector reform adopted by New Labour following the 2001 general election was ‘more choice for customers and the ability, if provision is poor, to have an alternative provider’ (Cabinet Office, ‘The Second Phase of Public Sector Reform: the Move to Delivery’, 22 March 2002) (<http://www.cabinet-office.gov.uk/eeg/secondphase.htm>). Choice in this sense remains a central plank in the present government’s modernisation program. The choice agenda was reinforced by the policy statement, ‘Creating a Patient-led NHS’, following the reform strategy set out in the NHS Development Plan in June 2004. The role of PCTs is not to direct patients to particular providers, but to offer a choice amongst local NHS hospitals, Foundation Trusts, and ‘nationally procured’ Independent Sector Treatment Centres (ISTCs).

policy documents: (i) as a necessary supplement to choice, ‘shaping and extending the range of choices/opportunities on offer’; and (ii) as a means of ensuring the ‘best fit’ or responsiveness of services to patient needs and preferences, through improved communication between patients and the PCT responsible for purchasing and specifying services on their behalf.¹⁰

By contrast in Wales, the purchaser-provider split entails less competition and a greater emphasis on partnership and ‘collegiate contracting’ with hospital providers that remain more firmly within the NHS. Since there are no corporatized semi-independent NHS Foundation Trusts, contracts between Local Health Boards (LHBs) and NHS providers are not legally enforceable. Prices are fixed locally through negotiation rather than nationally. Besides reduced choice and diversity of service provider compared with England, there is a lack of direct patient choice of secondary care. In the comparatively limited ‘Second Offer’ scheme that has been introduced as a temporary measure in Wales, patients may be offered an alternative hospital for an operation where the standard waiting list time is exceeded. Here ‘choice’ is restricted to a yes or no answer, and many patients do not take up the second offer. Since there is no intention that the patient’s involvement should subject commissioners or providers to incentives, or directly influence the pattern of commissioning by LHBs, ‘voice’ also carries different connotations.

Our on-going research in the two countries is examining the different forms of patient and public involvement in commissioning with reference to the institutional economics and collaborative/relational approaches to social learning. English reforms directed at strengthening competitive incentives and improving the quality and availability of information to commissioners and patients are clearly illustrative of economic institutionalism. In Wales as well as England, learning in the commissioning process presupposes communicative competence both in relations between purchasers and providers, and in their relationship to patients and the public more generally.

(b) *The role of representative bodies*

As described in detail below, the Government in England has sought to increase stakeholder involvement through the replacement of Community Health Councils (CHCs) by a plethora of new representative bodies. Some of the bodies created after 2000 will themselves be abolished, or their roles redefined, under the 2007 Act. The legislation will also establish a completely novel type of representative organization in the form of Local Involvement Networks (LINKs). In Wales, the voice agenda is more concerned with increasing democratic legitimacy through improved stakeholder representation in political processes at both local and national levels. To this end Wales has retained the twenty or so Community Health Councils (abolished in England in 2003) and indeed extended their remit.

We are examining the role of representative bodies primarily with reference to the collaborative/relational and pragmatic (democratic experimentalist) conceptions of social learning. In the past such bodies may be regarded as having been more or less deficient (as ‘channels of communication’) in *presupposing* the existence of cognitive, institutional, and personal capacities on the part of patients, users and other stakeholders that are necessary for their effective participation in, and contribution to, social

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learning. We will compare how far the conditions of more effective social learning in this sense may be being established in England and Wales through contrasting strategies of capacitation, combined in the former country with radical institutional reform, and in the latter with the flexible adaptation and evolution of traditional representative structures.

(c) *Economic regulation and the regulation of involvement*

In England the PPI reform agenda includes stronger and more integrated economic regulation under the Health and Social Care Act 2008, with proposals for the merger of three existing regulatory bodies (the Healthcare Commission; the Commission for Social Care Inspection; and the Mental Health Act Commission) into a single agency with increased powers analogous to established models of independent regulation in the privatized public utilities sector. This part of the reform agenda is clearly amenable to analysis in terms of economic institutionalism.

In addition, however, under the ‘New Framework for User and Public Involvement’ due to be introduced by the 2007 legislation, certain NHS organisations will be required to respond to patients and the public in planning and decision-making (strengthening the existing duty under the Health and Social Care Act 2001 to ‘involve and consult’). Commissioners of services will be under a duty to report regularly on what they have done differently as a result of consultations. In proposals for the ‘regulation of involvement’, the new regulator will have the power to develop assessment criteria whereby the performance of NHS bodies in involving patients and public will be taken into account in Annual Performance Reviews. This part of the reform agenda in England will be considered with reference to the second (Schönian) strand of the pragmatic approach, together with the genetic approach to social learning. Here we will investigate the social learning potential of requirements on the part of commissioners of healthcare to ‘respond’ to patients and public, and to ‘report’ on what they have done differently as a result, compared with more narrowly construed legal duties to consult and involve.

2. Statutory framework – England and Wales

Primary legislation of the Westminster Parliament on the NHS has traditionally extended to England and Wales. The statutory framework consisted of the National Health Service Act 1977, amended and supplemented by the National Health Service and Community Care Act 1990, the Health Authorities Act 1995, the National Health Service (Primary Care) Act 1997, the Health Act 1999, and the Health and Social Care Act 2001. The Health Act 1999 Act abolished GP fundholding in England and Wales, made provision for the establishment, functions and funding of PCTs, and reformed the legislative framework governing NHS Trusts. The Health and Social Care Act 2001 also extended to England and Wales. Public and patient involvement was strengthened through provision for Overview and Scrutiny Committees to scrutinise NHS bodies and represent local views, and the creation of a duty on NHS organisations (each Health Authority, PCT, and NHS Trust) to make arrangements with the aim of involving patients and the public in the planning and decision making processes of that body.¹¹

¹¹ The majority of provisions of the Health and Social Care Act 2001 were implemented at different times as specified in separate statutory instruments in England and Wales. For example, section 11 was brought into effect in Wales on 1st December 2002 by Welsh Statutory Instrument 2002 No. 1475

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The most radical and far-reaching reforms of the structure and organisation of the NHS, however, have occurred through primary legislation applying to England only. The National Health Service and Health Care Professions Act 2002 modified the structural framework of the health service in England (and separately in Wales¹²). As a result, English Health Authorities (HAs) were renamed Strategic Health Authorities (SHAs), responsible for the performance management function for the health services provided within their boundaries. Most of the functions of the old HAs were transferred to PCTs. Part 1 of the Health and Social Care (Community Health and Standards) Act 2003 made provision for the establishing of Foundation Trusts as public benefit corporations authorized under the Act to provide goods and services for the purposes of the health service in England, subject to regulation by Monitor; and for the reform of the inspection and monitoring regime for other NHS bodies under the auspices of the Healthcare Commission.

The main provisions of this legislation have recently been consolidated in separate Acts for England and Wales – the National Health Service Act 2006, and the National Health Service (Wales) Act 2006, together with the National Health Service (Consequential Provisions) Act 2005.¹³ The fact that separate statutes were deemed necessary at this stage in the life of the NHS is significant. According to the Department of Health note explaining the consolidation: ‘Health law in England and Wales now diverges in so many respects that one Act covering both would be neither concise nor comprehensible to users of the legislation.’¹⁴ Forthcoming legislation will further increase the scope for differentiation of the healthcare systems in England and Wales. Most of the provisions of the Local Government and Public Involvement in Health Act (such as the revised ‘section 11’ duty and the creation of Local Involvement Networks) will apply to England only. The legislation will confer on the Welsh Assembly ‘framework powers’

(W.147)(C.41) [The Health and Social Care Act 2001 (Commencement No.2)(Wales) Order 2002]. Section 13 (on Assembly intervention powers) was brought into effect by Welsh Statutory Instrument 2003 No. 713 (W.87)(C.36) [The Health and Social Care Act 2001 (Commencement No.4)(Wales) Order 2003].

¹² In Wales, the Act provided for the creation, functions and funding of LHBs, in effect extending the existing role of Local Health Groups. It placed a duty on each LHB and each Local Authority in Wales to formulate and implement a ‘health and well-being strategy’ for the population in the area, and to have regard to the strategy in exercising their functions. The Act also empowered the Assembly to make regulations imposing a duty on LHBs and Local Authorities to co-operate with other persons and organisations (such as NHS Trusts, Community Health Councils, voluntary bodies and local businesses) in formulating their strategy.

¹³ The purpose of the consolidation is to make the statutory framework more accessible, rather than to effect substantive legal changes. The Acts affected by consolidation are: Health and Social Care (Community Health and Standards) Act 2003; National Health Service Reform and Health Care Professions Act 2002; Health and Social Care Act 2001; Health Act 1999; National Health Service (Private Finance) Act 1997; National Health Service (Primary Care) Act 1997; National Health Service (Residual Liabilities) Act 1996; Health Authorities Act 1995; National Health Service and Community Care Act 1990; Health and Medicines Act 1988; Hospital Complaints Procedure Act 1985; Health and Social Security Act 1984, Health Services and Public Health Act 1968, and the Ministry of Health Act 1919.

¹⁴ The note continues: ‘A separate Bill for Wales has no constitutional implications; it does not affect the position of the Assembly, which currently has no primary law making powers and the Bills do not substantively change the law’ - www.dh.gov.uk/assetRoot/04/13/42/47/04134247.pdf. See *Devolution and the Centre Monitoring Report*, Devolution Monitoring Programme 2006-08, September 2006.

to make provision on a range of local government matters in accordance with amendments to Schedule 5 to the Government of Wales Act 2006.¹⁵

The Government of Wales Act 2006 (compared with the original 1998 Act¹⁶) heralds a trend towards increasing independence and autonomy of the Welsh Assembly on a wide range of issues. The limited application of the Local Government and Public Involvement in Health Act to Wales is indicative of how the relationship between Westminster and the Assembly on public service reform is likely to develop in future. For our current research on the SDO/REFGOV projects, however, the more interesting question concerns policy divergence in the early post-devolution era (say 1999-2006). Given that in this period the UK Parliament continued to legislate on the NHS in Wales, how was health service policy in England and Wales able to diverge so significantly?¹⁷ The simple answer appears to lie in the relative lack of prescription of the key legislation in relation to Wales.¹⁸ The irony here is the coexistence of increasing autonomy for Wales with growing centralization and control from Whitehall of the NHS in England.

¹⁵ The Government of Wales Act 2006 implements the Richard Report recommendations (Report of the Commission on the Powers and Electoral arrangements of the National Assembly for Wales, March 2004) that the Welsh Assembly Government should be established as an entity separate from the National Assembly (separating the executive and legislative functions), and that the Assembly should be able to make primary legislation for Wales. Part 3 and Schedule 5 of the Act introduce the mechanism whereby legislative competence may be granted, with the approval of the UK Parliament, concerning specified matters set out in the Schedule as amended by Orders in Council. Assembly legislation made under these provisions will be known as ‘Assembly Measures’. Part 4 and Schedules 6 and 7 specify the subject-matter on which the Assembly would be able to legislate without further recourse to the UK Parliament (so-called ‘primary’ legislative powers) following approval in a referendum.

¹⁶ The Government of Wales Act 1998 established the National Assembly for Wales as a corporate body exercising functions on behalf of the Crown. Sections 22-26 made provision for the statutory powers and duties hitherto exercised by the Secretary of State for Wales to be transferred to the Assembly. This was achieved under the National Assembly for Wales (Transfer of Functions) Order, SI 672 of 1999, which came in to force on 1st July 1999.

¹⁷ The situation is different in Scotland where health is one of the areas of competence devolved to the Scottish Parliament, and greater policy divergence is to be expected. Since devolution the development of the health service has emphasized partnership and collaboration within existing structures, with no Foundation Trusts, and only a very limited role for the market. The Scottish National Party administration is considering issuing bonds as a means of raising finance for new hospitals, ending private involvement through the Private Finance Initiative which has become the standard mode of procurement in England. Free personal care for older people, introduced in 2002, is being extended. The Government has a manifesto commitment to work towards the abolition of prescription charges by 2012 – *The Guardian*, 22nd August 2007.

¹⁸ Post-devolution, the UK Ministry of Justice (previously Department for Constitutional Affairs) has published ‘Devolution Guidance Notes’ (DGNs) setting out advice on working arrangements between the UK government and devolved administrations – <http://www.justice.gov.uk/guidance/devolutionguidancenotes.htm>. With regard to Wales, ‘The UK Government has agreed that Parliamentary Bills should be drafted in a way which gives the Assembly wider and more permissive powers to determine the detail of how the provisions should be implemented in Wales. The UK Government has agreed with the Welsh Assembly Government that they will normally consult each other from an early stage on the development of relevant legislative proposals, in confidence where necessary. The Welsh Assembly Government should always be consulted on Bills that confer new functions on the Assembly; alter the Assembly’s existing functions; or otherwise affect areas which are the responsibility of the Assembly. The same procedure should be followed for Bills being published in draft, and for Private Members’ Bills that are to be supported by the Government’ (GN 9, ‘Post-Devolution Primary Legislation affecting Wales’).

3. PPI in England 2000-2006

The traditional model of governance in the NHS attached little importance to public and patient involvement. In the immediate post-war period, the public interest in healthcare was maintained through a combination of professional self-regulation, voting in elections and ministerial responsibility to Parliament, with an emphasis on trust in clinicians and deference to managers.¹⁹ Within this paternalistic system, patients were the passive recipients of technocratic and medical expertise.²⁰ While limited representation was achieved through the creation in 1974 of Community Health Councils (CHCs), by the end of the 1990s such bodies were considered as failing due to a combination of lack of consistency in working practices and an inability to reflect adequately the diversity of local communities.²¹ Just as a series of medical scandals was contributing to a further loss of confidence in existing management structures and accountability mechanisms,²² the UK government was coming under pressure from European institutions to increase citizen participation in decision making affecting healthcare. In 2000 the Council of Europe recommended that governments of member states develop participation in all aspects of healthcare systems at national, regional and local levels. Governments were enjoined specifically ‘to create legal structures and policies that support the promotion of citizens’ participation and patients’ rights’, ensuring that accompanying guidelines be reflected in their law.²³ Policies directed at increasing citizen and user involvement in public services are generally justified on two main grounds: first, as part of the agenda for ‘democratic renewal’, increasing the legitimacy of decision making processes and supplementing traditional accountability through elections;²⁴ and second, as contributing to improved quality and the better adaptation of public services and facilities to the needs of the population.²⁵

Against this background we distinguish two main waves of modern PPI reform in England, the first occurring roughly between 2000 and 2006, and the second beginning around 2006. In this section we outline the main features of the PPI system in the first phase of reform.

(a) *Overview and Scrutiny Committees (OSCs)*

¹⁹ Citizen participation initiatives in the UK are part of a world-wide trend towards the development of more direct democratic mechanisms, in response to declining public confidence in representative democracy and established political institutions – P. Abelson, G. Forest, J. Eyles, A. Casebeer, and G. Mackaen, ‘Will It Make a Difference if I Show Up and Share? A Citizen’s Perspective on Improving Public Involvement Processes for Health System Decision-making’ (2004) 9 *Journal of Health Services Research and Policy* 205-212, p 206.

²⁰ R. Rowe and M. Shepherd, ‘Public Participation in the New NHS: No Closer to Citizen Control?’ (2002) 36 *Social Policy and Administration* 275-290, p 276.

²¹ J. Tritter and A. McCallum, ‘The Snakes and Ladders of User Involvement: Moving Beyond Arnstein’ (2006) 76 *Health Policy* 156-168, 158.

²² I. Kennedy, *Learning from Bristol: The Report of the Public Inquiry into Children’s Heart Surgery and the Bristol Royal Infirmary 1984-1995* (London: Bristol Royal Infirmary Inquiry, 2001).

²³ Council of Europe, ‘The Development of Structures for Citizen and Patient Participation in the Decision-Making Process Affecting Healthcare’, Recommendation Rec(2000)5, adopted by the Committee of Ministers of the Council of Europe 24 February 2000, Council of Europe, Strasbourg, p 9.

²⁴ Citizen participation is a ‘fundamental and integral part of any democratic society’ (Council of Europe, Guideline 1.1, p10).

²⁵ Council of Europe, p p22. See also M. Barnes, J. Newman, and H. Sullivan, *Power, Participation and Political Renewal: Case Studies in Public Participation* (Bristol: Policy Press, 2007), pp 23-25.

OSCs were established by local councils under section 21 of the Local Government Act 2000, amended by section 7 of the Health and Social Care Act 2001 (now section 244 of the NHS Act 2006). The 2001 Act gave OSCs an extended role in reviewing health and social care services. OSCs have powers: to request information and summon people before them to explain actions; to examine the efficacy of efforts to involve patients and public; to request action to be taken; to scrutinise any subsequent report; and to recommend an independent inspection of premises. OSCs must be consulted by NHS organizations in the event of proposed major changes to health services. They may investigate matters referred by Patient and Public Involvement Forums, and may refer matters upwards to the Secretary of State for review in certain circumstances (see below).²⁶

(b) Patient Advice and Liaison Services (PALS) and Independent Complaints Advisory Service (ICAS)

PALS and ICAS were set up to take over the advisory and redress functions previously performed by CHCs. Based in each NHS Trust, PALS provide a range of information, advice, and support to patients, families and carers.²⁷ The replacement of the original term ‘Advocacy’ in the acronym by ‘Advice’ is a reflection of the current emphasis on resolving problems reported by patients in an informal manner, rather than through resort to litigation. Local formal complaints are now dealt with by ICAS,²⁸ an independent charity commissioned by the Department of Health to provide support for patients with complaints regarding their NHS treatment.²⁹

(c) Foundation Trust Boards of Governors

The first Foundation Trusts (FTs) created under the Health and Social Care (Community Health and Standards) Act 2003 came into existence in 2004. By the end of 2007 there were sixty five FTs, with Foundation status expected to be open to all NHS Trusts by 2008. The legislation places FTs under a duty to engage with their local community, and to encourage local people to become members of the organisation. Accordingly FTs are required to establish a Board of Governors (also called ‘Members Council’), nominated and elected by the local community. The majority of places on the Board must be taken by representatives elected from the public and patient membership of the Trust. At least three governors must be elected from staff membership, with a further one from the Local Authority, one from the local PCT, and one from a local university if there is one. The legislation provides for the appointment and removal of the Chair and non-executive directors of the Board; the approval and appointment of a Chief Executive; the appointment of auditors; and consideration of the Trust’s annual forward plan.³⁰

(d) The Healthcare Commission

²⁶ House of Commons Health Committee (HCHC), *Patient and Public Involvement in the NHS*, Third Report of Session 2006-07, HC 278-1, 20 April 2007, para 51.

²⁷ Department of Health website, http://www.dh.gov.uk/en/Policyandguidance/Organisationpolicy/PatientAndPublicinvolvement/Patientadviceandliaisonservices/DH_4081305, accessed

²⁸ ICAS was established under s 12 of the Health and Social Care (Community Health and Standards) Act 2003. The creation of PALS did not require legislation.

²⁹ <http://www.seap.org.uk/icas/>

³⁰ HCHC, para. 60.

The Commission for Healthcare Audit and Inspection, known as the Healthcare Commission, was established under Part 2 of the Health and Social Care (Community Health and Standards) Act 2003 with wide-ranging responsibilities for promoting improvement in the quality of health and healthcare.³¹ The Commission's PPI responsibilities include conducting the patient survey programme, and involving patients groups through service user consultation in examining specific issues.³² The Commission applies Core Standards on PPI in its 'annual health check' of NHS organisations: 'The views of patients, their carers and others are sought and taken into account in designing, planning, delivering and improving healthcare services.'³³ The Commission also supervises the process of self-assessment by Trusts on whether they have achieved this and other Core Standards, seeking additional views on this from patient groups and representatives, OSCs, FT Boards of Governors, SHAs, and Patient and Public Involvement Forums (below).³⁴

(e) *Duties to involve and consult*

SHAs, PCTs, and NHS Trusts are required by section 11 of the Health and Social Care Act 2001 (s 242 of the NHS Act 2006) to involve and consult patients and the public in: (i) the planning and provision of services; (ii) the development and consideration of proposals for changes in the way services are provided; and (iii) decision making by the body affecting the operation of those services.³⁵ Under section 7, NHS organizations are under a further duty to consult OSCs in the case of any 'substantial development or variation' of health services (the section 11 duty is different in not limiting the duty to 'substantial' changes). Under this section OSCs have powers to review and scrutinise matters relating to the health service in the authority's area, and to make reports and recommendations. Regulations further provide: 'In any case where an OSC considers that the proposal would not be in the interests of the health service in the area ... it may report to the Secretary of State in writing who may make a final decision on the

³¹ A key new responsibility is for regulating the independent healthcare sector, a task previously performed by the National Care Standards Commission (NCSC). The term 'independent healthcare' refers to any private, voluntary, not for profit or independent healthcare establishment under the regulatory remit of the Commission. This is defined as any establishment (or service, agency, practice or business) required to register with the Commission under the Care Standards Act 2000, as amended by the Health and Social Care Act 2003, and to comply also with Private and Voluntary Health Care (England) Regulations 2001. Associated responsibilities are: to maintain a register of independent (private and voluntary) healthcare providers; to inspect registered services annually to ensure that they are meeting national minimum standards; to assess the performance of healthcare organizations generally; to award annual performance ratings for the NHS; to coordinate reviews of healthcare by other bodies; to encourage improvement in the quality, effectiveness, economy, and efficiency of healthcare provision; to track how well public resources are being used; to carry out investigations into serious service failures; to report serious concerns about quality to the Secretary of State; to publish annual performance ratings for all NHS organisations and produce annual reports to parliament on the state of healthcare; to collaborate with other relevant organisations including the Commission for Social Care Inspection (CSCI)(created under the same Act); and to carry out an independent review function for NHS complaints. The Commission takes over the role previously performed by the Commission for Health Improvement together with the NHS 'value for money' work previously carried out by the Audit Commission, in addition to regulation of independent sector bodies previously performed by the NCSC.

³² HCHC, para. 68.

³³ Department of Health, *Standards for Better Health* (July 2004), Core Standard C17

³⁴ HCHC, para. 71.

³⁵ The duty to consult on changes in health services was not new. A duty on SHAs to consult on proposals for any substantial development or variation to health services was introduced in 1996 – Community Health Council Regulations 1996.

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proposal and require the local NHS body to take such action, or desist from taking action, as he may direct.³⁶ The Secretary of State, who has extensive powers of intervention under the NHS Act 1977, may also refer the case to the Independent Reconfiguration Panel for advice.

(f) *Independent Reconfiguration Panel (IRP)*

The IRP was established as an advisory non-departmental public body in 2003 to provide independent expert advice to the Secretary of State for Health on contested proposals for health service change in England, in cases where local agreement on service changes cannot be achieved.³⁷ The Panel also offers ongoing support and advice to the NHS and other interested bodies on successful service changes, with the aim of sharing good practice and avoiding formal referrals at a later date. The Chair, Chief Executive and Panel members represent a wide range of expertise in clinical healthcare, NHS management, and public and patient involvement. This breadth of expertise is claimed to enable independence, transparency and credibility in the conduct of the Panel's work.³⁸

In providing expert advice, the Panel is required by its terms of reference to take account of: (i) patient safety, clinical and service quality; (ii) accessibility, service capacity and waiting times; (iii) other national policies, for example, national service frameworks; (iv) the rigour of consultation processes; (v) the wider configuration of the NHS and other services locally, including likely future plans; and (vi) any other issues Ministers direct in relation to service reconfigurations generally or specific reconfigurations in particular.³⁹ The terms of reference further provide that: 'The advice will normally be developed by groups of experts not personally involved in the proposed reconfiguration or service change, the membership of which will be agreed formally with the Panel beforehand.'⁴⁰ Furthermore: 'The advice will be delivered within timescales agreed with the Panel by Ministers with a view to minimising delay and preventing disruption to services at local level.'⁴¹

Once the referral of a contested proposal has been accepted, the Panel consults with interested parties and may make site visits, hold meetings, conduct interviews, and request written evidence. While the focus throughout is on the quality of patient care, a principal concern is with the rigour of local involvement and consultation processes. On completion of the review, a final report containing recommendations is published and submitted to the Secretary of State, who makes the final decision on any disputed proposal.⁴²

(g) *Patient and Public Involvement Forums (PPIFs)*

Created under the National Health Service and Health Care Professions Act 2002, PPIFs (approximately 550 in number – one for every NHS Trust, PCT, and later

³⁶ Local Authority (Overview and Scrutiny Committees Health Scrutiny Functions) Regulations 2002 (SI 2002, No 3048).

³⁷ <http://www.irpanel.org.uk/view.asp?id=0> Before a case can be referred to the Panel, 'all other options for local resolution need to have been fully explored'.

³⁸ The Patients' Forums (Functions) Regulations 2003 (SI 2003/2124)

³⁹ Terms of Reference, para. A2.

⁴⁰ Terms of Reference, para. A3.

⁴¹ Terms of Reference, para. A4.

⁴² The Panel therefore has no powers of enforcement, its recommendations being advisory only.

Foundation Trust) became operational at the same time as CHCs ceased to exist on 1st December 2003. The Forums are supported by approximately 140 Forum Support Organisations – not-for-profit bodies working under contract to the Commission for Patient and Public Involvement in Health (below). Each Forum consists of around eight volunteer members appointed by the Commission.

The statutory duties of Forums are: (i) to monitor and review the operation of services; (ii) to obtain the views of patients and their carers, and report on those views to the trust; (iii) to provide advice, and make reports and recommendations; and (iv) to make available to patients and their carers advice and information about those services. Reflecting their importance in the overall governance regime, PCT Forums were originally allocated additional functions. Under secondary legislation PPIFs have further powers to refer matters to the relevant OSC, to enter and inspect premises, and to require NHS bodies to supply information as requested.⁴³ In the case of independent providers, Forums have a similar power through terms in the contract with the PCT, made in accordance with Directions issued by the Secretary of State. The work of PPIFs includes conducting patient surveys, carrying out investigations, compiling service review reports, maintaining a presence on PCT and hospital trust boards/committees, and visiting and inspecting hospital premises. Investigations typically focus on issues such as infection control, GP services, transport and parking, mental health, and community involvement.

(h) *Commission for Patient and Public Involvement in Health (CPPIH)*

The 2002 Act also established on a statutory basis the CPPIH as a non-departmental public body to oversee the new system of PPI. Most of the £28m annual budget is spent on contracts with independent organisations to support Patient Forums, with approximately one third on administration. The Commission sets up, manages and appoints members of Forums; establishes quality standards and carries out national reviews of services from patients' perspective; and submits reports to the Secretary of State and to bodies such as the Healthcare Commission.

4. Evaluation of existing PPI arrangements in England

There is an abundance of evidence from a variety of sources pointing to the deficiencies in the existing system of PPI in England, and its failure to achieve policy objectives. In this section we focus on the current PPI debate as reflected in the Government's own policy documents and parliamentary papers, and in the wider academic literature.

(a) *Practical issues*

Some aspects of the PPI system introduced after 2000 have been overtaken by organizational changes in the NHS. By October 2005, the Government had plans in place to reconfigure PCTs into a reduced number of bodies covering larger geographical areas. This rendered impracticable the original model of PPIFs with special powers and responsibilities based in old-style PCTs, leading to the announcement by Ministers of a strategic review of the entire PPI framework. The Government justified its ensuing decision to abolish Forums, which had only been in existence since 2003, by reference to unanticipated and fundamental changes in the

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nature of delivery of health and social services.⁴⁴ These changes included the move towards greater choice of service providers and service delivery, the increased emphasis on the role of PCTs as service commissioners, and the growing importance of the commissioning process as a means of managing, controlling, and developing services. Similarly unanticipated, according to the Government, was the shift in social care towards greater individual choice and control through personalisation of services, self-directed support, and direct payments. The extent of integration of health and social care, the delivery of more services within the community, and the emergence of NHS Foundation Trusts were also unforeseen.⁴⁵

The CPPIH's contribution to the review of PPI in 2006 pointed to major failings in the operation of Forums,⁴⁶ recommending their replacement by a system of 'local networks'. Deficiencies included: (i) excessive preoccupation with monitoring and review of services, stifling innovation and creativity; (ii) the attempted performance of too many functions (improving services, engaging the community, holding the NHS to account, etc); (iii) unrealistic expectations as to what could be achieved in many cases, especially given the over-reliance on volunteers; (iv) lack of diversity in the pool of participants, with current arrangements failing to be representative of local populations and tending to exclude employed people or those with other commitments such as caring responsibilities; (v) failure to encompass the patient's journey through a variety of health and social care services, due to the attachment of Forums to particular NHS institutions; (vi) confusion in the relationship between internal PPI activity of Trusts, the role of Forums, and the role of OSCs; (vii) confusion also between the functions of service improvement and long-term service planning; and finally (viii) the undermining of the accountability role of Forums, resulting in loss of public confidence in their ability to engender service improvements.⁴⁷

Other problems with current PPI arrangements are more far-reaching and not associated with organizational changes just described.⁴⁸ While in theory there exists an effective

⁴⁴ Department of Health, *Government Response to 'A Stronger Local Voice'* (December 2006).

⁴⁵ *Response*, para. 2.2. This justification for the abolition of PPIFs was doubted by many witnesses in evidence given to the House of Commons Select Committee scrutinizing proposed further legislative reform. The suggestion instead was that this was connected with the Government's reform agenda for the CPPIH: 'Some witnesses did not believe that the Department had given the real reasons for the changes' (HCHC, para 83), several arguing that Forums could be improved without being abolished and that their role could be extended (HCHC, para 91-92). The Government had already announced plans to abolish CPPIH in its review of NHS arm's length bodies carried out in 2004, (Department of Health, *Reconfiguring the Department of Health's Arm's Length Bodies*, 22nd July 2004)) as part of a strategy for saving at least £500m and channeling resources to frontline NHS patient care. Despite the impending demise of CPPIH, the widely held view at that time was that Forums would remain a cornerstone of PPI, with the appointment of members being taken over by NHS Appointments Commission.

⁴⁶ Overview Paper: Input into PPI Review Panel, *Keeping Accountability Alive* – (CPPIH 2003-2006).

⁴⁷ CPPIH, para 50.

⁴⁸ 'There is much confusion. There is lack of clarity about scope and purpose. Should patient and public involvement be about more accountability, better services or health promotion?' (HCHC, para 3); 'Just as the landscape of organisations through which patients and the public can express their views is complex and confusing, equally the overall aim of patient and public involvement often seems elusive ... used to serve several different purposes simultaneously' (HCHC, para 20). For an overview of main criticisms of the current system, including under-resourcing, lack of capacity, and complexity and fragmentation, see R. Baggott, 'A Funny Thing Happened on the Way to the Forum? Reforming Patient and Public Involvement in the NHS in England' (2005) 83 *Public Administration* 533-551.

and comprehensive system of public consultation, the practical experience has often been disappointing. For example, ‘section 11’ consultations are widely perceived as insincere,⁴⁹ with many NHS bodies suspected of seeking to avoid their statutory duties or interpreting narrowly the range of situations in which they are required to consult, often with the collusion of the Department of Health. This has been the case with decisions on the role of Independent Sector Treatment Centres (ISTCs), which the Government has been particularly keen to promote as part of its agenda for increasing patient choice. The lack of public consultation on ISTCs followed clear Ministerial direction that this was not necessary either before the making of the contract or in its award.⁵⁰ Similarly, according to the Government, there was no need to consult on the reconfiguration of PCTs since this was a managerial and administrative matter having no direct connection with service delivery.⁵¹ In those instances where PCTs have consulted with OSCs, and OSCs have then referred the issue to the Secretary of State, there is evidence of significant under-use of the Independent Reconfiguration Panel. Among the estimated hundreds of organizational changes within the remit of the statutory scheme at the time of the Health Committee hearing, approximately twenty-three were referred to the Secretary of State, who referred only four cases to the Panel.⁵²

Witnesses to the Health Committee stressed the limited powers of OSCs following investigations, and their perceived ineffectiveness especially at the time of elections when no scrutiny was carried out at all, creating incentives for the NHS to push through unpopular changes at this time.⁵³ Others pointed to the lack of independence of OSCs, perceived by many as being too close to NHS Trusts; there is no public or lay representation, local councillors fill all the seats, and the seats may be occupied by the majority party rather than being representative of the council as a whole. In addition, the Committee was told that ‘OSCs can only be reactive rather than proactive.’⁵⁴

There are significant weaknesses elsewhere in the PPI system. While the official national evaluation of the first year of operation of PALS concluded from case study research that ‘the results have been very positive ... PALS enable and empower patients and others to use services effectively and appropriately, and usefully address the issues they have,’⁵⁵ evidence given to the House of Commons Health Committee was highly critical of their lack of independence. Concerns were also expressed over the marginalisation of PALS, with some services threatened with closure due to financial constraints.⁵⁶ As to ICAS, witnesses criticized poor standards in arrangements for handling complaints, lack of consistency throughout the country, and weak public profile and lack of capacity in the service.⁵⁷ In particular, there were difficulties accessing the complaints system ‘due to perceived reluctance by trusts to advertise the

⁴⁹ HCHC, para 239. There is evidence in some cases of outright dishonesty, with decisions having already been taken and peoples’ views consequently ignored – para 241

⁵⁰ Department of Health lawyers have a vested interest in avoiding consultation – HCHC para 251

⁵¹ HCHC, para 253.

⁵² HCHC, para 268.

⁵³ HCHC, para 52.

⁵⁴ HCHC, para. 54

⁵⁵ Department of Health, ‘Developing the Patient Advice and Liaison Service: Key Messages for NHS Organisations from the National Evaluation of PALS’,

<http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/>

⁵⁶ HCHC, para. 56

⁵⁷ HCHC, para 57.

procedure and support services available'. Access problems were exacerbated by lengthy delays, with both trusts and the Healthcare Commission failing to deal with complaints within their targets. Generally there was 'a culture that is defensive rather than responsive, failing to provide complainants with explanations of what went wrong, or apologies when mistakes were made.'⁵⁸

Finally, the Health Committee received mixed evidence on FTs' patient and public involvement arrangements. The British Medical Association criticised the new governance arrangements as 'a failing area in terms of PPI ... there is a lack of evidence to show that they may be working.'⁵⁹ The Independent Regulator of Foundation Trusts (Monitor) pointed to the lack of coordination with other aspects of PPI policy, warning of the danger of duplication of effort: 'Where patient and public involvement initiatives overlap there is a potential for confusion as to the different responsibilities of each organisation.'⁶⁰

(b) *The academic debate*

While the introduction of an element of democratization into healthcare governance has generally been welcomed in the academic literature, policy analysts have remained sceptical of the 'new architecture' of PPI.⁶¹ The reforms have coincided with a period of financial stringency in the public sector generally, suggesting that they may be part of a strategy for legitimating unpalatable changes such as rationing or user charges.⁶² Tokenistic patient and public involvement has arguably served as a means of co-opting citizens into a political agenda of downsizing,⁶³ at the same time as legitimating quasi-markets as the predominant form of organization of health and social care.⁶⁴ In this vein, Rowe and Shepherd view public participation as a management technique whereby the 'public interest' on healthcare issues remains defined by clinical and managerial professionals through their continued ability to mediate the views expressed by citizens as to their needs.⁶⁵ The failure of early PPI initiatives is attributed to their incorporation within the paradigm of the New Public Management, which is not

⁵⁸ HCHC, para 58

⁵⁹ HCHC, para 64

⁶⁰ HCHC, para 67

⁶¹ T. Milewa, 'Local Participatory Democracy in Britain's Health Service: Innovation or Fragmentation of a Universal Citizenship' (2004) 38 *Social Policy and Administration* 240-252.

⁶² D. Rutter, C. Manley, T. Weaver, M. Crawford, and N. Fulop, 'Patients or Partners? Case Studies of User Involvement in the Planning and Delivery of Adult Mental Health Services in London' (2004) 58 *Social Science and Medicine* 1973-1984, p 1974.

⁶³ J. Church, D. Saunders, M. Wanke, R. Pong, C. Spooner, and M. Dorgan, 'Citizen Participation in Health Decision-making: A Conceptual Framework' (2002) 23 *Journal of Public Health Policy* 12-32. 'Given the growing potential gap between what political elites and the public are thinking, governments may be afraid that too much citizen participation will derail the political agenda.' (p 14).

⁶⁴ S. Harrison and M. Mort, 'Which Champions, Which People? Public and User Involvement in Health Care as a Technology of Legitimation' (1998) 32 *Social and Policy Administration* 60-70, pp 67-8. The authors argue that quasi-markets cannot be legitimized in the same way as markets (by reference to outcomes not intended by any individual actor but made according to the hidden hand) or hierarchies (by reference to traditional sources of authority).

⁶⁵ Rowe and Shepherd, p 279. '...Patient and public involvement could be seen as a means of manipulating patients and the public rather than empowering them. Those concerned with funding of the NHS have acknowledged that partnership with patients and carers may promote a more efficient and cost-effective system, financially sustainable in the long term' – R. Baggott, 'A Funny Thing Happened on the Way to the Forum? Reforming Patient and Public Involvement in the NHS in England' (2005) 83 *Public Administration* 533-551, p 546.

concerned with democratic renewal or increasing responsiveness to consumer or citizen needs, but rather values public participation as an aid to organizational learning.⁶⁶ Generally, consultation has too often been used by those with decision making power to mask hidden agendas, or as a means of claiming public support for predetermined policies.⁶⁷ Increased participation, where it may be observed as occurring, may reinforce dominant managerial and medical discourses through the ‘proto-professionalization’ of patients and public who may more readily submit to existing inequalities in power relations.⁶⁸ Again, citizens may be unwilling or unable to engage in the type of role that government assigns to them.⁶⁹ Health providers and service users may have different aims in collaborating on PPI schemes, the former focusing on the process of involvement and the need to widen participation, while the latter are more concerned with the agenda for reform and with influencing change in policy and practice.⁷⁰ Were citizen control to be achieved through PPI, and the policy regarded as ‘successful’, this might ‘lead to service provision that meets the needs of some people more than others.’⁷¹

The majority of such criticisms of the existing PPI system are based on an analysis of healthcare governance in terms of power relations.⁷² The underlying problem with the reforms, it is argued, has been the failure to alter existing patterns of power and influence,⁷³ particularly at the local level.⁷⁴ The dominant ‘discourse of power’ in the academic policy literature owes much to Arnstein’s seminal study of user involvement:

⁶⁶ This pejorative use of the term ‘organizational learning’ is not contextualized with reference to any particular theoretical literature. In any event, the concept of social learning is radically different to that of organizational learning – see for example: C. Agyris and D. Schon, *Organizational Learning: A Theory of Action Perspective* (Reading: Addison Wesley, 1978); D. Miller, T. Lant, and F. Milliken, ‘The Evolution of Strategic Simplicity: Exploring Two Models of Organizational Adaptation’ (1996) 22 *Journal of Management* 863-887; H. Berends, F. Boersma, and M. Weggeman, ‘The Structuration of Organizational Learning’ (2001) Working Paper 01.12, Eindhoven Centre for Innovation Studies, submitted to *Organization Studies* for special issue on ‘Knowledge and Professional Organizations’; M. Easterby-Smith, ‘Disciplines of Organizational Learning: Contributions and Critiques’ (1997) 50 *Human Relations* 1085-1114. The conception of organizational learning in this literature tends to focus on a particular entity or body, whereas social learning in the REFGOV sense may be construed as a set of processes occurring within networks and involving a wider range of organizations and interests.

⁶⁷ J. Abelson, P.-G. Forest, J. Eyles, A. Casebeer, and G. Mackaen, ‘Will It Make a Difference if I Show Up and Share? A Citizen’s Perspective on Improving Public Involvement Processes for Health System Decision-making’ (2004) 9 *Journal of Health Services Research and Policy* 205-212, p 209.

⁶⁸ M. Dent, ‘Patient Choice and Medicine in Health Care: Responsibilization, Governance and Proto-Professionalization’ (2006) 8 *Public Management Review* 449-462. Consultation may be manipulative in obscuring the exercise of power – see G. Callaghan and G. Wistow, ‘Publics, Patients, Citizens, Consumers? Power and Decisionmaking in Primary Health Care’ (2006) 84 *Public Administration* 583-601, p 596

⁶⁹ Church et al, 24. Thompson concludes that ‘many patients support greater involvement in service delivery, but they want professionals to recognize that this needs to be optional and varies according to the context and probably over time too’ – A. Thompson, ‘The Meaning of Patient Involvement and Participation in Health Care: A Taxonomy’ (2007) 64 *Social Science and Medicine* 1297-1310, p 16 of Science Direct version.

⁷⁰ Rutter et al.

⁷¹ Tritter et al, p 163.

⁷² For case studies of public participation in different sectors underpinned in various ways by the power perspective, see M. Barnes, J. Newman, and H. Sullivan, *Power, Participation and Political Renewal: Case Studies in Public Participation* (Bristol: Policy Press, 2007).

⁷³ For example, Rowe and Shepherd contend that attempts to establish relationships between the public and the NHS on a partnership basis have been unsuccessful due because ‘the distribution of power

Citizen participation is a categorical term for citizen power. It is the redistribution of power that enables the have-not citizens, presently excluded from the political and economic process, to be included in the future.⁷⁵

In the ‘ladder’ ranking different degrees of citizen participation and non-participation, citizen control is presented as the pinnacle of involvement.⁷⁶ For models derived from Arnstein, user involvement is conceived as ‘a contest between two parties wrestling for control over a finite amount of power. Involvement is conceptualised in competitive terms: ‘a zero-sum game.’⁷⁷ Closely linked with citizen control is the role of citizens in decision making processes,⁷⁸ whether as taxpayers concerned with what services should be funded by the state, as residents concerned with how services are provided to the local community, or as patients concerned with the criteria for the allocation of services based on clinical or socio-demographic considerations.⁷⁹ The success of PPI in these terms depends on the extent of citizen participation in decision making at these different levels.

Rejecting this model on the ground that it is unduly adversarial and tends to underestimate the importance of collaboration,⁸⁰ Tritter and McCallum focus instead on deliberative processes and the difficulties inherent in attaining consensus: ‘A truly empowering system would demonstrate safeguards ... to provide space for people with dissenting views, or those for whom services need to be tailored differently.’⁸¹ The plea here is for a more nuanced model of user involvement, entailing ‘constructive dialogue aimed at reshaping the relationship between patients, healthcare professionals and the public and as a catalyst to more widespread cultural change.’⁸² The role of users in framing problems as well as contributing to the design of solutions is argued to be a missing element in Arnstein’s model.⁸³ In place of a linear, hierarchical ladder representing degrees of power, the authors propose a ‘scaffold’ model in which multiple interests and types of expertise are represented in varying relationships:

is still heavily weighted towards professionals working in the NHS’ – R. Rowe and M. Shepherd, ‘Public Participation in the New NHS: No Closer to Citizen Control?’ (2002) 36 *Social Policy and Administration* 275-290, p 288.

⁷⁴ T. Milewa, ‘Local Participatory Democracy in Britain’s Health Service: Innovation or Fragmentation of a Universal Citizenship’ (2004) 38 *Social Policy and Administration* 240-252, p 245. ‘The perception of a centralist bureaucracy has remained’ – Tritter et al, 158.

⁷⁵ S. Arnstein, ‘A Ladder of Citizen Participation’ (1969) 35 *Journal of the American Planning Association* 216-224, p 216 (quoted in Tritter and McCallum, 157).

⁷⁶ At the lowest rungs Arnstein locates two forms of non-participation (manipulation and therapy), followed by three degrees of tokenism (informing, consultation, and placation), and finally three degrees of citizen power (partnership, delegated power, and citizen control). In the gloss provided by Tritter and McCallum: ‘The sole measure of participation is power to make decisions and seizing this control is the true aim of citizen engagement’ – Tritter et al, p 157

⁷⁷ Tritter et al, p 165

⁷⁸ These processes tend also to be conceived in ‘zero-sum’ terms. For Thompson, the distinction between the lower and higher ‘levels’ of patient involvement and participation respectively concerns ‘the degree to which patients take part in the decision-making process, connoting a degree of transfer of power from the professional to the patient in the form of increased knowledge, control, and responsibility’ - A. Thompson, ‘The Meaning of Patient Involvement and Participation in Health Care: A Taxonomy’ (2007) 64 *Social Science and Medicine* 1297-1310, p 16 of Science Direct version.

⁷⁹ Church et al, p 24

⁸⁰ Tritter et al, p 164

⁸¹ Tritter et al, p 163

⁸² Tritter et al, p 158

⁸³ Tritter et al, p 162

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One aim of user involvement may be to break down boundaries, share experience, and build understanding. This suggests not a hierarchy of knowledge – relevant professionals versus irrelevant lay – but rather a complementarity between forms of knowing, set within a willingness to acknowledge differences.⁸⁴

Similarly, Dent stresses the potential contribution of patients to processes of dialogue and deliberation, in contrast to voting systems that are suitable only as the ‘ultimate arbiter’ in cases of disagreement. In this conception, communicative competence is at the heart of the ideal of participation.⁸⁵ Such Habermasian analyses are consistent with the collaborative and relational approach to social learning, and may even be suggestive of elements of democratic experimentalism. However, they remain limited in failing explicitly to consider social learning as an alternative rationale for increasing patient and public involvement in healthcare governance.

(c) *Conclusion*

The deficiencies in the design and operation of the current PPI system are numerous and widely acknowledged. Proposals for reform (including pleas for increased clarity of purpose and improved accountability mechanisms⁸⁶) have done little to address the fundamental question of how PPI is supposed to lead to improved quality in the management and organisation of healthcare. This limitation remains even where power is conceived as a variable set of capacities for involvement that can be developed and maximised simultaneously by stakeholders through different forms of knowledge and social capital, rather than as a finite resource to be gained by one group at the expense of another.⁸⁷

In REFGOV terms, the disappointing results of PPI to date may be explained by the failure, both in official discourse and in the wider policy literature, to consider the potential contribution of patient and public involvement to improved healthcare governance from the perspective of social learning. In this light, the key question for the next wave of PPI is not whether it will result in a significant shift of power, but whether the new framework is capable of facilitating the development of institutions and processes for such involvement that are conducive to more effective social learning.

5. The 2007 reforms – a new regulatory landscape?

As has been seen, the Government’s plans for the reconfiguration of old-style PCTs into larger units, coupled with other organizational and policy changes including the creation of Foundation Trusts, led in 2005 to a fundamental review of the PPI system.⁸⁸ The Expert Panel set up to examine evidence from the review concluded:

⁸⁴ J. Titter and A. McCallum, ‘The Snakes and Ladders of User Involvement: Moving Beyond Arnstein’ (2006) 76 *Health Policy* 156-168, p 162.

⁸⁵ M. Dent, ‘Patient Choice and Medicine in Health Care: Responsibilization, Governance and Proto-Professionalization’ (2006) 8 *Public Management Review* 449-462, p 457, citing J. Newman, *Modernising Governance: New Labour, Policy and Society* (London: Sage, 2001).

⁸⁶ Abelson et al, p 210.

⁸⁷ G. Callaghan and G. Wistow, ‘Publics, Patients, Citizens, Consumers? Power and Decisionmaking in Primary Health Care’ (2006) 84 *Public Administration* 583-601, p 586.

⁸⁸ The White Paper on the future of primary care and community services, published in January 2006, set out broad policy towards PPI but without going into details – Department of Health, *Our Health Our Care, Our Say: A New Direction for Community Services*, chapter 7

There is insufficient focus on involvement in relation to commissioning, generating a real risk that services do not meet the changing needs and preferences of the people who use them. Above all, it would be fair to say that patient and public involvement in health has suffered badly from a combination of stop-start policy, complicated legislation, duplication of functions and an over-prescriptive, centralised model (CPPIH and Patient Forums) of how to achieve it. The result is disjointed and resource-intensive, and cannot be justified either by clear outcomes or as value for money.⁸⁹

Just two months after this report, in July 2006 Ministers issued the White Paper, *A Stronger Local Voice*.⁹⁰ This was followed in December by the publication of the Government's own response to the key questions that had been set out in the White Paper,⁹¹ and subsequently by the Local Government and Public Involvement in Health Act 2007. Both the Expert Panel and the White Paper maintained that PPI should reflect four principles. Systems of PPI should be independent of, but engaged in debate with, commissioners and providers, and they should provide transparency and accountability on the part of service commissioners and providers.⁹²

This section analyzes the proposed new regulatory landscape (Annex A) and its rationale. The different areas of reformed PPI policy in England show variation in significant respects: in the range and scope of issues intended to be subject to public and patient involvement; in the forms or structures of involvement and engagement; in the role of government, commissioners and providers in PPI; in the role of participants as service users and members of the public; in the power of participants to influence decisions or exercise choice; and in the support provided for development of capacity for effective involvement in patients and public. The significance of these aspects of PPI stems in part from the way in which they have bearing on whether, or how, policy reflects the principles of independence, engagement, transparency and accountability. Moreover, the treatment of these different aspects of PPI in policy will have implications for the approach to social learning. However although legislation and guidance indicate the possibilities and direction that PPI will take, at present there is significant uncertainty over the form of implementation, and so many questions remain open.

(a) *Local Involvement Networks (LINKs)*

In its report of May 2006, the Expert Panel was highly critical both of the £28m expenditure on CPPIH in support of Patient Forums for every NHS Trust, FT, and PCT in England, and of the scope and workings of the Forums themselves.⁹³ The Panel

⁸⁹ Department of Health, *Concluding the Review of Patient and Public Involvement: Recommendations to Ministers from the Expert Panel* (12th May 2006), para. 3.4.

⁹⁰ Department of Health, *A Stronger Local Voice: A Framework for Creating a Stronger Local Voice in the Development of Health and Social Care Services* (July 2006).

⁹¹ Department of Health, *Government Response to 'A Stronger Local Voice'*, December 2006.

⁹² ASLOV, 11-12, Expert Panel, Sections 4 and 5.

⁹³ Members of Forums were themselves dissatisfied, their work often not taken seriously by local NHS organisations. Inspections were cosmetic activities achieving little real change (para 11.2). Membership was drawn from too narrow a section of the population (para 7.4) Since Forums had failed to keep pace with developments such as increased plurality of providers, payment by results and practice based commissioning, they should not continue in their present form. [It should be noted that the abolition of the CPPIH had been announced in the Department of Health Report *Reconfiguring the Department of Health's Arm's Length Bodies* \(2004\) p 18. However this report did not anticipate the abolition of the Patients' Forums.](#)

recommended their replacement by LINKs, a new type of representative body with functions spanning health and social care, supported by a Local Involvement Fund to encourage the development of a stronger public and user voice. The subsequent White Paper adopted this recommendation as one of five key elements of the ‘New Framework for Public and User Involvement’, and the Local Government and Public Involvement in Health Act 2007 makes provision for the creation of LINKs.

The 2007 Act states that LINKs will promote and support the involvement of people in ‘commissioning, service provision, and scrutiny of local health and social care services.’⁹⁴ This appears to allow potential support for public involvement in a broad range of issues, particularly in contrast to the revised section 11 consultation duty (discussed below) which is limited to consultation on issues affecting service users’ experiences and choice. Further LINKs should ‘ensure that equality and human rights principles are integral to [their] work.’⁹⁵ In principle, this could mean that LINKs express judgements on what equality and human rights would require of commissioning and service provision, judgements which may go beyond representation of the needs and preferences of service users.⁹⁶ In keeping with the principles intended to underlie PPI, the White Paper described one purpose of LINKs as ensuring that purchasers and providers of local health and social care services are more accountable to the public.⁹⁷ Another key role is the promotion of increased responsiveness to the needs and preferences of users, through information gathered from a wide range of sources.⁹⁸ The White Paper described the intention that “LINKs will have the flexibility to work with the changing landscape of the NHS and social care systems and to fit in with their local circumstances.”⁹⁹ In contrast to Patient Forums, LINKs will be ‘separated from institutions,’ a move which the Expert Panel recommended in light of ‘the introduction of increased plurality of providers, payment by results and focus on commissioning’.¹⁰⁰ Further, the White Paper set out the aim that:

LINKs should operate in an inclusive way with a membership that includes user groups, local voluntary and community sector organisations and interested individuals. It is important that these arrangements offer scope to groups such as children and young people, especially those who are not always included.¹⁰¹

This statement responds to concern by the Expert Panel that membership of Patient Forums ‘despite good intentions, is drawn from a relatively narrow section of

⁹⁴ Local Government and Public Involvement in Health Act 2007, Section 221

⁹⁵ Department of Health *Getting Ready for LINKs: Contracting a host organisation for your Local Involvement Network* (August 2007), p 18

⁹⁶ For instance, there may be tensions between needs of different group, or between the preferences of a majority, and significant needs of a smaller group. Concern for principles of equality may require that judgement is expressed as to the way in which competing preferences and needs should be met.

⁹⁷ ASLOV, 14

⁹⁸ ASLOV, 14. In their role of promoting increased responsiveness LINKs can: (i) gather information from range of people and sources, about needs and experiences of using services in areas, from PALS, complaints, surveys, websites, user groups, focus groups; analyse information and make recommendations to commissioners, providers, managers, OSCs, regulators; (ii) serve as a means whereby OSCs, commissioners, and regulators access the views of the local population; and (iii) encourage and support users in participating in commissioning.

⁹⁹ ASLOV, 14

¹⁰⁰ Expert Panel, para 7.3

¹⁰¹ ASLOV, 15

society.¹⁰² Moreover this might be understood as promoting the wider aim of PPI reform to ‘build the capacity of local populations as well as voluntary and community organisations to engage with health and social care.’¹⁰³ The emphasis on involvement of local voluntary organisations seems to reflect the government’s wider belief in the value of the third sector in engaging service users¹⁰⁴ and in their ability to campaign and act as advocates.¹⁰⁵

LINKs will obtain views from people about health and social care needs, convey those views to organisations responsible for commissioning, providing and managing local health and social care services, and make reports and recommendations to those bodies on how services may be improved. LINKs will have powers to enter health and social care premises and observe and assess the nature and quality of services¹⁰⁶ (however this is a power which contrasts with Patients’ Forums powers to inspect NHS premises, along with other premises providing primary NHS services¹⁰⁷). LINKs will engage in monitoring by actively seeking views directly through contributions from individuals and groups, and indirectly from representatives or advocates, complaints and PALS, surveys, comment cards, websites, and other methods.¹⁰⁸ LINKs will also have powers to refer matters relating to social care to Oversight and Scrutiny Committees. While the 2007 Act makes no reference to referral of health matters to OSCs,¹⁰⁹ the Department of Health has noted in its 2007 consultation paper that the Government intends to ‘amend the current secondary legislation in relation to the referral of health matters to OSCs to mirror the policy set out for social care OSCs in the Bill.’¹¹⁰ In replacing the power of Patients’ Forums, with power for LINKs to refer matters to OSCs, the PPI reforms are in keeping with the Expert Panel’s view that:

The role of overview and scrutiny is an important and increasingly effective mechanism to deliver public accountability. It has the benefit of a democratic mandate, coupled with existing powers which both NHS and social care organisations are now familiar.¹¹¹

¹⁰² Expert Panel, para 7.2

¹⁰³ ASLOV, 12

¹⁰⁴ An ability attributed to the third sector by Ed Miliband on BBC Radio 4 *Analysis* (5 July 2007). For discussion of the government’s view of third sector involvement in health and social care, see for instance, Marks, L and Hunter, D *Social Enterprises and the NHS; Changing patterns of ownership and accountability* Centre for Public Policy and Health, Durham University (July 2007).

¹⁰⁵ See for instance, Speech by Ed Miliband at the Fabian conference on democracy (8 September 2007) available at http://www.cabinetoffice.gov.uk/upload/assets/www.cabinetoffice.gov.uk/publications/speeches/milibande/pdf/democracy_speech.pdf (Accessed 10 April 2008)

¹⁰⁶ This will include the power to observe services from independent providers, although in this case the power will not be provided by the 2007 Act. The DH explains that ‘the Secretary of State will direct commissioners of services to amend new contracts so that the same duties will apply. These include contracts awarded by Primary Care Trusts (PCTs), NHS trusts and local authorities with social services responsibilities.’ Department of Health, *Local involvement networks: Briefing for independent providers* (April 2008) p3

¹⁰⁷ National Health Service Act 2006, Section 239

¹⁰⁸ GovResp para 1.43

¹⁰⁹ Patients’ Forums had the power to refer health matters to OSCs

¹¹⁰ Department of Health *Have Your Say: Consulting on the regulations for Local Involvement Networks (LINKs)* (September 2007)

¹¹¹ Expert Panel, para 5.3

Each LINK will report annually to the Sec State for Health. The report will be independent of the Local Authority, providing details as prescribed in the legislation and regulations.¹¹²

The 2007 Act and related secondary legislation, imposes duties on services-providers responsible for commissioning care services, to respond to reports or recommendations made by a LINK, regarding any of the services they commission. The response must ‘provide an explanation to the referrer of any action it intends to take in respect of the report or recommendation or an explanation of why it does not intend to take any action in respect of that report or recommendation.’¹¹³ It can be noted that this requirement echoes the new duty that the 2007 Act places on PCTs and SHAs to report ‘on the influence that the results of consultation have on its commissioning decisions’¹¹⁴ (this duty is discussed below). This duty could be understood as formalising a method of engagement between services-providers and the LINK, as well as providing a degree of accountability on the part of services-providers, therefore reflecting two of the principles intended to inform PPI. However the extent and sense in which engagement and accountability will be reflected in this duty will depend on the depth of reasoning provided in response to recommendations and reports.

According to the Government, a major advantage of the new LINKs compared with previous representative bodies will be their ability to work with commissioners across health and social care boundaries. While LINKs will build on the work of PPIFs, they will be established for a geographical region rather than based within a particular organisation.¹¹⁵ Furthermore LINKs will be free to decide locally on issues of membership and participants¹¹⁶, appointments, and work priorities, which are intended to ‘include a wide range of existing local groups representing patients and the public and to provide a channel for local health and social care organisations engage with those groups.’¹¹⁷ In these respects, LINKs offer the prospect of meeting two concerns of the Expert Panel: that a PPI body should be independent of, rather than ‘controlled or influenced by the health or social care organisation with which it is involved,’¹¹⁸ and that PPI should look ‘at the individual’s journey through a variety of health and social care services.’¹¹⁹ Further, the move to leave issues of membership open to local decision making, appears to offer the opportunity to meet the government’s aim that LINKs will include ‘user groups, local voluntary and community sector organisations and interested individuals’¹²⁰ During the transition period from PPIFs to the full implementation of LINKs, Forum members will be encouraged to become involved in their successors. A number of ‘early adopter’ projects developed by CPPIH are being

¹¹² 2007 Act, Section 227; see also GovResp para 1.44

¹¹³ Statutory Instrument 2008, Number 528 *The Local Involvement Networks Regulations 2008*, Section 5

¹¹⁴ 2007 Act, Section 24A

¹¹⁵ GovResp (2006), para 1.5

¹¹⁶ The difference between a member and a participant of a LINK is explained in Department of Health Guidance: *Getting Ready for LINKs: Planning your Local Involvement Network* (August 2007), paras 1.7-1.8

¹¹⁷ GovResp (2006), para 1.6.

¹¹⁸ Expert Panel, para 4.1. The Panel expressed concern that there were cases in which Community Health Councils and Patient Forums had suffered either from being too close to, or too independent of, the institution to which they were attached.

¹¹⁹ Expert Panel, para 7.3

¹²⁰ ASLOV, 15

used to pilot the approach of LINKs. Work with the Healthcare Commission will ‘collect learning from two test site projects that it has been running for over a year, which focus on a model that may be applied to LINKs.’¹²¹

The 2007 Act requires each Local Authority with social service responsibilities to make contractual arrangements with someone other than the authority (the ‘Host’) for the establishment of a LINK in its area, roughly corresponding with the new geographical map of PCTs. The contracts tendered and awarded by Local Authorities must conform to a specification developed by the Department of Health, taking into account the views of respondents to the White Paper consultation.¹²³ The support to be provided by the Host organization includes the recruitment of members, the coordination of priorities and activities, data management and record keeping, compliance with equality legislation, and assisting in the development of effective working relationship with partners.¹²⁴ Not-for-profit bodies that currently support Forums are expected to bid for contracts to support LINKs. Local Authorities will be strongly encouraged to involve local people and organisations in the process of awarding the first contract, after which LINK members are expected to be involved in the awarding of subsequent contracts.¹²⁵ Nevertheless there may be a question of whether there is tension between the Local Authority’s roles both in commissioning and providing social care, and in awarding the contract for the Host, and the aim of independence for LINKs. Further potential concerns for the independence of the LINK stem from the possibility that the body contracted to host the LINK may itself be a provider of health or social care services, and from the possibility that a not-for-profit body may have its own agenda.¹²⁶ In response to concern that a host may also be a provider, the DH have stated that any prospective host ‘will need to state what interests it has and show that it has a protocol or plan in place to address potential conflicts of interest.’¹²⁷ The Government Response to the White Paper provides some (rather limited and indirect) reassurance for concerns about any host organisation agenda, through its response to suggestions that LINKs could become dominated by single issue campaigns. The Government notes that:

The host organisation will guide the LINK to seek to access the views of the whole community, making use of the different powers that LINKs will have, and if they are unsuccessful in this they will be failing in one of their contractual obligations, and will be liable to sanctions or removal of contract.¹²⁸

While the proposed relationship between Local Authorities and Hosts appears reasonably clear,¹²⁹ there is considerable uncertainty as to both the form that LINKs will

¹²¹ GovResp, para 2.8

¹²³ The Department of Health has published guidance. *Getting Ready for LINKs: Contracting a host organisation for your Local Involvement Network (August 2007)*

¹²⁴ GovResp, para 1.20

¹²⁵ GovResp, para 1.22

¹²⁶ Julian Le Grand makes the general point that not-for-profit organisations may have an agenda which ‘isn’t necessarily concerned with the same agenda as the government or indeed the users’ of health or social care services. BBC Radio 4 *Analysis* (5 July 2007).

¹²⁷ DH *Getting Ready for LINKs: Contracting a host organisation for your Local Involvement Network* (August 2007), p 13

¹²⁸ GovResp, para 1.36

¹²⁹ Local authorities will be at one remove from LINKs, their control being indirectly exercised through the contract – a perfect example of the New Public Contracting. The role of the Local Authority will be to manage the contract with the host, and ensure that its contractual obligations are met (GovResp, para 1.27).

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take and how they will operate in relation to other representative bodies. The Department of Health maintained that the lack of detail in the Bill was deliberate in order to promote flexibility.¹³⁰ The House of Commons Health Committee described how LINKs might take either one, or a combination of two basic models.¹³¹ A first model builds on best practice of current Forums, having a core group of members running the LINK, sitting on Trusts' boards, undertaking surveys or visits, producing reports, challenging Trusts on various aspects of their work, and developing expertise on NHS issues.¹³² The second model is very different from current PPIFs, having no real core so the concept of membership does not apply. Rather than attempting to operate on behalf of patients and seeking to represent the community, in this interpretation LINKs will be 'a sort of junction box or a sort of facilitative mechanism.'¹³³ In both models the emphasis is on the organization as a network with no limits on the number or diversity of members;¹³⁴ for example, it is envisaged that local service providers may also become a member of the LINK.¹³⁵ The HCHC felt that the Government intended LINKs to use a combination of the two models,¹³⁶ and the DoH guidance, *Planning Your Local Involvement Network*, appears to allow for this combination, while emphasising that the structure of the LINK should be dependant on local decisions and conditions.¹³⁷ The Government maintain that '[t]he changes that we are implementing by establishing LINKs will increase the ways by which people can voice their views and share their experiences, and as a result improve and change the services they receive.'¹³⁸

However, this case for flexibility does not directly address questions and concerns over lack of detail about the structure and workings of LINKs. In particular the HCHC noted:

The lack of clarity about LINKs role and structure is likely to create confusion and inactivity. This may mean that LINKs will have difficulty deciding what they are going to do and how to do it and as a result lose the interest of volunteers. This would be particularly unfortunate at a time when significant change is occurring in the NHS and social care services.¹³⁹

The flexibility in legislation about the form of LINKs, also creates uncertainty over the approach that any LINK will take in its work, and in arriving at recommendations or reports, and further uncertainty about how a LINK will decide what approach to take. At present there are open questions on the processes of debate or deliberation that a LINK may use: for instance, whether there will be debate among a relatively small forum which could allow for greater depth of debate, whether there will be moves to involve far wider groups of people. Moreover, will a LINK aim to present a single agreed

¹³⁰ Discussed in ASLOV, 14

¹³¹ House of Commons Health Committee, *Patient and Public Involvement in the NHS, Third Report of Session 2006-7*, Vol. 1, paras 115-126

¹³² HCHC, para 115

¹³³ HCHC, para 116. A number of potential problems exist with this 'conduit' model, including lack of focus; limited ability to hold NHS bodies to account, duplication of effort with existing networks, and ineffectiveness in increasing representation of hitherto marginalized groups (para. 150).

¹³⁴ GovResp, para 1.35

¹³⁵ GovResp, para. 1.45

¹³⁶ HCHC, paras 122-126

¹³⁷ *Planning your Local Involvement Network*, Section 5

¹³⁸ GovResp, para 1.16

¹³⁹ HCHC, para 152

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judgement to health and social care bodies, or will it allow different members of the LINK to present their own, possibly conflicting, recommendations?¹⁴⁰ Further questions surround way in which a LINK engages with health and social care bodies: if deliberation and debate occurs within a LINK and the finding or judgement is then presented to health and/or social care bodies, then the result may be different to a judgement which results from debate involving the LINK and health or social care bodies. However any decision to involve health and social care bodies in the debate raises questions about the independence of the LINK.

To some extent, the 2007 Act does provide greater detail on the working and requirements of LINKs, than existed in the Bill. In contrast to the Bill, the 2007 Act,¹⁴¹ and secondary legislation,¹⁴² imposes requirements on LINKs to develop and publish procedures for making decisions. Moreover, it may be held that LINKs and Hosts could develop direction by considering the ways in which they are to be held accountable, and how they are performance managed. However, with respect to accountability and performance management, there is further uncertainty. The DoH guidance, *Planning Your Local Involvement Network*, explains:

In the context of LINKs, we think of accountability as the process for explaining or justifying actions and decisions, and demonstrating the progress of work that the LINK has undertaken in relation to its roles. No national system of accountability has been put in place, as this should be determined locally.¹⁴³

The Local Authority will agree with the Host, indicators for monitoring the performance of the Host,¹⁴⁴ and the ‘host and the LINK will need to clarify expectations about accountability early on in their relationship.’¹⁴⁵ In addition to producing an annual report to the Secretary of State, the LINKs need to ‘measure and demonstrate how they have performed to the local communities, to the host, to the local authority and, through this local approach, to the Government.’¹⁴⁶ While there is not a national system of accountability, Government has stated that it will ‘be developing national quality benchmarks for LINKs, including tools for localised performance management, peer review and recognisable success criteria for key areas, including the performance of hosts.’¹⁴⁷

(b) *Service commissioning*

One of the Government’s main justifications for the abolition of Forums was that the centrality of commissioning and the increasing plurality of providers in the healthcare system in England had made the performance of representation and scrutiny functions within individual healthcare bodies no longer appropriate.¹⁴⁸ Rather than looking at

¹⁴⁰ It might be relevant to compare the possibilities for LINKs with National Voices, which intends to take both the approach of presenting a unified case, and of enabling members individually to put their own case to government (see discussion on National Voice below)

¹⁴¹ Section 223

¹⁴² Statutory Instrument 2008, Number 528, Sections 2,3,4

¹⁴³ *Planning Your Local Involvement Network*, Section 9.1

¹⁴⁴ *Contracting a host organisation for your Local Involvement Network*, Ch 2 Section 4.1

¹⁴⁵ *Planning Your Local Involvement Network*, Section 9.5

¹⁴⁶ *Planning Your Local Involvement Network*, Section 9.11

¹⁴⁷ *Planning Your Local Involvement Network*, Section 9.14

¹⁴⁸ DCLG, *Local Government and Public Involvement in Health Bill: Regulatory Impact Assessment*, December 2006, para. 7, p 49. Commissioners are the ‘power base of the NHS system’ – para. 2, p 49.

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services in isolation, the aim is for the ‘joined-up’ PPI system to follow the whole user experience across health and social care, requiring the involvement of all those people who use, or might use, any health or social care services in the area.¹⁴⁹

The 2007 Act places SHAs and PCTs under a statutory duty (below) actively to respond to local people, and to explain the activities they are undertaking as a result of what people have said throughout the year. SHAs and PCTs will have to demonstrate that views of patients and public are effectively represented in their prospectus, and show how commissioning decisions have been responsive to the community. The Update and Commissioning Framework published in July 2006 specifies a number of objectives of effective commissioning. This should be directed at improving health and well-being; reducing health inequalities and social exclusion; securing access to a comprehensive range of services; improving the quality, effectiveness and efficiency of services; increasing choice; and ensuring a better experience of care through increased responsiveness to peoples’ needs.¹⁵⁰ Commissioning organisations (such as Practice Based Commissioning Groups, PCTs, Specialised Commissioning Groups, commissioners within local authorities, and joint commissioning groups) will have to decide how to involve local people and service users. ‘This will enable the commissioners to understand the services people wish to receive, and to then negotiate contracts with local providers, both existing and new, to supply them in a responsive and convenient way’.¹⁵¹

As outlined in the discussion above, the Government intends that LINKs should play a major role in commissioning:

LINKs will have a strong relationship with all the decision makers in health and social care to ensure the commissioning of services is informed by the views and preferences of people at all levels. They will become involved in assessing community needs, deciding priorities and influencing decisions about what services should be commissioned ... They will recognize the importance of integrating equality and human rights principles into the strengthening of local voices.¹⁵²

The Government maintains that LINKs will be ideally placed to monitor contract performance and service provision in a rigorous and robust way by going out to groups and communities.¹⁵³ The aim is that they will form part of the incentive structure encouraging commissioners and providers ‘to talk to local people, to seek their views and insights, and to involve them in how to plan, prioritise and decide their activities’.¹⁵⁴

(c) *Revised ‘section 11’ consultation duty*

The House of Commons Health Committee had expressed concerns over the implementation of the ‘section 11’ consultation duty of the Health and Social Care Act 2001. The evidence given to the committee suggested that:

Too often it seems to the public that decisions have been made before the consultation takes place. Too often NHS bodies have sought to avoid consultation under Section 11

¹⁴⁹ DCLG para. 8, p 50

¹⁵⁰ DH, *Health Reform in England: Update and Commissioning Framework*, July 2006, para 1.14

¹⁵¹ Update and Commissioning framework, para 1.15

¹⁵² GovResp, para 2.6

¹⁵³ GovResp, para 2.7

¹⁵⁴ GovResp, para 2.9

about major issues. Unfortunately the Department of Health has supported those NHS organisations in trying to limit the scope of Section 11.¹⁵⁵

However the Committee felt that these concerns could be better resolved by guidance and a willingness to follow cases of good practice, than by amendments to legislation. The Expert Panel had recommended that the consultation duty be extended to include all providers of health and social care services (whether NHS or independent).¹⁵⁶ The 2007 Act amended the ‘section 11’ duty, clarifying and altering the range of issues on which the public must be involved; changing the wording of what ‘public involvement’ should consist in; and creating a new duty for PCTs and SHAs to respond to consultations. However the Act does not extend the revised section 11 duty to include independent providers.

It appears that the effect of the new legislation will be to narrow the range of issues on which involvement will be required, and further alter to the nature of the involvement. To see this, it is worth setting out the relevant clause of the 2007 Act:

(1B) Each relevant English body must make arrangements, as respects health services for which it is responsible, which secure that users of those services, whether directly or through representatives, are involved (whether by being consulted or provided with information, or in other ways) in—

- (a) the planning of the provision of those services,
- (b) the development and consideration of proposals for changes in the way those services are provided, and
- (c) decisions to be made by that body affecting the operation of those services.

(1C) Subsection (1B)(b) applies to a proposal only if implementation of the proposal would have an impact on—

- (a) the manner in which the services are delivered to users of those services, or
- (b) the range of health services available to those users.

(1D) Subsection (1B)(c) applies to a decision only if implementation of the decision (if made) would have an impact on—

- (a) the manner in which the services are delivered to users of those services, or
- (b) the range of health services available to those users.

(1E) The reference in each of subsections (1C)(a) and (1D)(a) to the delivery of services is to their delivery at the point when they are received by users¹⁵⁷

Subsections 1C, 1D, and 1E restrict the range of issues on which users must be involved to those which would affect the users’ experience of the service, or the choice of service available. It is interesting to compare this section of the Act with the corresponding sections of earlier versions of the Bill. The Bill had also sought to limit the areas in which consultation was required, stating that they must be ‘significant’, meaning those changes/decisions which have a ‘substantial’ impact on: (i) the manner in which services are delivered to users of those services at the point when they are received by users; and (ii) the range of health services available to those users.

Clarification of the issues on which involvement should take place, might be defended by the reason that there is a need to clarify “circumstances in which formal Section 11 consultations should not take place either because they would be a waste of money or

¹⁵⁵ HCHC, para 271

¹⁵⁶ Expert Panel, para 10.3-10.5

¹⁵⁷ Local Government and Public Involvement in Health Act 2007, Section 233

because they would compromise safety.”¹⁵⁸ However the changes to section 11 that are made in the 2007 Act cannot adequately be explained on this basis. One concern raised is that the Government’s real aim in altering the wording of section 11, ‘is to remove the case law relating to section 11’, thereby giving the Department a better chance in court. Further, the change from the wording in the original Bill to the wording in the Act, along with the debate that surrounded this change, indicate that the government’s intention is to limit involvement to issues which affect user experience and choice. In doing this it excludes the need for ‘section 11’ public involvement on other issues of how services are provided, or who provides these services (such as issues of whether services are taken on by independent providers). Indeed the government has been clear that this is its intention:

We want consultation activity to be meaningful and we certainly want to avoid consultation being undertaken when there is no significant change or decision with which local people can meaningfully engage. For these reasons, we are placing a requirement for consultation only to be required when there is a meaningful impact on the range of services or the manner in which they are provided – for example, this would cover a change in opening hours, or a change of site, rather than managerial changes that do not affect service provision.¹⁵⁹

Further clarification was given by Phil Woolas (then Minister for Local Government) who explained that the government did not accept there should be public involvement in decisions to change service providers, if this did affect not service provision.¹⁶⁰ One question this raises is whether it would be plausible to maintain that a change in provider would not affect service delivery. A further question is whether the government intends a narrow interpretation which only requires involvement where change will occur in the near-term, rather than requiring involvement on long term change (for instance as might be bought about through introduction of independent providers).

Whereas in the 2001 Act, patients and the public were to be ‘involved in and consulted on’ changes, the 2007 Act replaces this wording with the phrase ‘involved (whether by being consulted or provided with information, or in other ways).’ The government have emphasised that they do not intend that “involvement” should be understood as something less than “consultation.”¹⁶¹ The wording of the 2007 Act supports this by indicating that involvement can include consultation. Nevertheless this same wording also allows involvement to be the more minimal ‘providing with information.’ The government intend that the question of whether it is consultation, provision of information, or another method, which is used in any given case, will depend on the

¹⁵⁸ HCHC, para 257

¹⁵⁹ Government Response to the Health Committee’s Report on Patient and Public Involvement in the NHS, 2007, p 22.

¹⁶⁰ House of Commons Public Bill Committee on the Local Government and Public Involvement in Health Bill, 6 March 2007 (afternoon), Column 570

¹⁶¹ Baroness Morgan of Drefelin, Lords Hansard, 15 Oct 2007, Column 592. Baroness Morgan states that the government’s position on this is in contrast to a Court of Appeal judgement, which ruled that in at least one case, involvement may be less than consultation (Court of Appeal, R. (on the application of Fudge) v South West Strategic HA [2007] EWCA Civ 803; (2007) 10 C.C.L. Rep. 599; [2007] LS Law Medical 645; (2007) 98 B.M.L.R. 112)

circumstances of that case.¹⁶² This flexibility might be understood in the context of concern that the 2001 Act does not provide for differentiation of the level of consultation required in different cases, ‘however minor they may be.’¹⁶³ The 2007 Act imposes a duty on NHS bodies to take account of Department of Health guidance that will be issued on the question of the level of involvement which should be used in different circumstances.¹⁶⁴

The 2007 Act places a new duty on each PCT and SHA to report on the consultation that they have carried out, or propose to carry out, and on the ‘influence that the results of consultation have on its commissioning decisions’¹⁶⁵ This move may go some way to address the concerns that often ‘decisions have been made before the consultation takes place.’¹⁶⁶ Further the duty to respond appears to be in keeping with the principles of engagement and accountability which the government believes should underlie PPI. As with the analogous duty to respond to recommendation and reports from a LINK, the sense, and extent to which this duty will be successful in reflecting these principles will depend in part on an assessment of the account and reasons that PCTs and SHAs provide in their responses. This assessment may in turn be determined by the guidance which will be forthcoming from the Department of Health, and which PCTs and SHAs will be required to follow in providing their responses. To date there has been little indication of what content will be expected from PCTs and SHAs in responding to consultation, although the government has said that LINKs may choose to review the ways in which responses are made.¹⁶⁷ Judgement of how principles of engagement and accountability are reflected by the duty to respond may also depend on the scope of the consultation that will be responded to. If the range of issues subject to consultation is limited to those which affect user experience and choice, then the scope of responses to consultation, and hence the scope of engagement and accountability, will be limited accordingly.

The Expert Panel had recommended that section 11 be strengthened and its scope extended ‘to require *every body* which is responsible for delivering health and social care services (commissioners and providers) to involve, consult, and respond to users and the public’, including in relation to the reconfiguration of services and significant organisational change.¹⁶⁸ This recommendation was expressly acknowledged as entailing new obligations on *providers* to involve the public in processes of service improvement: ‘This should be delivered through contractual arrangements with commissioners’.¹⁶⁹ In the 2007 Act, this broad vision is not reflected and the duty to consult is limited to NHS bodies. Commissioners are being instructed by the Secretary of State to amend contracts, placing a duty on independent providers to respond to LINKs. However this duty requires only that the providers allow LINKs members to enter and observe premises, and that they provide LINKs with information when it is

¹⁶² Baroness Morgan, Lords Hansard, 15 Oct 2007, Column 592

¹⁶³ Phil Woolas, House of Commons Public Bill Committee, 6 March 2007 (afternoon), Column

568

¹⁶⁴ The DH have said that guidance will be issued in Spring 2008 (See Department of Health, *Duty to Involve Patients Strengthened, Briefing on section 242 of NHS Act 2006* (December 2007))

¹⁶⁵ 2007 Act, Section 234

¹⁶⁶ HCHC, para 271

¹⁶⁷ GovResp, para 1.51

¹⁶⁸ Expert Panel, para 10.5

¹⁶⁹ Expert Panel, para 10.5

requested; it does not mention any duty to involve the LINKs (or the wider public) in making decisions for change.¹⁷⁰

(d) *Scrutiny*

As has been described above, the evidence given to the House of Commons Health Committee included substantial concerns over the procedure for referral and review of proposed organizational changes, and the failure of the Secretary of State to make proper use of the Independent Reconfiguration Panel. In light of this the Committee made the following recommendation:

The Secretary of State's interventions following extensive local consultations threatens to undermine public confidence in the consultation procedure system. We are also concerned that few referrals from Overview and Scrutiny Committees are subsequently referred by her to the Independent Reconfiguration Panel. We recommend that the Secretary of State refer all OSC referrals to the Panel. She should also seek the advice of the Panel before exercising her extensive powers to intervene in reconfigurations.

The Panel is also available for advice before formal consultation begins and wide use of this advisory service should help to make formal consultation more acceptable.¹⁷¹

The 2007 Act does not address these concerns. The government response to the Committee emphasised that since the Secretary of State is accountable for the NHS, she is right to take 'a view on important contested service changes, where asked to do so through the local democratic process.' The government also states that the Independent Reconfiguration Panel should only be used as last resort, and so few referrals should be expected. It also expresses confidence that the IRP is well utilised by organisations seeking informal advice on development of proposals for NHS service change. Finally, the government maintains that '[i]t is for the Secretary of State to determine when she wishes to seek independent advice from the IRP.'¹⁷²

(e) *National voice*

The Expert Panel and the House of Commons Health Committee both recommended moves to strengthen and make more systematic, patient and public involvement in contributing to debate on national policy. The House of Commons Health Committee maintain that:

[W]here patient and public viewpoints can make a genuine contribution to debate, consultation on national policy may be valuable both in terms of enhancing accountability and improving policy making, even if final decisions must ultimately rest with elected representatives. We have heard that at a national level patient and public involvement is fragmented and lacking a coherent strategy; we recommend that the Government should address this as a priority.¹⁷³

In response to this the government have stated their support for the creation of 'National Voices', which will be a charitable body comprising voluntary sector organisations with

¹⁷⁰ This duty was promised in the *Local Government and Public Involvement in Health Bill Committee Stage Report* (March 2007), p 21. It has been explained in Department of Health, *Local Involvement Networks, Briefing for independent providers* (April 2008).

¹⁷¹ HCHC, para 273

¹⁷² Government Response to the Health Committee's Report on Patient and Public Involvement in the NHS (June 2007), p 23

¹⁷³ HCHC, para 278

interests in supporting users of health and social care services.¹⁷⁴ Those developing National Voices emphasise that, while the body will compliment government measures on PPI, it has been developed independently of government policy.¹⁷⁵ The government hopes that:

National Voices could have two new and valuable roles in helping the DH to engage with users and the public in a more coherent manner. Firstly, to gather and articulate views on generic issues, such as choice, system reform or electronic patient records where it is recognised there are often gaps in engagement, as there is no obvious user group with which to initiate discussions. Secondly, to act as a broker to put the Department in touch with specialist groups and with seldom-heard voices in user groups.¹⁷⁶

These aims suggest this systematic engagement should include involvement on a range of issues ('choice, system reform or electronic patient records') which is broader than those of user experience and choice which will be subject to the revised 'Section 11' duty. Moreover, these aims point to an intention to involve people both as service users (including carers) and as the public. National Voices however, are clear that their organisation will focus on the voice of users and carers:

'National Voices' will create an 'organisation of organisations', a network of national not-for-profit organisations that champion the interests of service users, patients and carers and will give them a complementary, co-ordinated voice.¹⁷⁷

National Voices propose that in the role of giving voice to user interests, their organisation will be concerned with an extensive range of issues, such as 'payment by results, commissioning, patient and public involvement [PPI], access, information, self care, care plans, reorganisations or regulation'¹⁷⁸ Nevertheless, with its focus on the interests of service users, the scope of National Voices is more limited than would be the case for a system of involvement which was also concerned with the involvement of people as members of the public.

National Voices aim to give voice to user interests by developing policy recommendations and working with the government 'in a systematic and officially recognised way to help formulate health and social care policy, and advise and feedback on implementation of policy', arranging and co-ordinating engagement between member organisations and government bodies,¹⁷⁹ and by building capacity within member organisations 'to enable them to build their capacity to influence'¹⁸⁰ In this, and in keeping with the government's hopes, National Voices intends to '[w]ork to enable all service user, patient and carer voices to be heard, including those that often find it difficult to be heard'¹⁸¹ National Voice are proposing a two pronged approach to involving user voice in policy development. The first will be through developing policy

¹⁷⁴ Gov Resp to HCHC, p 24

¹⁷⁵ Emma 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* (January 2007), pp 8-9. Page 18 of the same document raises the possibility of National Voices working with LINks in the future.

¹⁷⁶ Gov Resp to HCHC, p 24

¹⁷⁷ National Voices proposal, p 5

¹⁷⁸ National Voices proposal, p 7

¹⁷⁹ National Voices proposal, p 11

¹⁸⁰ National Voices proposal, p 12

¹⁸¹ National Voices proposal, p 12

recommendations as an organisation and taking these recommendations to government. In this approach the aim is that collective policy recommendation will be developed through an internal process ‘based on shared ownership and shared learning’ among members in which ‘all voices have equal value.’¹⁸² The second approach will be setting up systems which will give member organisations the opportunity to debate with members of government, perhaps through roundtable discussions. The aim of this second approach ‘is not to communicate a single view to ministers but rather to enable a range of views to be heard in one place and at the same time.’¹⁸³

(f) *Role of regulatory agencies*

Economic regulation is an integral part of the Government’s current reform strategy in England. The 2006 Consultation Paper, *The Future Regulation of Health and Adult Social Care in England*,¹⁸⁴ sets out the reformed regulatory framework necessary for the choice mechanism to function to ensure that services are made more responsive to the needs and preferences of patients and service users:

The simplest and most direct way to increase peoples’ control is to give them more choice. The Government aim for reform of public services is that, wherever practical, individual service users should be offered a choice over what is provided and how it is provided and have better information on which to make these choices. This will create healthy competition and encourage providers to develop new models of care. Once chosen, providers will need to cooperate with other providers to deliver smooth pathways of care.¹⁸⁵

To this end the Government proposes the merger of three current regulators: the Healthcare Commission, the Commission for Social Care Inspection (CSCI), Mental Health Act Commission (MHAC). The remit of the independent regulator of NHS Foundation Trusts, Monitor, is specific to FTs and will remain unchanged.¹⁸⁶ The Audit Commission is also a key player because of its role in ensuring that public money is spent economically, efficiently, and effectively.

A principal reform objective is therefore greater integration of the regulation and assessment of health and adult social care.¹⁸⁷ A further aim is to promote continuous improvement in quality, efficiency, and responsiveness by maximising economic incentives for organisations to achieve excellence. Hence the Government’s proposals are set firmly within the institutional economics paradigm. Five main risks to the effective operation of economic incentives are identified: monopoly power (where customers cannot choose to go elsewhere); asymmetric information (one party has more information than another – providers tend to have more information than

¹⁸² National Voices proposal, p 10

¹⁸³ National Voices proposal, p 16

¹⁸⁴ Department of Health, *The Future Regulation of Health and Adult Social Care in England* (November 2006).

¹⁸⁵ Para 1.14

¹⁸⁶ The Office of the Independent Regulator of Foundation Trusts (Monitor) was created under Part I of the Health and Social Care (Community Health and Standards) Act 2003. While FTs are not subject to central direction by the Secretary of State, the regulator is required to exercise regulatory functions in a manner consistent with the performance by the Secretary of State of duties under the National Health Service Act 1977 (s 3). The regulator is required to make a code for determining borrowing limits of any FT (s 12). The regulator is charged with administering the process of ‘authorisation’ of FTs to provide goods and services for purposes related to the provision of health care.

¹⁸⁷ Para 1.15

commissioners, patients and service users); externalities and public goods (unintended consequences and indirect impact on others, either immediately or later); agency (the tendency for choices to be made by patients on the basis of quality rather than price, since citizen is not paying for services directly); and finally, equity (while competitive markets create incentives to improve quality, they do not necessarily achieve equity of provision either geographically or across all population groups).¹⁸⁸

The remedies to these risks (the seven ‘regulatory functions’) are suggested by the experience of regulation in other public service utilities contexts, and of health and social care systems around the world:¹⁸⁹ (i) Independent safety and quality assurance; (ii) Promoting choice and competition – encouraging diversity of provision and creating choice and competition as key drivers of quality and innovation; (iii) Assurance of effectiveness of commissioning – through performance management and/or performance assessment; (iv) Information provision and performance assessment of providers – patients and users need timely and reliable information on which to base choices, while commissioners need such information on which to base commissioning decisions and manage contracts; (v) Price setting and equitable allocation of resources; (vi) Stewardship of publicly owned assets; and (vii) Distress and failure interventions – entailing a clear rules-based regime which holds publicly owned providers to account for performance, enables intervention to deal with significant failings, makes possibility for failure real, but ensures continuity of services in the event of failure of provider in any sector.

The adult social care system in England is said already to benefit from many of these regulatory features. ‘As this develops within the NHS, the role of independent regulation will change and focus on public accountability to the taxpayer and assurance to patients and service users that all providers meet national standards of safety and quality.’¹⁹⁰ To the extent that economic regulation is effective in achieving its stated aims (improving information flows, increasing competition, etc) benefits to the individual and society in terms of price and quality should result. During the Committee Stage debate two concerns were raised which would arguably impact on the ability of the Commission to achieve these aims.¹⁹¹ First is the concern that the Commission is not sufficiently independent of Government, particularly in view of the requirement in the Bill that the Commission ‘must have regard to such aspects of government policy as the Secretary of State may direct.’¹⁹² The worry was that government policy may be in conflict with judgements that the Commission would otherwise make. The Health Minister (Ben Bradshaw) denied this clause would be used to prevent the Commission from acting as it judged fit.¹⁹³ The second concern was ~~that~~ the Commission’s ‘need to drive efficiency from an economic point of view might conflict with the need to warn about the potential of declining standards.’ In rejecting this, the Health Minister maintained ‘that there was a strong correlation between high

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¹⁸⁸ Para 2.4

¹⁸⁹ para 2.5

¹⁹⁰ para 2.10

¹⁹¹ Health and Social Care Bill Committee Stage Report, (11 February 2008) p 13

¹⁹² Health and Social Care Bill 2007-08, Chapter 1, Section 2 (4)

¹⁹³ House of Commons, Public Bill Committee on the Health and Social Care Bill, Tuesday 15 January 2008 (Morning)

performance on financial management in respect of care quality.¹⁹⁴ These concerns did not lead to alteration of the Bill in committee.¹⁹⁵

(g) *The regulation of involvement*

The Expert Panel made two main recommendations for ‘a stronger voice in regulation’. First, there should be increased user involvement in regulatory processes, including the work of regulatory bodies.¹⁹⁶ The second and more far-reaching proposal is for the regulation of involvement itself.¹⁹⁷ These recommendations were embodied in the subsequent White Paper, with the comment that:

Whilst we are not seeking any legislative change in this area, the proposed merger of current health and social care regulation and inspection bodies does provide an opportunity to integrate and build on the current strengths.¹⁹⁸

The Health and Social Care Bill 2007-08 requires that the new Care Quality Commission ‘must have regard to - (a) views expressed by or on behalf of members of the public about activities to which the functions relate’ and (b) levels of satisfaction with such activities amongst members of the public.’¹⁹⁹ An advisory committee will be set up ‘for the purpose of giving advice or information to it about matters connected with its functions,’ and the Commission must ‘have regard to relevant advice and information given to it by the advisory committee (whether or not given at its request).’²⁰⁰ In Committee Stage debate the Health Minister stated that the advisory committee ‘would cover patients’ and users’ views.’²⁰¹ Further, in response to concerns that this provision for public and patient involvement was not sufficiently strong, the Health Minister commented that ‘he was still reflecting on the question of public and patient involvement’²⁰²

¹⁹⁴ Health and Social Care Bill Committee Stage Report, p 13

¹⁹⁵ The Committee Stage Report (p 10) explains that all opposition amendments and new clauses failed in committee.

¹⁹⁶ ‘The input of users and the public into assessing service quality should be central to the regulators’ work ... We recommend that the legislation merging the regulators should set out how the single organisation will both regulate stronger voice and how it will involve users of services and the public and put their interests at the heart of its regulatory activities,’ Expert Panel, paras 11.4 -11.5.

The Government has accepted this recommendation. The regulators (i.e. Healthcare Commission, Monitor, CSCI, and the Mental Health Act Commission) will be encouraged to involve service users in their work, including: in some inspections; in the design of systems and inspection methodologies; the use of systematic patient and service user feedback to help bring about improvements in the quality of care (GovResp, para 2.15). This is echoed in DH guidance which states that ‘[LINKs] should also feed their findings into key bodies such as the Healthcare Commission and the Commission for Social Care Inspection. This will enable them to establish a local agenda driven by the priorities and interests of local communities.’ Contracting a host organisation for your Local Involvement Network, Annex A, para 1.5 (p17)

¹⁹⁷ We recommend that explicit assessment criteria are established to enable regulators to assess the performance of commissioners ... including an assessment of how local arrangements for involving service users and the public, in particular the LINKs, are supported and utilised, and how well commissioners have sought and responded to the views and needs of communities and needs within their populations – Expert Panel, para 11.6

¹⁹⁸ ASLOV White Paper, 20

¹⁹⁹ 2007-08 Bill, Chapter 1, Section 2 (3).

²⁰⁰ 2007-08 Bill, Schedule 1 (6)

²⁰¹ Health and Social Care Bill Committee Stage Report, p12

²⁰² Health and Social Care Bill Committee Stage Report, pp12-13.

The purpose of ‘the regulation of involvement’ is to ensure that NHS organisations comply with and fulfil their duties to involve and consult.²⁰³

The regulators will seek to develop assessment criteria to measure performance against national standards ... Current core standards for the NHS include the need to seek out and take account of the views of patients, carers and others in designing, planning, delivering, and improving healthcare services. LINKs and OSCs will help commissioners be more accountable to local people. There is a formal line of accountability from PCTs to SHAs, and LINKs and OSCs will be able to make formal representation to an SHA if they have concerns.²⁰⁴

The assessment criteria should form part of an organisation’s annual performance rating, including (i) assessment of how local arrangements for involving service users, the public and the LINKs are supported and utilised; and (ii) how well commissioners and providers of health and social care services have sought and responded to the views and needs of the communities and groups within the populations.²⁰⁵ The 2007-08 Bill provides for the Care Quality Commission to develop indicators, which must be approved by the Secretary of State, and which will be used to assess PCTs, English NHS providers and English Local Authorities.²⁰⁶ In its current form the Bill does not specify how (or whether) these indicators will include assessment of public and patient involvement.²⁰⁷

(h) Conclusion

The Foreword to *The Future Regulation of Health and Adult Social Care in England* from the Secretary of State for Health states:

In public services, we are making a radical shift from top-down, target-driven performance management to a more bottom-up, self improving system built around individual needs of service users and influenced by effective engagement with the public. Increasingly, improvement will be driven by the choices made by service users and healthy competition between different service providers. The NHS and adult social care are no exception.²⁰⁸

It is doubtful, however, whether the PPI reforms really reflect the claimed policy shift from top-down prescription by central government, towards more bottom-up processes built on genuine engagement with patients and the public. The Government has been highly selective in what it has taken from the various reviews of the current PPI system. Reference has already been made to the dilution in the legislation of the original Expert Panel and White Paper recommendations on the ‘section 11’ consultation duty. Moreover the government has rejected the concerns that the House of Commons Health Committee raised over interventions by the Secretary of State following consultations. In the relatively narrow terms of the official discourse on PPI, it must be doubted whether the proposed new system of PPI will resolve the problems of excessive complexity, centralization, and duplication of functions referred to by the Expert Panel in its review of the first wave of reforms.

²⁰³ ASLOV, 20

²⁰⁴ ASLOV, 20

²⁰⁵ ASLOV, 21

²⁰⁶ Health and Social Care Bill 2007-08, Chapter 3, Sections 41-42.

²⁰⁷ Bill as introduced to House of Lords 20 Feb 2008.

²⁰⁸ The Future Regulation ..., 4.

While the analysis of the PPI reforms suggests that they are intended to strongly reflect the government's 'choice' agenda, there is also potential for some of the reforms to result in public involvement on broader issues. As was argued, the changes to 'section 11' limit the scope of public involvement to issues that will affect user experience and choice, and deliberately omit other issues of how services are provided (despite some doubts over the long-term effect on users of these other issues). Further the creation of the new Care Quality Commission firmly supports the choice agenda. Given its purpose in reflecting and representing the interests of service users, there is a sense in which National Voices also adds to the focus on choice. However there is a potential for the scope of issues taken up by National Voices to be broader, not only because their independence from government will enable them to set their own agenda, but also because they will be making recommendations on behalf of whole groups of users. In this latter sense they will need to go beyond straightforward representation of needs and preferences, to considering how policy should treat possibly conflicting interests of different users. If they are to fulfil their remit to integrate equality and human rights principles into their work, LINKs will also need to go beyond representation of needs and preferences, to consider how different interests can be met. Moreover in their rather open remit of 'promoting, and supporting, the involvement of people in the commissioning, provision and scrutiny of local care services,'²⁰⁹ LINKs have the possibility of including issues which are not directly related to user experience.

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As the discussion has shown, there is uncertainty over the forms of deliberation and engagement that will be used by LINKs, and by NHS commissioners and providers responding to the revised section 11 consultations. There is also some uncertainty about the way in which the agendas of voluntary organisations will influence debate and deliberation. Finally, while the government expects that voluntary organisations have the ability to engage people, their success in achieving this within LINKs remains to be judged. Understanding the ways in which the new regulation is implemented will be significant in assessing the nature of the reformed PPI, particularly in its implications for social learning.

6. Divergent PPI Policies in Wales

During the 1990s Welsh policies on patient choice and public involvement did not differ greatly from those of England. The discourse of patient as consumer accompanying the introduction of the NHS internal market, while perhaps embraced less enthusiastically in Wales than across the border, brought improving services for patients to the top of the policy agenda. Although uptake of the GP fundholder scheme was weaker in Wales, there was the same appeal to the notion that competition would bring increased choice of hospital treatment location and to the role of the GP as surrogate decision maker for the patient. Following the introduction of the Patient's Charter in 1992, Charter guarantees (especially those on surgical waiting times) became a major preoccupation of the Welsh Office Health Department. Breaches of Charter targets led on many occasions to strong top-down action, and most Welsh purchaser/provider contracts of this period incorporated financial penalties for delayed

²⁰⁹ Local Government and Public Involvement in Health Act 2007, Section 221

treatments.²¹⁰ As in England, consumerist policies co-existed with another policy strand promoting improved consultation and greater public participation in service planning. The 1992 policy document, *Local Voices: The Views of Local People in Purchasing for Health*²¹¹ resulted in a plethora of initiatives in Welsh health authorities aimed at incorporating public views into local commissioning strategies, though the effect of these in changing patterns of purchasing was limited.²¹² This section will examine how this picture of broadly similar approaches gave way to significant policy divergence between England and Wales over PPI and the health care system more generally.

(a) *Early differences*

The 1997 English White Paper, *The New NHS – Modern, Dependable* promised a re-integrated national service in which competition would be replaced by co-operation and greater attention to quality, within a of stronger performance management framework. The Welsh White Paper, *Putting Patients First*, also signaled a reassertion of central control and stress on managing performance, though with less emphasis on formal targets. The document focused more on improving service quality for patients than on any radical extension of patient or public involvement *per se*. It stated that the NHS ‘should be people centred, managing its services for the benefit of patients and informed by patients’ views’.²¹³ There were references to developing a new NHS charter with a content reflecting the views of the public, and a short section on ‘Patient Responsiveness’ mentioning ‘involving patients in decisions about their treatments’. However, these aspects of the paper lacked detail. Health authorities were to continue in a strategic role, but new Local Health Groups (LHGs) – created initially as sub-divisions of Health Authorities – would be developed to take over responsibility for commissioning.

Interviews carried out for our related SDO project with two special advisors who became involved with NHS Wales at this time suggest a growing preoccupation with the health of local communities and the development of bottom-up policy initiatives. This meshed with concerns about health inequalities and awareness that Wales contained some of the most disadvantaged and least healthy communities in Western Europe. Although the notion of ‘community’ had received no more than a passing mention in the White Paper, it quickly assumed greater prominence in health policy discourse. The Assembly’s first major policy document, the 2001 NHS Plan for Wales,²¹⁴ articulated a new vision of partnership encompassing both individual patients and communities. The First Minister’s introduction set the Plan firmly in the context of Assembly policies to counteract disadvantage and social exclusion, emphasizing ‘the importance of building and supporting strong *communities* where the values of citizenship and collective action can grow.’²¹⁵ The Plan required ‘individuals and communities to participate in decisions affecting their lives’, arguing that both problems

²¹⁰ Hughes, D. and Griffiths, L. ‘On penalties and the Patient’s Charter: centralism v decentralised governance in the NHS’, *Sociology of Health and Illness*, 21(1): 71-94, 1999.

²¹¹ London: Department of Health, 1992..

²¹² Griffiths, L. and Hughes, D. ‘Purchasing in the British NHS: does contracting mean explicit rationing’, *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 2: 349-71, 1998.

²¹³ NHS Wales 1998, 1.13.

²¹⁴ NHS Wales, *Improving Health in Wales: A Plan for the NHS with its Partners*, Cardiff, 2001.

²¹⁵ NHS Wales, 2001, p.5.

and solutions needed to be ‘owned by them’. Chapter 3, entitled ‘The people’s NHS: public and patient involvement’, gives equal prominence to public engagement (‘developing further the involvement and participation of the people of Wales in their National Health Service’) and the role of patients in influencing patterns of care (‘building the health service around their perceptions of need.’). Patient choice was not ruled out, but it was ‘patient voice’ – the right to be informed, to express views and be understood – that received explicit endorsement.²¹⁶

The Plan proposed a radical strengthening of LHGs as autonomous bodies working in close working relationship with local authorities, with membership extended to include local authority representatives.²¹⁷ This was the basis of the ‘new localism’ of the NHS in Wales.²¹⁸ The creation in 2003 of 22 Local Health Boards operating alongside 22 local authorities saw the emergence of a system different from anything else in the United Kingdom NHS. Together with the retention of Community Health Councils, this was the central plank of the Assembly’s strategy to ‘bring a greater local voice to NHS decision making’.²¹⁹

(b) *Public involvement and community regeneration projects*

The institutional infrastructure to support PPI policies was developed through initiatives at various levels. At the community level, a number of umbrella social development programmes provided programme- or project-based funding for schemes initiated by local people and organisations. In most cases these did not have an exclusive health focus but were concerned with more general issues of disadvantage and social exclusion. There was the paradox that while most schemes were brought into being as part of the strong policy direction set by the Welsh Office and Assembly, their *raison d’être* was the creation of sustainable bottom-up developments whose content by definition could not be determined from above. Those featured in the NHS Plan were: (1) *Communities First*, a project to support bottom-up social development projects launched by the WAG’s Department for Social Justice and Regeneration in 2002, which continues to the present time aided by European funding and has so far encompassed 142 communities. (2) *Local Health Alliances*, a Welsh Office initiative dating back to 1999 which required local authorities, NHS bodies and other stakeholders to come together to identify and deal with health issues in local communities. (3) *Sustainable Health Action Research Programmes*, an initiative arising from *Better Health Better Wales*²²⁰ to support action research projects in the areas of health, housing, unemployment, social distress and poor access to services, and which encouraged local people and agencies to participate and provide evidence of what works and does not work. Other programmes that could be linked to the broader engagement policies included: (4) *The Inequalities in Health Fund*, a programme dating from 1991 aimed at developing community-based health promotion and prevention, initially focusing on coronary heart disease; and (5) *Health Challenge Wales*, a 2004

²¹⁶ ‘The importance of the patient’s voice is recognised as being centrally important in the drive for service improvement. Patients want to be seen quickly in conditions that respect their privacy and dignity. They want to be cared for by professionals who understand their needs and concerns.’ (p.31)

²¹⁷ NHS Wales 2001, p. 62.

²¹⁸ Greer, Scott, L. *Four Way Bet: How devolution has led to four different models for the NHS*. London: The Constitution Unit, 2004.

²¹⁹ Jane Hutt, *Assembly Record*, 20 October, 2002.

²²⁰ *Better Health, Better Wales* Cm 3922. TSO, 1998, 8.5.

initiative encouraging individuals and organisations to share responsibility for health with the NHS, and providing information and support to help with this.

In addition Wales benefited from UK national schemes such as *Communities that Care*²²¹ and *Sure Start*,²²² both of which funded projects concerned with the well-being of young people. Many of these projects are directed at health promotion and prevention, including a community view of how these objectives should be taken forward, rather than acute hospital care. This accords with the notion that health policies are not just concerned with an illness service, and that measures to influence the social determinants of health need to have a PPI dimension just as much as the core NHS.²²³

(c) *PPI in the NHS and other formal organisations*

As far as NHS bodies are concerned, NHS Trusts and LHB were required to undertake a baseline assessment and annual reports on progress in PPI, which are an element in the performance assessment framework monitored by WAG. Some Trusts have created patients forums of various kinds but there is no equivalent to the English PALS. The independent Patient Information Forums (PIFs), established by the King's Fund in 1997, exist in both England and Wales. There is a Welsh Patient Involvement Forum which operates as an additional conduit for information relevant to service users. In 2002 the WAG funded six 'pathfinder' projects to provide patient support services in NHS Trusts, giving 'on-the-spot' help and advice to service users requiring assistance. These were encouraged to try a range of approaches and were subject to formal evaluation from university-based researchers. After a positive evaluation report on the PSS projects, the initiative was rolled out to all Welsh NHS Trusts.

Following the publication of the NHS Plan, more detailed and practical suggestions for the elaboration of Welsh PPI policies were set out in the guidance paper, *Signposts*.²²⁴ The paper distinguished the collective level, 'the involvement of patients and the wider public in decisions concerning the delivery and planning of services', from the individual level, including 'the involvement of patients in discussions and decisions concerning their own individual care and treatment'. It allowed that the latter may include 'getting involved in choices about care and treatment options', but significantly the main emphasis was on greater responsiveness to patient needs. *Signposts* provided greater detail and discussion of the PPI proposals from the NHS Plan, and included illustrative case studies from Health Authorities, and NHS Trusts and Local Authorities. The latter describe local initiatives to promote inclusive communication, build relationships and assess patient satisfaction, and outline several projects that had

²²¹ Fairmington A. *Communities that care: a case study of regeneration from Wales*, *Critical Public Health* 14, 1, 2004, pp. 27-36.

²²² Goodwin, M and Armstrong-Esther, D. *Children, social capital and health: increasing the well-being of young people in rural Wales*, *Children's Geographies* 2, 1, 2004: 49 – 63.

²²³ Questions have been raised about the sustainability of individual projects when core funding ends, and a degree of disconnection between micro level projects and macro policy (which cannot be overly prescriptive about grassroots schemes). As time passed most schemes moved away from funding shorter term projects to offer support for at least 3 years. Welsh policy makers continue to see these programmes as 'slow growth', long term ventures that will need to learn lessons over time. The Assembly has delivered substantial annual funding for programmes of this kind up until the present time.

²²⁴ Welsh Assembly Government *Signposts – A Practical Guide to Public and Patient Involvement in Wales*. Ldn: OPM, 2001.

experimented with engagement techniques such as stakeholder conferences, targeted consultation meetings citizens' juries, panels, focus groups, service user interviews, patient questionnaires and participatory appraisal. In late 2003 a follow-on document, *Signposts Two*,²²⁵ was prepared with the intention of assisting NHS organisations to develop PPI in a more mature form. The theme of engaging communities continued to feature prominently, with a discussion of how different kinds of communities can be defined, targeted and reached. There was a self-assessment tool to help NHS bodies to gauge progress in increasing PPI in areas such as better patient information, improved feedback and greater opportunities to influence service delivery. The last has been the most difficult to achieve. One of the major claimed examples in NHS Wales was significant public participation in the agreement of the standards incorporated in National Service Frameworks (NSFs).²²⁶

(d) *Retention of Community Health Councils*

The more incremental approach to PPI reform adopted in Wales is illustrated by the WAG decision, announced in January 2001, to retain Community Health Councils when they were due to be abolished in England. Section 22 of the National Health Service Reform and Health Care Professions Act 2002, which abolishes Community Health Councils in England, made provision for the National Assembly to exercise power under the 1977 Act to retain CHCs in Wales and establish a new body to advise and assist them. Welsh policy makers responded to the alleged shortcomings of CHCs by giving them significant additional powers. The Health (Wales) Act 2003 – based on the first all-Wales Bill to undergo pre-legislative scrutiny by the National Assembly and the Westminster Parliament – amends the 1977 Act to make provision for a range of new duties and powers for Welsh CHCs.²²⁷ These include a statutory right for CHCs to be consulted about major service changes. Subject to certain caveats, relevant NHS bodies have a duty to involve CHCs in 'the planning and provision of (...) services' and 'the development and consideration of proposals for changes in the way those services are provided, and decisions to be made by that body affecting the operation of those services.'²²⁸ NHS bodies are required to provide a CHC 'with such information about the planning and operation of health services in its area as the Council may reasonably require in order to discharge its functions'. One identified weakness of CHCs had been their inability to exercise scrutiny over primary care. The new regulations extended their remit to allow entry to, and inspection of GP and dental surgeries, opticians and pharmacies, and also to visit private nursing homes where NHS patients are being treated. CHCs were given responsibility for providing on behalf of the Assembly the independent advocacy services required to be provided in England and Wales under

²²⁵ Welsh Assembly Government, *Signposts 2: Putting public and patient involvement into practice in Wales*. London: OPM, 2003.

²²⁶ NSFs set out standards and an outline of the desirable pattern of services for a number of conditions and service user groups. For example, current NSFs include those for cancer, coronary heart disease, mental health, children, young people and maternity services, and older people.

²²⁷ Welsh Statutory Instrument 2004 No. 905 (W.89), *Community Health Councils Regulations 2004* (March 2004).

²²⁸ Para 18.1. This 'shall not apply to any proposals on which the relevant NHS body is satisfied that, in the interests of the health service or because of a risk to safety or welfare of patients or staff, a decision has to be taken without allowing for consultation; but in such case, the relevant NHS body shall notify the Council immediately of the decision taken and the reason why no consultation has taken place.' (para 18.4)

s.19A of Health and Social Care Act, 2001. In this role, CHCs assist members of the public who wish to make complaints, guiding and supporting them through the relevant formal complaints making processes. Additionally, the regulations provide for the creation of a statutory all-Wales body, the Board of Community Health Councils, to support and advise CHCs.

Currently there are 19 CHCs in Wales,²²⁹ each having between 12 and 20 members appointed by the Assembly Minister for Health and Social Care. Half are local authority nominees, and about a quarter are nominated by voluntary agencies. Each CHC has a full-time Chief Officer and a small number of employed staff. The link to local communities through local authority and voluntary agency representation was seen by Welsh politicians as part of a conscious strategy to strengthen local democratic accountability. Thus, in commending the Health (Wales) Bill to the House of Commons, the member for Aberavon, Hywel Francis, suggested that: ‘it is thoroughly appropriate that the CHCs have a strong democratic element that is achieved through local authority and other representation. That is a major local democratic reaffirmation and a return to the best values of the Tredegar Medical Aid Society and other similar voluntary health organisations of the past’.²³⁰ However it is debatable whether real CHC power increased greatly compared with the previous regime. A special advisor interviewed for the SDO project observed wryly that initially the new model of ‘involvement’ meant only that CHC members (not wider communities) were involved.

(e) ‘Clear red water’

By 2002 the return to the managed market in England was gathering pace. The Secretary of State for Health, Alan Milburn, had started his term with a drive to strengthen performance management and targets, but was becoming increasingly sympathetic to an injection of market incentives and choice. Plans were taking shape for a provider market constructed from the building blocks of Foundation Trusts, greater private sector participation, and increased consumer choice. In December 2002 Assembly First Minister, Rhodri Morgan, gave a lecture in which he launched a thinly veiled attack on the Blairite policies.²³¹ Bluntly rejecting the English patient choice approach, The First Minister said: ‘Approaches which prioritise choice over equality of outcome rest, in the end, upon a market approach to public services, in which individual economic actors pursue their own best interests with little regard for wider considerations.’ Morgan criticized the English plans for Foundation Trusts and enhanced patient choice, and predicted that ‘the experiment will end, not with patients choosing hospitals, but with hospitals choosing patients.’ He said that in the Assembly’s second term there would be ‘clear red water’ between Cardiff Bay and Westminster. Public services in Wales would remain free at the point of use, universal and unconditional. Foundation hospitals and the privatisation of public services would be rejected.

²²⁹ They coincide roughly with the xx LHBs, but there are some differences because certain CHCs were merged.

²³⁰ 27th November 2001.

[http://hywel Francis.co.uk/articles/Health%20\(Wales\)%20Bill%202007.11.02.doc](http://hywel Francis.co.uk/articles/Health%20(Wales)%20Bill%202007.11.02.doc)

²³¹ Morgan, R. Third Anniversary Public Lecture, National Centre for Public Policy, University of Wales Swansea, December, 11th, 2007. See also: Davies, S. Across the clear red water, www.publicfinance.co.uk: the internet magazine of the public sector. http://www.cipfa.org.uk/publicfinance/search_details.cfm?News_id=16332, 2003.

Morgan's stand had an obvious ideological content,²³² which was not shared fully by all those advocating a different path for Wales. Some within the Welsh policy community, including many civil servants, articulated a different set of concerns bound up with issues of geography, population sparsity and local monopoly/monopsony situations with a single purchaser and acute provider, which would all limit the applicability of competition and choice. There was a perception that, while patients might well exercise choice where local alternatives existed, they would not travel to do so, and also that choice implied excess capacity which did not exist in NHS Wales. However, it was political rather than merely pragmatic opposition that strengthened markedly as the English choice policies came to be seen as part of an overall market package encompassing Foundation Trusts, practice-based commissioning, independent sector treatment centres, and widespread use of PFI funding. The mood was well captured in a public lecture in which the WAG Health Minister approvingly quoted the words of the commentator Julian Tudor Hart: 'Though the market model may give patients a louder voice, this will be the shrill cry of consumer choice, not the sceptical thought and responsible voice of the citizen.'²³³

The developments in Wales provide an unusual example of how national and regional politicians from the same political party, both dependent on an electoral mandate, had to accommodate divergent policies within a shared legislative programme. Ultimately national politicians took a step back from trying to prescribe Welsh policies, but this does not tell the full story of the conflict and tensions that arose along the way. Senior civil servants and advisors interviewed for our SDO study reported strong and sustained attempts by Westminster politicians and civil servants to push Wales closer to the English position in certain key areas. In the period before full devolution, Welsh policy makers were well aware of the fundamental divide between policies that could be implemented through administrative means, and those requiring legislation, which at that time constituted a major stumbling block in the absence of support in Westminster. Among other things, this helps to explain Wales' incremental approach to the development of Local Health Groups, and the delay in the emergence of the stronger Local Health Boards.

Pressure from the English side was applied at several points. The determination of Welsh politicians to retain CHCs was one early area of disagreement, which rumbled on from the original policy announcement in 2001 to the legislation in 2003. Informants in our SDO interviews recounted how the then Health Secretary met with the Assembly First Minister and his special advisors to tell them that there were limits to what would be accepted. By then the 'clear red water' speech had raised further tensions, and resulted in a visit to Cardiff Bay from the Prime Minister's special advisor in which there was a discussion about the rationales of the English and Welsh policies with counterparts. There was a serious wrangle about Wales' decision to create an independent inspectorate more attuned to Welsh standards and public engagement policies. There were further spats over Westminster's alleged failure to consult Wales on the changes in primary care policies proposed by Sir Nigel Crisp, and later regarding the issue of access and Welsh surgical waiting times in the run up to the 2005 general

²³² Chaney, P. and Drakeford, M. The primacy of ideology: Social policy and the first term of the National Assembly for Wales, *Social Policy Review* 16, 2004.

²³³ Nye Bevan Lecture 2004, Unpublished manuscript – delivered by WAG Health and Social Services Minister Jane Hutt, 1st December 2004.

election. One factor that helped Welsh policy makers hold the line was support from the other UK Celtic countries, who often lined up alongside Wales in common opposition to the English market reforms. There was also the issue of the electoral needs of a single governing party, consisting of a New Labour wing in England and more traditional wings in the other countries. Effectively a pact was made in which Welsh Labour politicians, in return for delivering the Labour votes necessary for a general election victory, were given flexibility by national leaders to adapt policies that fitted with local political preferences. The publicity attracted by high profile internal rows about waiting lists and greater use of the private sector in the 2005 election campaign seems to have had costs for both sides. Informants in the SDO study reported that after 2005, there was a virtual cessation of interference from Westminster in Welsh health policy making.

(f) *The ‘Second Offer’ scheme*

Against this background there was never any prospect that Wales would emulate the English ‘Choose and Book’ reforms. However, despite resistance from opposition politicians on the ground that it was choice policy, the WAG did introduce a ‘Second Offer’ scheme in April 2004,²³⁴ offering an alternative treatment option for patients experiencing excessive delays on surgical waiting lists. Initially this scheme offered treatment at a second hospital for patients waiting more than 18 months, but the threshold was reduced to 12 months in March 2005. The cost of transfers of patients falls either on the Trust or the LHB in accordance with official pricing rules and the responsibilities of the respective parties as set out in service agreements. A CHAI report published in July 2005 found that about 11,500 patients had taken up a second offer by that date, and identified the scheme as one of the main factors accounting for a reduction in the numbers of long waiters in Wales. Nevertheless it has also been reported that significant numbers of patients declined to participate, usually because of reluctance to travel. Currently the WAG Health Department is developing a strategy to reduce maximum waiting times to 26 weeks within three years (‘Access 2009’), and it is anticipated that this will lead to a winding down of the Second Offer scheme.

It is important to note that ‘Second Offer’ plays a much less central role in the NHS commissioning process than does ‘Choose and Book’ in England. There is no attempt in Wales to develop a patient choice mechanism that will shape initial referral pathways and patterns of service purchasing. The scheme is not about allowing patients to choose between alternative providers, but a means of achieving targets on reduced waiting times. Patient choice is restricted to exercising the option of stepping out of a long queue into a shorter queue at a different hospital. WAG Health Department guidance states that routine recourse to the scheme should be avoided through a combination of effective commissioning and effective delivery. Welsh LHBs and Trusts must therefore steer a careful path between over-use and failure to use a mechanism which may help to facilitate the achievement of waiting times targets.

(g) *Health Inspectorate Wales*

In April 2004 the former Commission for Health Improvement became part of a new body, the Commission for Healthcare Audit and Improvement (CHAI), responsible in England for setting and monitoring standards in the NHS, voluntary and private

²³⁴ See: WHC(2004)15; WHC(2004)27..

healthcare sectors. Its significance as an arms length regulatory body, able to oversee the plurality of providers participating in the new English market and providing information on quality for patients making choices, was not lost on Welsh policy makers. From the Welsh perspective CHAI was perceived as part of the English market framework that the Assembly had rejected. In particular there was a concern that CHAI would not be sufficiently responsive to Welsh health care standards and the different approach to public engagement. Informants in our SDO study suggested that these were the main factors behind the decision to establish a separate oversight body in the shape of Health Inspectorate Wales (HIW).²³⁵

PPI is one of six domains used to assess the performance of LHBs and NHS Trusts, and forming part of HIW's inspection remit.²³⁶ HIW investigates progress towards achieving standards relating to PPI both by scrutinising inspection data from LHBs and Trusts and through its own direct information gathering exercises with the public, using methods such as focus groups, questionnaires and telephone polling. The latter are used to corroborate the information provided by NHS bodies, partly through self-assessments. These are incorporated into the overall assessments and ratings of LHBs and Trusts contained in HIW inspection reports.

Two senior HIW staff interviewed for our SDO project conceded that PPI assessments had not always gone well and involved a steep learning curve. From 2004 onwards HIW had experimented with a number of approaches to engagement with the public, using different methods in different exercises, and trying to avoid prescription regarding the favoured PPI process. Early PPI developments in Trusts and LHBs had often been tokenistic, for example where limited patient representation on Trust committees was assumed to equate to genuine participation. HIW's own engagement exercises, especially in the early days, often experienced problems in reaching beyond the 'usual suspects' to get views from a more representative cross-section of the population.

(h) Consolidation of 'Voice' not 'Choice'

While ten years of implementing PPI policies in Wales since Labour's election victory in 1997 have arguably seen considerable progress towards framing a coherent macro-policy vision, the development of structures and processes at the micro-level has been patchy. PPI policies emerged during a period of considerable turmoil in the National Assembly, a time when there was no formal legal separation of the legislative and executive arms, uncertainty about the terms of the devolution settlement and much ongoing re-engineering of the constitution.²³⁷ Nevertheless the Assembly was successful in imprinting its distinctive stamp on PPI. The policies evolved from an amalgam of somewhat unconnected ideas concerning the public and the patient to a more particular focus on engagement and voice, with people cast in the role of citizens rather than consumers. Generally the emphasis has been on collective rather than individual action, at the level of the community or the patient group rather than

²³⁵ Chapter 4 of the Health and Social Care (Community Health and Standards) Act 2003 gives the Assembly primary responsibility for reviewing the provision of health care by and for NHS bodies in Wales and this duty is discharged through HIW, an operational independent body within WAG.

²³⁶ The original circular WHC(2003) 69 listed 5 domains including patient experience and information, but PPI has been added in later guidance.

²³⁷ McAllister, D. and Stribu, D. Measuring the Richard Commission's contribution to Wales' evolving constitutional debate: influence, impact and legal. Paper presented at PSA Conference, Bath, April 2007. <http://www.psa.ac.uk/2007/pps/McAllister.pdf>

individual or single treatment decisions. As stated in the 2005 policy document *Designed for Life*, the WAG's strategy is to: '... empower the community to have its voice heard and heeded, rather than simply being given a choice of treatment location.'²³⁸

Over time an attempt has been made to align the health policies more closely with policies on inequalities and community regeneration, and also with the Assembly's more general strategy for the public sector. Thus the 2004 policy document *Making the Connections* sets out the case for an integrated, collaborative model of public sector service organisation, better suited to Welsh conditions than the English model of autonomous provider units in a quasi-market. The paper explains how such services will be citizen focused, responsive to the needs of communities, concerned with equality and social justice, and also efficient and effective. The issue of better integration of local services is considered in the 2006 Beecham Report,²³⁹ which proposes the formation of 'local service boards' bringing together the service delivery organisations in each local government area. All these developments supported a policy strand emphasising citizenship and engagement that was fully compatible with the direction of travel of policies on PPI.

(i) *The 2008 Consultation Paper Proposals*

The future direction of PPI policies has been thrown into doubt by proposals to end the purchaser/provider split and restructure the Welsh NHS published in April 2008.²⁴⁰ Although a commitment to abolish the internal market was included in the *One Wales Coalition Agreement* between the Labour and Plaid Cymru Parties made in 2007,²⁴¹ the details and timetable outlined in the recent Consultation Paper surprised many observers. Among other things there are plans to channel funding to hospitals via a single central NHS Board, and an intention to replace the present 22 LHBs with 8 merged bodies, that will then act in the role of primary care providers rather than purchasers. The Consultation Paper appears to foreshadow a return to centralism and seems to threaten the 'localism' associated with LHBs, small country governance and the associated PPI policies.

As yet the revised structure of the Welsh NHS remains unclear. If the proposals to move to eight LHBs go ahead, each of these new bodies will be aligned with an NHS Trust and a grouping of local government authorities. The previous arrangement of one-to-one coterminosity of LHBs and local authorities will be lost, and the principle of securing democratic accountability via inclusion of local government representatives on NHS bodies will be weakened. The Consultation Paper acknowledges that: 'With fewer organisations, patient and public engagement will have to be secured in new ways.'²⁴² Although the Consultation Paper states that 'the principle of localism is of fundamental

²³⁸ Welsh Assembly Government (2005) *Designed for Life: Creating World Class Health and Social Care for Wales in the 21st Century* Cardiff: Welsh Assembly Government.

²³⁹ *Welsh Assembly Government, Beyond Boundaries: Citizen-centred Local Services for Wales* (Beecham Review Report). Cardiff: WAG, 2006.

²⁴⁰ Welsh Assembly Government, Consultation Paper, Proposals to Change the Structure of the NHS in Wales, Cardiff: WAG, April 2008.

²⁴¹ Welsh Assembly Government. *One Wales: A progressive agenda for the government of Wales*; June 2007

²⁴² WAG Consultation Paper, p. 6.

importance²⁴³ there is an obvious question about how this can be reconciled with the new more centralised organisational framework. For instance, there are no easy answers concerning how larger LHBs will be able to work with the several local service boards²⁴⁴ that will exist within each of the new LHB catchment areas, or how the boards of the new LHBs will be constituted to retain genuinely local connections. There is also the question of how local voices can influence the deliberations and decision making of a powerful new National Board, which while technically not a purchaser organisation, will assume some of the old LHBs' powers to determine patterns of resource allocation

The planned changes are to be made by April 2009, a timetable for organisational restructuring that is unprecedented in recent NHS history in terms of its rapidity. Several NHS insiders interviewed in the course of our SDO project believed that the proposals and compressed time scale had a clear political dimension, linked to the recently announced retirement date of the Assembly First Minister and his determination to end the internal market before he leaves office. There were concerns that this was a rushed, politically-driven initiative that would undermine much of the ongoing development work that had been taking place in areas such as commissioning and PPI. There was also an anticipation that many LHB staff in particular would need to move to new posts and that a time of considerable organisational turbulence was ahead.

7. Evaluation of existing PPI arrangements in Wales

While the Assembly has undoubtedly succeeded in articulating a distinctively Welsh version of PPI, a number of problems have arisen during policy implementation. At times, the engagement policies have been overshadowed by more pressing policy concerns, which may have impeded progress. There have also been concerns about a degree of disconnection between the macro policies and grassroots developments, and questions about whether participation has extended to representative actors who understand the policy context. The recent Consultation Paper proposals raise question marks about the continuity of PPI policies over time, and may signal a shift away from the pattern of incremental development that had been emerging.

(a) *Policy displacement by high-profile issues*

The PPI policies were introduced in a period when both the details of the devolution settlement and the wider shape of the NHS in Wales were being worked out, and against a background of sharp party political differences and lack of a clear Assembly majority for the governing Labour Party. From 2001 onwards there were a series of crises and controversies that knocked PPI from the top of the list of Health Department priorities. These revolved around criticisms of management in NHS Wales and unfavourable comparisons with English waiting lists, culminating in 2004 in the Assembly's initial refusal to approve the WAG's health and social care programme.²⁴⁵ In the early days of the WAG much energy was expended on further strengthening of performance management, which our informants characterised as very weak at that

²⁴³ WAG Consultation Paper. p. 9.

²⁴⁴ These are the multi-agency boards for local service delivery organisations introduced in the wake of the Beecham Report, and coterminous with the local authority areas. At present local service boards have been implemented in six experimental areas but they will cover all areas by 2010.

²⁴⁵ Institute of Welsh Affairs *Wales is Waiting: Monitoring the National Assembly September - December 2003*

time, and development of national standards, to be incorporated in National Service Frameworks and used in the performance management and inspection regimes. Perceived poor performance in the area of access and waiting times tended to re-focus attention on the acute sector. Funding continued for the community initiatives described earlier. However some of our civil servant and advisor respondents suggested that the macro policies now risked disconnection from micro-level programmes and projects.

(b) *Disconnection of macro policy and grassroots developments*

The difficulty for central policy makers was that community-based engagement projects had almost by definition to be driven forward by local communities. Although policy makers could establish a national framework of engagement policies, any attempt to prescribe the content of micro level initiatives would be self-defeating. Here they were reliant on longer-term processes of education, developing community capacity and building social capital which extended beyond the sole remit of the Health Department. For example, a recent action research study from the Sustainable Health Action Research Programmes (SHARPs) describes how the scale of the problems of working in areas of multiple deprivation still recovering from economic dislocation, policy failure and scepticism about regeneration initiatives were underestimated.²⁴⁶

Where central policy makers may make a difference is in supporting intermediate institutions that contribute to community initiatives, and in creating spaces in formal NHS processes for deliberation and participation. The early experience in Wales suggests that development in this area have been quite limited and that the gap between grass roots and public organisations been difficult to bridge. A senior civil servant interviewed for our research suggested that PPI policies had travelled a long way but policy makers had now reached the stage where they needed to decide how serious they were about the new direction, and whether public engagement would become a core activity necessitating a change in decision making processes that had developed over the past 60 years of the NHS. In this view the spaces so far created for the public to exercise voice within bodies such as Health Commission Wales, the LHBs and the NHS trusts are still not adequate to allow sufficient participation in decision making.

(c) *Representativeness and capabilities of grassroots actors*

In our ongoing fieldwork in Wales, one recurrent theme among informants in the WAG, Health Inspectorate Wales, Health Commission Wales, LHBs and Trusts has been the difficulty of developing engagement mechanisms that reach beyond ‘the usual suspects’ to include people of all kinds. This and the related issue of how well health policies have been communicated to the general public were brought to the fore by some particularly acrimonious public consultations on service changes that occurred in 2006-07. The 2002 Wanless Review called for a radical redesign of health and social care in Wales,²⁴⁷ a message was repeated in the strategy document *Designed for Life*. By 2006 these proposals had worked their ways through to plans for re-configuration of the NHS in Wales, including rationalisation of tertiary neurosurgical services, maternity and community hospital services. The public consultations on these planned changes provided a dramatic illustration of how public involvement could lead, not to the

²⁴⁶ O’Neill, M and Williams, G. Developing community and agency engagement in an action research study in South Wales. *Critical Public Health*, 14, 1, 37–47, 2004.

²⁴⁷ Welsh Assembly Government, Review of Health and Social Care in Wales (Wanless Review Report). Cardiff: WAG.

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development of consensus, but to the exposure of deeply held differences of opinion. In essence the organisations and individuals consulted were concerned more with proposed closures of local services than with arguments about advantages of scale or cost economies that had been central to the policy discourse. There was strong opposition to change. A press briefing from the Board of Community Health Councils wrote of a ‘failure to appreciate that the public are not interested in strategies but in the nuts and bolts of how changes will affect the services they use,’ and stated that the ‘health economist’s view of health services is not acceptable to the public.’²⁴⁸ Opposition politicians joined in a chorus of criticism that the consultation arrangements had paid little attention to dissenting local voices. Several senior informants interviewed in our SDO study were concerned that the consultation process had been captured by unrepresentative interests and in some cases hijacked by political opponents of the Government. For some informants this was a clear indication that the reconfiguration policy had not been adequately communicated to the public, and that more thought needed to be given to how engagement could reach representative groups.

Looking back on the May 2007 NAW elections, the First Minister, Rhodri Morgan acknowledged that the most important ‘bread and butter’ issue had been opposition to hospital closures. He requested the health minister to re-examine the hospital reconfiguration programme and determine what had gone wrong. The First Minister suggested that a ‘full rethink process ... will be able to look for different ideas and approaches to the public, to persuade people to get onboard, and to listen to alternative ways forward.’²⁴⁹

(d) *Policy continuity*

While it is too early to predict whether the proposals in the 2008 Consultation Paper will be implemented in anything like their present form, there is a risk that a reform programme that is primarily about the balance between markets and planning in the Welsh NHS will have unanticipated consequences for PPI policies. Whatever its other drawbacks, the WAG approach to localism and integrated service delivery within a small country governance model had a clear logic and connected well with policies based on enhanced community participation and strengthened deliberative mechanisms. A shift to larger bodies and the creation of a powerful central NHS Board seems certain to cast the vision of ‘localism’ into doubt. If such changes go ahead they would seem to have more to do with the political agendas of the ruling parties and their determination to safeguard an integrated state NHS, than with lessons gained in the course of implementing the downstream PPI policies considered in earlier sections.

8. PPI – prospects for social learning

To recap, our evaluation of PPI focuses on the potential of the different PPI governance frameworks in England and Wales to facilitate the development of institutions and

²⁴⁸ Press Briefing, NHS service reconfiguration consultations, 21 June 2006, <http://www.wales.nhs.uk/sites3/Documents/236/Press%20Release%20NHS%20Reconfiguration%20210606.pdf>

²⁴⁹ IWA http://www.iwa.org.uk/publications/pdfs/Wales_Sept07.pdf.

processes that are conducive to more effective social learning.²⁵⁰ The basic criterion of the adequacy of governance is the degree of reflexivity in the organisation of conditions of social learning in collective actions to resolve problems in the general interest. Reflexive governance cannot result spontaneously from the expression of individual preferences, as assumed by neo-classical economics, but requires instead the creation and maintenance of specific institutional conditions. Such conditions vary according to the particular analytical level (economic institutionalist, collaborative/relational, pragmatic, or genetic) at which the evaluation of reflexivity of learning operations is conducted. The four approaches and their associated conditions are supplementary rather than mutually exclusive – each adding value in building our understanding of the role of reflexivity in social learning, rather than displacing or simply superseding the less developed approach.

As explained in section 1 above, we consider the neo-institutionalist and collaborative/relational approaches to social learning in healthcare governance in England and Wales under the respective headings: *economic coordination*, and *capacitation and communicative competence*. We proceed to examine the democratic experimentalist and pragmatic approaches respectively in terms of *experimentalism and joint inquiry*, and *capacitation and cognitive reframing*.

(a) *Economic coordination*

In markets and in quasi-markets for healthcare services in England, a variety of external mechanisms is directed at overcoming obstacles to efficiency, including economic regulation and the exercise of governmental control through arm's length regulatory agencies. The Government's economic reform agenda may be seen as an attempt, through hierarchical framing or external integration, to correct market deficiencies by subjecting players in the healthcare environment to incentives that will lead to improved economic performance. Our empirical focus here is on the success or failure of the reforms (most notably the impending merger of the three existing Commissions into a single 'super-regulator' with new powers and a revised regulatory remit under the Health and Social Care Act 2008) in combating the problems of monopoly power and asymmetric information that are portrayed as barriers to competition and the effective operation of the choice mechanism. As regards the exercise of choice by PCTs that commission services on behalf of patients, the fundamental and widely acknowledged problems of quasi-market organisation can only partially be addressed through Government intervention. The exercise of choice by patients is still more problematic, with major doubts as to the workability of the 'Choose and Book' scheme and uncertainty surrounding the future of this strand of PPI policy.

The Welsh strategy for policy development in the public sector, *Making the Connections*, explicitly rejects the model of decentralised semi-independent providers operating in a quasi-market with an arms-length regulator in favour of integrated public provision and internal hierarchical regulation. The key question is how far traditional bureaucratic organisation is being modified through the incorporation of novel forms of

²⁵⁰ i.e., the evaluation should be not simply in terms of the balance of power between bureaucrats/professionals on the one hand and patients/citizens on the other hand, as portrayed in the majority of academic and policy analysis (section 4 above).

performance management and inspection that serve to promote social learning by aligning individual behaviour with the goals of the organization.

(b) *Capacitation and communicative competence*

The importance of patient and public involvement in healthcare governance has long been recognized, although usually more for reasons connected with democratic accountability and legitimacy than with the improvement of services through social learning. We suggested in section 7 that the Habermasian strand in the current academic and policy literature on PPI is consistent with (while not expressed in terms of) the collaborative/relational approach. At this level we analyze in both England and Wales different forms (venues, fora, conduits) of negotiation and representation of patient and public interests, together with respective ‘empowerment’ strategies directed at building communicative competencies, strengthening argumentative capabilities and increasing opportunities for dissent and counter-argument in dialogic processes.

In England, the Government’s agenda for ‘voice’ reform is more complex and difficult to evaluate than that involving ‘choice’. The most significant *organizational* change to the existing PPI system is undoubtedly the abolition of PPIFs and their replacement by LINKs. An implicit policy objective is to improve communication, deliberation and participation among key stakeholders with interests in the service in question. One criterion of success here is the quality of dialogue, and the building of some form of weak consensus among the network of significant actors as to the nature of governance problems and how to address them, in spite of the presence of conflicting interests. However, the problem of governance at this analytical level is not reducible to one of communication or representation. What is required *in addition* is the development of cognitive, institutional, and personal capacities among all stakeholders, especially consumers and users of services, in order that they may more effectively participate in and contribute to learning processes. The Expert Panel emphasized the need for a sustained effort to build capacity in voluntary and community organisations and among citizens, so that they can contribute effectively to the development of health and social care.²⁵¹ While the commitment to building capacity among voluntary and community organisations is carried over into *A Stronger Local Voice*, there is little indication as to how this is to be achieved. Without such capacitation, the Government’s own proposed organizations (OSCs, LINKs) are unlikely to succeed. Given persistent problems of inequality, under-representation and social disadvantage, there must be major doubts as to how far significant service improvements will result from organizational reform alone. Furthermore, while suitable voice mechanisms are essential preconditions of effective social learning in the healthcare context, they are not sufficient (see (c) and (d) below).

It remains unclear whether and if so how LINKs will overcome widely acknowledged deficiencies of existing representative bodies. Potential problems with the implementation of LINKs include confusion and lack of clarity in their role, excessive local variation, the danger of taking on too much, and the duplication of work with FT Boards of Governors if they focus on service delivery.²⁵² While Ministers have been optimistic that LINKs would attract many new members, relatively few people are likely

²⁵¹ Hughes, D. Griffiths, L. and McHale, J. ‘Do quasi-markets evolve? Institutional analysis and the NHS’, *Cambridge Journal of Economics*, 21: 259-76, 1997 Expert Panel, para 6.1

²⁵² HCHC, para 150 (? check this)

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to be prepared to make general commitments to PPI beyond particular issues that have always attracted vociferous local support such as campaigns for hospital closures.²⁵³

In the Welsh context, certain deliberative (collaborative/relational) conditions of social learning may be regarded as having been established to some degree through the creation of new fora for public engagement with NHS bodies, and the redefinition of the duties of CHCs, LHBs, and NHS Trusts. Many grassroots community engagement programmes are primarily about developing new deliberative mechanisms, as are initiatives within some NHS Trusts and LHBs to develop non-standard fora to engage with particular community or service user groups. It remains unclear how far relations between service providers and service users have developed within the new deliberative fora to promote productive forms of co-operative working, though the recent furore over consultations regarding service reconfiguration suggest that progress has been limited.

In both England and Wales, the shift in focus from building consensus to encouraging dialogue among different constituencies and conceptions of the general interest may be interpreted as an attempt to establish further necessary conditions of social learning at the collaborative/relational level. Productive engagement may involve the expression of dissent, the brokering of compromises or the accommodation of difference. One academic criticism of the conception of active citizenship in Welsh political circles is that it is overly preoccupied with consensus and does not provide sufficient opportunities for dissent and constructive counter-argument.²⁵⁴ The general disquiet concerning the recent consultations on service re-configuration suggests that this may be a weak spot in the institutional framework supporting PPI. However, top-down policies that seek to drive patient and public involvement by helping to build intermediate institutions and appropriate stakeholder capacities are problematic for the reason mentioned earlier: too much ‘steering’ from the centre risks subverting the grassroots developments that policy seeks to encourage. Yet there remains the need for some facilitation and support, beyond simply funding a range of projects. Arguably PPI policy in Wales has still not paid sufficient attention to the capacitation of actors and there may be a need to develop more systematic support mechanisms to build communicative competencies.

(c) *Experimentalism and joint inquiry*

At this level it is necessary to distinguish the practical and potentially ‘experimental’ nature of development of policy and organisational decision-making on healthcare generally, from ‘democratic experimentalism’ as a way of approaching particular governance problems through techniques of joint-working, co-design, and benchmarking, characterised by qualities of ‘learning how to learn’ and ‘choosing how to choose’.²⁵⁵ As regards the former, in England there is little evidence that radical

²⁵³ HCHC, para 196. Given the inherent difficulty and complexity of the commissioning process, not enough thought has gone into making this more attractive to the public, who from past experience are more likely to be interested in service delivery (para. 179).

²⁵⁴ Hodgson, L. Citizenship, Civil Society and Community in Wales, *Contemporary Wales*, 18, 1, 2006, pp. 91-105.

²⁵⁵ Here we accept the criticism made in the second synthesis report of our first draft of the case study of PPI in England and Wales, which incorrectly associated the encouragement of different and competing conceptions of the general interest with democratic experimentalism, whereas the facilitation

reforms are the product of policy learning. While the Government contends that the proposals for LINKs were informed by nine ‘early adopter’ or pilot schemes running since December 2006,²⁵⁶ witnesses to the House of Commons Health Committee referred to the schemes as ‘pathfinders’ rather than ‘pilots’, concerned with ‘testing out ways of working ... given a set of objectives asking them to focus on particular aspects.’²⁵⁷ The publication of the Local Government and Public Involvement in Health Bill and the issuing of guidance while the pathfinders had been operating for such a short period mean that LINKs cannot be evidence-based as the Government has claimed.²⁵⁸ In Wales, by contrast, healthcare reform has been more incremental, with new structures building on the experience of past consultation and representation from the health authority period, and a good deal of ‘learning by doing’ in the organisational reform process. There has been a strong mimetic dimension to the reform process as the NHS has tried to emulate and build upon the experience of comparable projects initiated somewhat earlier in the fields of community regeneration, justice and economic development. Umbrella programmes such as *Communities First* have encouraged a range of approaches and structures within projects, with an emphasis on the development of best practice. Many projects have been subject to formal evaluations and an attempt to use feedback to modify behaviour. The action research project funded under SHARPs had the explicit objective of determining ‘what works and does not work’, again relying on a broadly experimental model. Regulation and inspection has itself been an evolving process, with a very steep learning curve associated with the creation of HIW in 2004, rapidly followed by a period of consolidation and recently an attempt to pick out best practice by a review of approaches across all the inspection and audit bodies involved in health and social care.

As regards experimentalism as a mode of social learning, the focus shifts from mechanisms of communication and representation to specific practices of joint inquiry addressing the problem of how to select among a number of possibilities. It is open to question how far the new representative and deliberative fora in England will be combined with such new forms of joint inquiry and investigation. Similarly in Wales, it remains uncertain how far existing representative fora are being combined with novel forms of joint inquiry and investigation of the sort regarded as essential elements of reflexive governance in the democratic experimentalist sense.

(d) *Capacitation and cognitive reframing*

The Schönian strand of the pragmatist approach re-focuses attention on the issue of capacitation of social actors, as distinct from (while nevertheless building upon) the experimentalist concern with forms of inquiry and investigation. Capacitation in this sense refers to a very different set of conditions than those required by the collaborative/relational approach. The question here is whether, in England and/or Wales, we can find examples of ‘learning operations’ involving cognitive processes of

of such increased dialogue in fact remains trapped within ‘wholly “deliberative” logic’- fn 18, second synthesis report, above.

²⁵⁶ Two have been run by the Healthcare Commission, and seven by the CPPIH.

²⁵⁷ HCHC, para 109.

²⁵⁸ HCHC, para 111. LINKs are less of a ‘trial’ and more of a discussion with stakeholders – what can be expected from Hosts is not being addressed (para 112). There is no fixed budget for each ‘early adopter’ making it difficult to determine what can realistically be achieved with money that will be available (para. 113).

representation and re-representation, the adjustment of frames and reframing, double vision ('seeing the other's point of view'), and evidence generally of governance techniques capable of overcoming 'defensive strategies' and of challenging preconceptions and hitherto entrenched positions of social actors and stakeholders in the healthcare environment.

In England, the major legal *institutional* change accompanying the replacement of PPIFs by LINKs is the reform of the 'section 11' duty to consult and involve patients and the public. The original Expert Panel and White Paper proposals for the 'regulation of involvement' may be interpreted as advocating a kind of meta-regulation – the regulation (by the new merged regulator) of the regulatory role performed by the patient and public in the new system of regulation. This system of regulation includes incentives on commissioners (and providers) to consult, involve, and respond by showing in regular reports to regulators what they have done differently as a result; the performance of commissioners on this dimension being evaluated and assessed by the regulator as a component of their annual performance rating. One question here is whether the duties to involve, consult and report, as supervised and monitored by the new Care Quality Commission, can serve to promote reframing or re-representation, or even perform the function of 'terceisation' in the sense required by the genetic approach to social learning. At present this element of our analysis remains underdeveloped and implicit. A crucial issue for further research is how far the potential for social learning in this sense has been undermined by the Government's dilution in the legislation of the original White Paper proposals to extend the scope of the 'section 11' duty beyond commissioning bodies.

It seems clear that this 'regulation of involvement' approach will not be transplanted to Wales. The PPI provisions in the Local Government and Public Involvement in Health Act apply only to 'relevant English bodies' and not to the NHS in Wales.²⁵⁹ While the Act provides for the exercise of the Assembly's framework powers to make legislation (Assembly Measures) in some of the areas of England-only provision, these relate to local government and do not signal any intention on the part of the Assembly to introduce a Measure in the PPI area.²⁶⁰ LINKs are being introduced in England in part because of the increasing plurality of providers associated with the creation of Foundation Trusts and growing private sector involvement. Given the pursuit of 'clear red water' policies intended fundamentally to differentiate the direction of reform in Wales from that in England on the issue of choice and competition, there is no place for new representative bodies such as LINKs, and correspondingly no need for a complex governance framework involving arm's length regulation. Meta-regulation in this context has centred mainly on internal hierarchical control through the performance management framework and the work of first CHAI and then HIW. Welsh policy makers have preferred to keep inspection bodies within an integrated public service, largely on grounds of democratic accountability.²⁶¹ Welsh policy makers have preferred

²⁵⁹ The explanatory notes say: "the amendments do not change how section 242 applies to NHS trusts all or most of whose hospitals, establishments and facilities are located in Wales".

²⁶⁰ The single planned measure in the health domain relates to the area of NHS redress, and aims to simplify the process by which the public can seek compensation for torts that arise as a consequence of NHS treatments.

²⁶¹ At a time when a number of Assembly Sponsored Public Bodies (ASPBs) were brought back into WAG with the aim of increasing democratic accountability, as part of the 'bonfire of the QUANGOs', there was no appetite for creating independent inspectorates.

to keep inspection bodies within an integrated public service, largely on grounds of democratic accountability.²⁶² ‘External inspection’ in the Welsh context refers only to ‘operational independence’ within WAG, rather than a more fundamental organizational separation. The new forms of regulation and inspection referred to in *Making the Connections* relate primarily to joint reviews by the inspectorates in different domains, re-directing the focus of inspection to put more weight on the experience of citizens. The WAG is leading a process aimed at establishing a concordat between the bodies regulating, inspecting and auditing health and social care services in Wales, involving the adoption of a set of common principles that will allow similar inspection strategies, sharing of information and joint working.²⁶³ This is fully in line with the Welsh strategy to develop a more integrated public sector with better mechanisms for internal co-ordination, collaboration and working across boundaries, which may provide an alternative model to economic regulation in small country governance situations.

The one area where parallel change may well occur is in the strengthening in Wales of the duty to ‘consult and involve’ under section 11 of the 2001 Act. It would be entirely compatible with existing engagement policies if Welsh policy makers opted to introduce a duty for commissioners to consult the public and explain decisions, along the lines of the English model. However, there are several reasons why even in this relatively restricted field, the Welsh approach is likely to be different. The baseline for change is the different institutional framework created by the decision to retain CHCs and establish LHBs corresponding with Local Authorities. This established forms of public representation and local democratic accountability that had no counterpart in England. The Beecham proposals to create local service boards aimed at increasing co-ordination between local service-providing agencies may open up another path for strengthening and integrating consultation processes, for example, at the interface between health and social care or in respect of community regeneration initiatives which have multiple dimensions.

A possible example of cognitive reframing in the Welsh context refers to an approach long advocated by some students of the policy implementation process, but rarely applied to date in real world situations, is ‘forward mapping’.²⁶⁴ This rests on the proposition that policy makers need to be more active in anticipating and supporting conditions for successful roll-out of policies, including matters such as identifying the actors who will be implicated, the local capacities required, and viable ways to offer support from a distance. In practice, against the background of the major organisational upheavals associated with devolution, the WAG had little opportunity to prepare actors and build capacities in advance in this sense. Local adaptation and learning appears to have followed implementation of PPI policies, rather than occurring in some prior phase of preparation for change. A more reflexive approach to implementation and ‘forward mapping’ may be one way in which the WAG government can support bottom-up community developments without throwing them off course.

²⁶² At a time when a number of Assembly Sponsored Public Bodies (ASPBs) were brought back into WAG with the aim of increasing democratic accountability, as part of the ‘bonfire of the QUANGOs’, there was no appetite for creating independent inspectorates.

²⁶³ *Making the Connections*, pp. 25-26.

²⁶⁴ Elmore, R.F. Forward and Backward Mapping. In K. Hanf and T.A.J. Toonen (eds), *Policy Implementation in Federal and Unitary Systems*, pp. 33-70. Dordrecht: Martinus Nijhoff, 1985.

9. Conclusions and recommendations

We draw two main conclusions from the foregoing analysis.

(1) First, the question of how to increase patient and public involvement through PPI in the United Kingdom should be conceptualized as a problem of regulation within a system of multi-level governance. European and North American scholars have accorded much attention recently to the phenomenon of ‘new governance’ in policy fields such as employment, health and education, focusing on a range of law mechanisms such as the Open Method of Coordination, democratic experimentalism, and the ‘new approach to standardization’. The new governance is commonly characterized by a ‘shift in emphasis away from command-and-control in favour of “regulatory” approaches which are less rigid, less prescriptive, less committed to uniform outcomes, and less hierarchical in nature.’²⁶⁵ Furthermore:

The idea of new or experimental governance approaches places considerable emphasis on the accommodation and promotion of diversity, on the importance of provisionality and revisability – in terms of both problem definition and anticipated solutions – and on the goal of policy learning. New governance processes generally encourage or involve the participation of affected actors (stakeholders) rather than merely representative actors, and emphasise transparency (openness as a means to information-sharing and learning), as well as ongoing evaluation and review. Rather than operating through a hierarchical structure of governmental authority, the ‘centre’ (of a network, a regime, or other governance arrangement) may be charged with facilitating the emergence of the governance infrastructure, and with ensuring coordination or exchange as between constituent parts.²⁶⁶

However, while there has been much discussion of new governance relationships in terms of interactions between EU, transnational and national institutions,²⁶⁷ the national and sub-national levels have remained relatively unexplored. It is precisely this gap that the present study seeks to fill. On the one hand, PPI policy in England may be interpreted as consistent with the relatively self-conscious and top-down development of the ‘new governance’ in the EU,²⁶⁸ involving a similarly sophisticated conception of inter-linked central and local regulatory processes in specific areas of reform promoted by government authority. On the other hand, the Welsh experience may be compared with the more bottom-up approach to the ‘new governance’ adopted in the US, with ‘non-traditional problem-solving approaches being practised and tried out in different regulatory fields at the prompting of different sets of actors.’²⁶⁹

As regards regulation, it is suggested that the new institutional and organizational landscape of PPI in England may be analyzed as a regulatory space comprising a range of actors and stakeholders engaging in processes of mutual standard setting, monitoring and enforcement, exercising powers and subject to duties of various kinds, in complex and interlocking relationships of control and accountability within an economic system

²⁶⁵ G. de Burca and J. Scott, ‘New Governance, Law and Constitutionalism’, in G. de Burca and J. Scott (eds.), *Law and Governance in the EU and US* (Oxford: Hart Publishing, 2006), p.2.

²⁶⁶ Ibid, p.3.

²⁶⁷ T. Hervey, ‘Europe: Governance of Health Care’, in G. de Burca and J. Scott (eds.)

²⁶⁸ G. de Burca and J. Scott, p. 2.

²⁶⁹ G. de Burca and J. Scott, p. 2.

driven by choice and competition.²⁷⁰ By contrast, the Welsh approach to small-country governance has created a regulatory field in which a central core of bureaucratic governance of public services coexists with a periphery of bottom-up community programmes subject to a lighter regulatory touch, and with a reduced emphasis on economic incentives and competition. In the context of PPI, programmes like *Communities First* and *SHARPs* are regulated mainly via the conditions attached to funding streams and the internal governance arrangements of the participating organisations and groups. This unusual split in the regulatory field reflects the belief, which runs through both the general public sector strategy and PPI policies in the NHS, that integrated public services still have a major role to play, but that this role is only viable in the modern era if they embrace new forms of public engagement.²⁷¹

(2) Second, government policy should give more explicit recognition to the importance of social learning in the institutional structures and processes contributing to service improvement. There is no necessary connection between PPI and social learning. Social learning should be adopted as a goal of regulation, and government policy then directed at helping to establish the conditions of social learning in its different forms.

What precisely this task entails may be thought of in terms of systemic or ‘dynamic’ efficiency, connoting the successful creation of ‘incentives for permanent adaptation and innovation through processes of social learning and normative change.’²⁷² In the present context, systemic efficiency should be seen as a property not only of individual organizations but also of healthcare networks. Regulators, government bodies, health authorities, commissioners, patients and citizens, and public and independent sector providers are members of such networks by virtue of their performance of healthcare

²⁷⁰ This conception differs markedly from the narrow definition of regulation presented in the recent *Future Regulation* White Paper: ‘The control of a particular market or industry through a system of rulemaking and adjudication, often managed by an independent organisation within a framework set by Government, interpreted into clear rules by the regulator. Its purpose is to assure the public that providers of services are fit for the purpose’ (*The Future Regulation*, Annex 1, p 69).

²⁷¹ Thus *Making the Connections* sets out a pact in which, in return for WAG investment in the core public services, those services play their full part in public participation and more flexible joint working with cognate services: ‘We will provide the structures, resources and incentives to see that the goals set out in this document are achieved. In return, we will ask our partners in the public service to engage actively in delivering the changes that are necessary to deliver the high-quality, citizen-centred services that Wales needs’ (*Making the Connections*, p. 39).

²⁷² T. Dedeurwaerdere, ‘Building Resilience through Dynamic Institutional Efficiency: The Case of Forest Biodiversity’, Amsterdam Conference on Human Dimensions of Global Environmental Change, 25th May 2007. In the organizational learning literature, whereas static efficiency is widely recognized as a powerful force for increasing consumer welfare through competition within existing technologies leading to decreased production costs, dynamic efficiency refers to gains to be achieved from constantly seeking and experimenting with entirely new ways of doing business – C. Agyris and D. Schon, *Organizational Learning: A Theory of Action Perspective* (Reading: Addison Wesley, 1978). Other writers in this tradition have depicted dynamic efficiency as compatible with an ‘opportunistic’ rather than ‘passive’ model of organizational adaptation ‘characterized by search for, and exploration of, a wide variety of alternative goals, activities, and modes of operation’. Rather than simply attempt to perform current activities more efficiently, this orientation seeks ‘to discover new purposes, new technologies, and new ways of achieving goals’ – D. Miller, T. Lant, and F. Milliken, ‘The Evolution of Strategic Simplicity: Exploring Two Models of Organizational Adaptation’ (1996) 22 *Journal of Management* 863-887, 865. This model is said to be appropriate in environments of instability or turbulence, requiring organizations to experiment with new strategies to stay successful. The current healthcare environment may be considered precisely to exemplify such (deliberately induced) turbulence and instability.

functions or their consumption of, or interest in, healthcare services. Social learning may occur, or fail to occur, at a number of levels: within particular organizations (for example, regulators, purchasers and providers), in the relationships between these bodies, and in healthcare networks as a whole. Social learning in this sense is unlikely to be achieved without a paradigm shift in the way that the regulatory problem is conceived.

Assuming that the different approaches to PPI that are emerging in England and Wales may be considered to meet some of these basic conditions of soft law or new governance,²⁷³ the question for REFGOV theory is what other conditions (triggers, checking mechanisms, other regulatory devices) are necessary for the social learning potential in such networks to be realized? In Wales there has been a pragmatic emphasis on learning by doing, combining a limited degree of top-down direction with community empowerment and loose regulatory oversight of the periphery. In England, the more top-down reform agenda has resulted in the development of new structures and processes in the attempt to create a learning environment through more complex regulation, monitoring and checking mechanisms. Both sets of governance arrangements may be interpreted or 'read' in terms of social learning – as attempts to facilitate deliberation, to encourage experimentation, and to achieve capacitation of social actors.

In both England and Wales, our analysis of the (in)adequacy of current PPI initiatives focuses mainly on the deficiencies of current PPI arrangements in securing the conditions of social learning at the economic, deliberative, and experimentalist 'levels' – corresponding respectively to the neo-institutional economic, collaborative/relational, and pragmatic (democratic experimentalist) approaches outlined in the second synthesis report. At this stage we can only speculate as to the potential for social learning in the pragmatist (Schönian) and genetic senses. It is not clear in either country whether, and if so to what extent, conditions of social learning have been established involving the development of capacities for reframing and re-representation, or even terceisation. In England, the major focus of ongoing research in such terms is the role of LINKs in the context of new duties to involve, consult and report, and the associated role of the new Care Quality Commission in social regulation.

As regards Wales, it is important at this stage to understand that the Welsh approach to governance and regulation has emerged from a period of fundamental and wide-ranging constitutional changes which are still settling and throwing up many operational problems. The character of the devolution settlement, the transition from a corporate body with single legal personality to a formal division between legislature and executive, and the range of devices used to give Ministers policy making powers in areas where the Assembly does not presently have legislative competence, mean that many of the existing institutions have been erected on somewhat inelegant legal

²⁷³ 'Guidelines, benchmarks and standards that have no formal sanctions are important elements in new governance. There is also a development of informal processes to resolve grievances and disputes, including negotiation and multi-stepped procedures' – see L. Trubek, 'New Governance and Soft Law in Health Care Reform', manuscript, p 13. 'Soft law allows for learning and feedback. It allows actors to take on multiple roles, and creates alliances between traditional adversaries. Further, soft law incorporates economic incentives into the governance framework while allowing diversity and experimentation. It allows public and private domains, and different regulatory clients, to interact more easily', p 14.

foundations which will inevitably be subject to further reform. The widespread use of delegated powers to allow Ministers to take forward policy in Wales under the umbrella of Westminster legislation may lead to pressure in future to set out the duties and powers of certain bodies such as Health Inspectorate Wales more explicitly in Assembly Measures. Initially, we had anticipated that changes in the next few years will take the form of incremental consolidation of existing Welsh policies, as opposed to convergence with England. However, the recent Consultation Paper proposals may result in a round of more radical, non-incremental reform, driven by wider political considerations concerning the overall shape of the Welsh NHS, that cut across past evolutionary developments in the area of PPI policies. It is too early at present to say whether such changes will derail the distinctive Welsh policy agenda of localism and PPI within a small country governance model. However, such a vision of integrated yet responsive public services is clearly worthy of further study as a rival to the English provider market model.

It may be suggested that some of the regulatory preconditions of social learning through public and patient involvement were identified in the prescient Kennedy Report, which outlined three key stages in an effective regulatory process.²⁷⁴ (1) It is necessary to establish the views of patients, public, professionals, and other bodies in healthcare networks as to what is important in various domains. (2) The views of stakeholders should be sought as to what would promote improvement in regard to the particular matter identified as important. (3) Finally, it is necessary to decide how best to measure progress in the achievement of improvement, through the development of indicators and data on performance in relation to those indicators. Indicators and measures of improvement are necessary since the cultural changes within and between healthcare organizations that are preconditions of effective social learning can only occur gradually. ‘Any new organisation, created to carry out a range of complex tasks, will need time to learn and develop ... and will need subtle measurement.’²⁷⁵

In REFGOV terms, however, the inherent limitations of such a purely regulatory approach are evident in Kennedy’s subsequent analysis:

Once it was *known* what the regulator was seeking to measure, because it was regarded as constituting good performance, those managing organisations would *direct their efforts so as to comply with what was called for*. In doing so, they would be doing the very things which those involved in providing and receiving care regarded as designed to promote improvement in care. Thus, the regulatory system creates a virtuous circle, listening to what promotes improvement, reflecting it in what is asked of organisations, measuring compliance, and thereby entrenching improvement.²⁷⁶

This account is surely correct in stressing the need for the regulatory process to be ‘owned by those within the system ... grown from the bottom up.’ What is measured is not imposed from outside as in command and control regulation. But the analysis omits to specify *how* improvement is to occur beyond the regulatory process itself. Improvement is supposed to result from *incentives* on regulated entities to improve, yet incentives are not enough in the absence of other conditions of social learning. Learning may occur to some degree simply as a result of the communication of information (e.g.

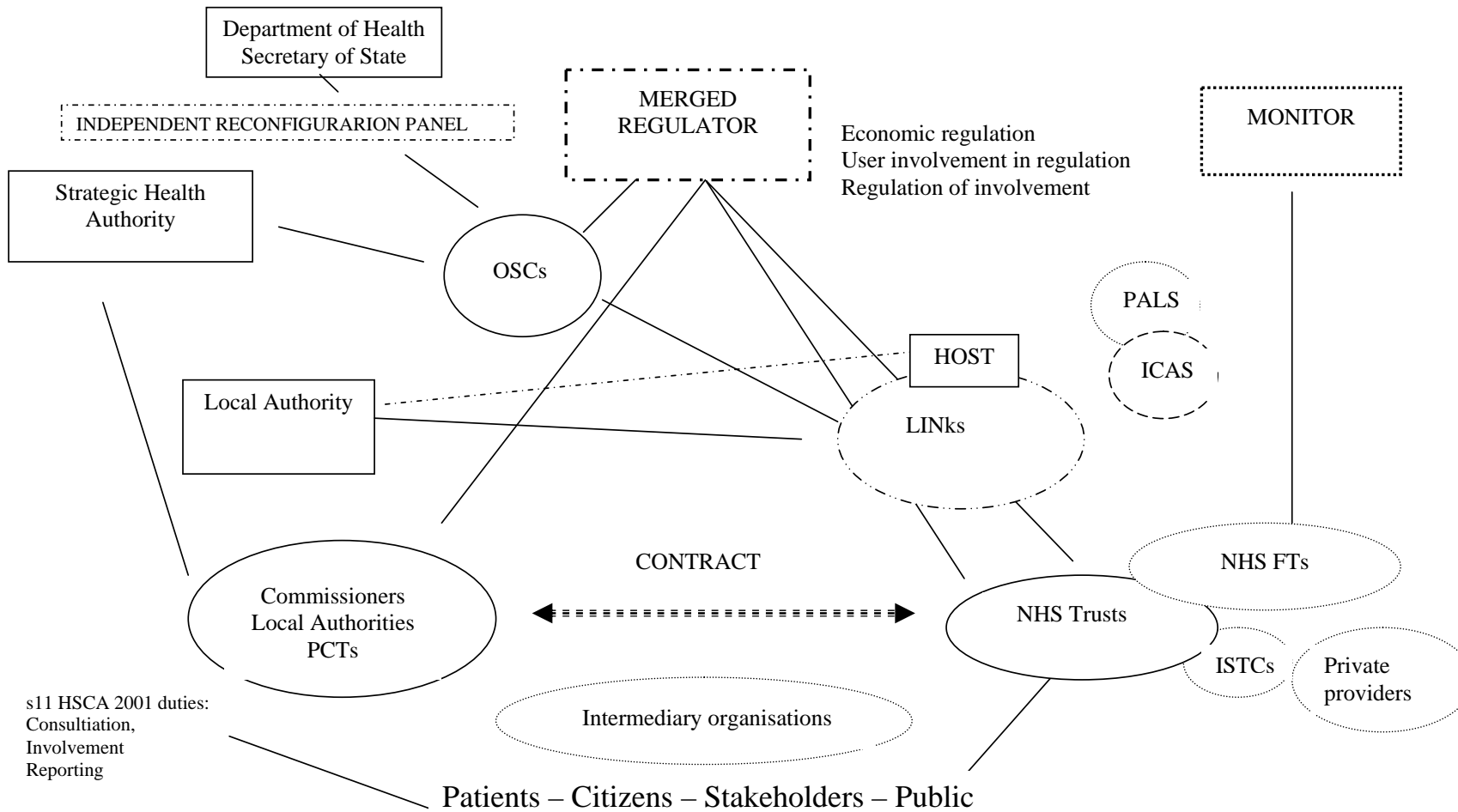
²⁷⁴ I. Kennedy, ‘Of Regulation’, in *Learning from Bristol: Are We?* (2006)

²⁷⁵ *ibid.*, 67. ‘The indicators of success may take a myriad of forms and be hard to discern ... the tools have to be designed.’

²⁷⁶ *ibid.*, p 63 (emphasis supplied).

‘listening’ to patients), but this presumes that both the problem and its solution are obvious. In reality, fully reflexive governance is likely to be dependent on deliberation and openness to alternative possibilities in the framing of problems and the suggestion of solutions, and on other conditions of capacitation as suggested by the pragmatic and genetic approaches to social learning.

Annex A, A New Framework for User and Patient Involvement (England), DH 2006.



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Abbreviations

CHAI	Commission for Healthcare Audit and Improvement (Healthcare Commission)
CHC	Community Health Council
CPPIH	Commission for Patient and Public Involvement in Health
CSCI	Commission for Social Care and Inspection
CQC	Care Quality Commission
DH	Department of Health
FT	Foundation Trust
HCHC	House of Commons Health Committee
HIW	Health Inspectorate Wales
HRG	Health Resource Group
ICAS	Independent Complaints and Advisory Service
IRP	Independent Reconfiguration Panel
ISTC	Independent Sector Treatment Centre
LHB	Local Health Board
LINK	Local Involvement Network
MHAC	Mental Health Act Commission
NHS	National Health Service
OSC	Oversight and Scrutiny Committee
PALS	Patient and Advisory Liaison Service
PCT	Primary Care Trust
PPI	Patient and Public Involvement
PPIF	Patient and Public Involvement Forum
REFGOV	Reflexive Governance in the Public Interest
SDO	Service and Delivery Organisation
SHARP	Sustainable Health Action Research Programme
WAG	Welsh Assembly Government