The Role of Patient Involvement in Practice Based Commissioning within the UK's National Health Service

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Abstract

Over the past decade there has been mounting debate about the desirability of public and patient involvement in the commissioning of health services in the UK. This issue has arisen partially due to the National Health Service management moving from a system control by health practitioners to that of a devolved managerial approach with tight central financial control and an agenda for efficiency. Yet, it is often unclear within this debate about what constitutes as public and patient involvement. The aim of this study is to investigate what is meant by public and patient involvement, and to assess the effectiveness of public involvement initiatives associated with Practice Based Commissioning. In order to achieve this, the study has utilised quantitative and qualitative methods to analyse health inequalities and public involvement within the North-east of England. In order to measure patient and public involvement qualitative interviews were conducted with patients and health professionals in the Easington area of East-Durham. The conclusion of the research was that the public had little interest in the process of commissioning, but volunteers were keen to be involved in practical projects such as fitness promotion programmes, long term care initiatives and projects to encourage healthy activities in the community. The authors construct a model of involvement ranging from 'passive' involvement where volunteers simply discuss issues at meetings to 'active' involvement where they actually help organise activities. The study suggests that active involvement schemes could promote health and reduce health inequalities.

Introduction

There has been considerable debate about to what extent the National Health Service (NHS), as the largest taxpayer funded organisation in the UK, should be accountable to local people. As a government-run organisation it is accountable to parliament, but recent reforms, including the Foundation Trust proposals, have put the emphasis on local accountability (Klein 2004, Robbins 2006). Under the Labour government (1997 to 2010) local councils have developed robust scrutiny mechanisms, while the NHS has actively developed partnerships with their patients and local health care services. This is necessitated by the growing number of people with long term conditions which require health management rather than cure. Furthermore, there has been a much greater emphasis on preventing disease by encouraging and supporting healthy lifestyle changes for individuals and within targeted communities (Hunter et al. 2010). It has been suggested that within the current health care system contemporary health issues cannot be achieved simply by treatment, but by the cooperation and help of the people concerned (Fleming and Parker 2008; Hunter et al. 2010). The Department of Health World Class Commissioning Team (2008) proposes there is also a case for the public to be able to influence what is happening rather than simply comment or criticise available NHS services. Hence, the move by NHS Primary Care Trusts (PCTs) to develop public/patient involvement in commissioning was an effort to do this. Commissioning is conducted on two levels. The PCT produces an overall plan for the health care it wishes to purchase. In some areas of health deprivation, like Easington in East-Durham, local GPs and other health professionals suggest initiatives for the PCT to commission. The new Coalition Government is seeking to develop this process (NHS 2010).

The general focus of this study is an attempt to understand how local NHS Primary Care Trusts (PCTs) include their local communities in the decision making process of practice based commissioning of health services. The study will evaluate the successfulness of patient involvement in practice based commissioning in the Easington area of East Durham within the UK. Historically, it could be suggested that the Easington area has been traditionally isolated and from a health point of view, neglected. One of the reasons was that it was on the edge of the catchment area of three hospitals, Hartlepool, Durham and Sunderland, and suffered as a result. The establishment of a separate PCT for the Easington area in 2002 led to considerable improvements. The PCT was able to lobby, together with the local authority, for more

resources, and met with some success. The Easington PCT worked with the District Council to run a large scale public involvement programme. The Easington PCT was merged into the larger County Durham PCT in 2006. This was followed by the District Council being reformed into the new unitary authority of County Durham in 2009. Many people appear to look back to the period when Easington had its own PCT and District Council as a "golden age" for public and patient involvement.

In order to understand the structural processes of public and patient involvement in Easington health services a wider understanding of NHS practice must take place. Academic analysis shows how the NHS has moved from a command system where professional judgements were left to professionals and most management decisions were made at the top, to a quasi-market based system (Exworthy and Halford 1999). Finance is tightly controlled centrally, but individual units are allowed freedom to operate, and collaborate if necessary with other bodies, so long as they produce the results. Services are "commissioned" which means a range of providers are eligible, including the private sector health services. This process is to be further developed if the proposals of the 2010 White Paper (NHS 2010) are implemented. There is also a much greater emphasis on community services to encourage healthy lifestyles, promote good health and prevent illness, as well as to manage long-term conditions. Public involvement is seen to have an important role, both as providing a public and patient "voice" in commissioning decisions, and also as a feed-back mechanism to see if services are performing properly. This study considers whether patients and the public can best be involved at a local level through the Practice Based Commissioning system. The large PCTs will engage with "stakeholders" to consider strategic issues, but direct involvement by the public at a local level is probably a more effective option for many people, where they can see results in their area. The study examines the effectiveness of public/patient involvement in Easington and aims to evaluate how successful County Durham PCT is at including communities within their decision making practices through the commissioning process.

This research paper is an evaluation of the practice of patient and public involvement through 'Practice Based Commissioning' in Easington. This study has been commissioned by the Department of Health and research has been undertaken by the University of Sunderland. The research was conducted over a 10 month period between October 2009 and June 2010. The study specifically examines how East Durham Practice Based Commissioning (PBC) Board incorporates the voice of local residents and patients in its decision-making processes. This research uses triangulation which incorporates both quantitative and qualitative research methods. This paper presents statistical findings on health inequalities within Durham, it examines the official process of incorporating local communities within health services in the locality of Easington and analyses qualitative data on perceptions of patient and public involvement within NHS services.

In order to achieve the objectives of the research, this paper has been organised into five sections. Section one is an evaluation of existing literature/policy on the rise of the NHS with a focus on Patient Public Involvement (PPI) in health care. This develops a theoretical framework drawing on models of management in order to assess the effectiveness of patient public involvement in the NHS. Section two outlines the study's methodology. Within section three the study develops a statistical analysis of regional health inequalities within the North East of England, with a specific focus on the locality of County Durham. Section four examines the process in which Easington Practice Based Commissioning Board incorporates the voices of its local communities in health related decision-making/developments through a local advisory board, and how this involvement relates to the County PCT. Section five, employs a qualitative analysis of participants who have been involved in the Monitoring and Advisory Board, The Practice Based Commissioning Board and GP Forums.

A Brief History of the NHS

When the NHS was established in 1948 it incorporated a variety of institutions, all with their own forms of governance and connections with the public. Some hospitals were run by local authorities, others by charities and bodies such as Trades Unions. There were also the remnants of the Poor Law which persisted up until 1948 (Timmins 1995; 2001; Webster 2002). What we now understand as the primary care aspects of the NHS, i.e. maternity and child welfare, district nursing, health centres and community health continued to be organised by Local Authorities until the reforms of 1974. (It may now be returned to them). Thus a whole range of connections with the public, either through local boards, elected councils or even voluntary groups involved in fund raising was eliminated when the centrally controlled NHS was established. Aneurin Bevan even boasted that 'the sound of a dropped bedpan in Tredegar would

reverberate around the Palace of Westminster' (Glasby et al, 2007).

The priority at the time was dealing with epidemics and putting right the ravages of the war. Thus the NHS focused on hospitals which were run by regional boards and management committees with some local government involvement. Although Local Authorities complained about their loss of influence, much medical opinion thought that not including primary care and community services in the new organisation was a retrograde step (Timmins 1995; Webster 2002). Sir George Godber, future Chief Medical Officer of Health, commented that these services would lose out. There was not much enthusiasm at the time for public involvement (Timmins 1995; Webster 2002). The main focus of attention was hospitals rather than health in the wider sense, which is still argued today (Hunter et al. 2010). The priorities at the time were treating people who were ill and dealing with the still prevalent infectious diseases (Webster 2002).

The next significant reforms, those of the Conservative Government in 1974, placed all health services under the control of Health Authorities, although welfare and social services remained with local authorities (Timmins 1995). A third of these new authorities consisted of councillors, so as to maintain the link with local government. At the same time local government itself was being reorganised following the recommendations of the Redcliffe Maud Commission (Elcock 1994). A major change in 1974 was the establishment of Community Health Councils (CHCs). These were intended to represent the public interest and included councillors (Timmins 1995). They were funded by the Department of Health and were accessible to the public, often with offices in town centres and a permanent member of staff to organise them and ensure decisions were implemented. The CHCs were able to investigate complaints and refer them to the hospitals' complaints procedures. They were also able to investigate issues and challenge the hospital authorities (Levitt 1980).

The performance of the CHCs varied, but they continued until the 2001 Health and Social Care Act and the establishment of the Commission for Patient and Public Involvement in Health (CPPIH) in January 2003. The 2001 changes were made against the background of major changes in the NHS. Following the NHS and Community Care Act of 1990 an internal market was introduced into the NHS (Henderson 2001; Martin et al. 2010). Area Health Authorities (these later became Primary Care Trusts) and GPs looked after community services and commissioned services from trusts which provided the acute services, with the overall supervision of a Strategic Health Authority.

Acute Trusts have been encouraged to act independently, and since 2004 have been able to become Foundation Trusts which although Government funded are on a per-patient basis and are independent of the NHS. The new status has mainly applied to hospital trusts, although some Primary Care Trusts (such as Hull) are currently considering this route (NHS 2010).

Involvement in various forms had been developing since 1974. Many hospitals established patients' councils to advise them on their concerns. These groups would often also contain ex-patients and members of the public who had an association with the hospital (HSCA 2001; Kennedy 2001). There were also groups of hospital volunteers and friends who raised funds for improvements. Yet, failure of the system was highlighted by the Kennedy Report (2001) into events at Bristol Royal Infirmary after the deaths of children receiving cardiac surgical services at the hospital between 1984 and 1995. Its conclusions about public involvement and the attitudes of some professionals to the public were very forceful:

The result, however, has not been a sense of growing empowerment, such that the public, as patients or as taxpayers, after all these years of supposed involvement, feel truly in partnership with the professionals who run and provide our healthcare service. Indeed, the evidence from Bristol is the opposite: a sense, among many parents, of disempowerment, of inability to get the healthcare service to address their needs, and of bewilderment about where or to whom they could turn for help (Kennedy 2001).

In evidence to the enquiry, the NHS Primary Care Group Alliance wrote:

Being sincere about involving patients and the public in making decisions about their own care or about local health services involves a shift of power. Until individuals working in the NHS are ready for that, any user or public involvement in decision making will be a token event (BRI Inquiry 2001)

Hence, it is this enquiry which has led to a renewed focus on patient led services within the health care system. As referred to by the Kennedy Report and the NHS Primary Care Group Alliance, if the NHS is committed to patient and public led services this will mean a 'shift of power' which will completely transform how the service has traditionally operated and how it has been managed. It is this issue of public/patient involvement which is to be a major challenge to the re-organisation of future NHS services.

Framework for Assessing

The report was undoubtedly a major force in the

pressure to overhaul the whole system of patient and public involvement. The 2001 reforms identified different strands of Patient and Public Involvement (PPI). It is worth considering them in some detail as they could provide a framework for assessing the effectiveness or otherwise of PPI. The different aspects were as follows:

1. Scrutiny by Local Authorities. Structural changes had to be referred to Local Authorities Overview and Scrutiny Committees (OSCs) who were obliged to ensure that proper consultations were carried out. They had the power to refer a reorganisation to the Secretary of State if they were not happy with it. This happened on Teesside in 2005 (OSC 2010)

2. Advocacy for Patients An Independent Complaints and Advocacy Service (ICAS) was established to give independent support to patients wishing to make a complaint to the NHS. They worked with the Trusts' own PALS officers (Patient Advice and Liaison Service). The function of PALS was to try and resolve problems without going through the sometimes complex complaints procedure (DoH 2008).

3. The Commission for Patient and Public Involvement in Health (CPPIH) This was an independent body funded by the Department of Health. Forums were established to 'shadow' each trust. Membership was by application, and the Commission attempted to gain a wide range of people, hopefully with wider community contacts. The Forums were not necessarily representative of the whole population but their remit was to establish contacts with all groups in the community, particularly 'hard to reach' groups. About half the Commission's budget went to supporting a central organisation with regional offices which provided back up and support so as to enable the forums to operate more effectively (DoH 2002).

The Commission assumed the role of a pressure group, and appointed a Parliamentary and Public Affairs Officer to help the forums lobby the government on health issues. There was also a press department. This was an interesting role for a body funded by the Department of Health. The Commission used its network of volunteers to produce reports, some of which attracted national attention (such as one on NHS dentistry in 2007). A later development was the establishment of Foundation Trusts in 2004 (Robbins 2006). These enable individuals to become members and elect Governors who will eventually elect the board. The governors scrutinise the Trust's activities (Robbins 2006). The new Trusts have been organising their members in various PPI-type activities.

So a complex structure of PPI has been created, with each part playing a different role. Each part has a different emphasis, but it may appear confusing to the public. In 2006 the NHS Act was passed, which strengthened the provisions for involvement. This strengthened Section 11 of the Health and Social Care Act 2001 which had established the OSCs and CPPIH. Section 11 became Section 242 of the new act, which was amended in 2007 when LINks was established. The Act states as follows:

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. (HSCA 2008: 242[1B])

Thus NHS organisations commissioning services must make arrangements to involve users. Guidance indicates that carers are included under 'patients or their representatives' (HSCA 2008).

The main change from the 2001 Act is that the users of services must now be consulted on major changes and restructurings as well as OSCs. This is now a legal requirement and users must be consulted about a change in services whether the OSC is involved or not. (See Real Involvement, Guidance for NHS organisations on the 2006 Act, published 2008) In 2008 the NHS Constitution was published. This sets out the provisions of the 2006 Act. This guarantees public involvement in the NHS as follows:

You have the right to be involved in discussions and decisions about your healthcare, and to be given information to enable you to do this ... You have the right to be involved, directly or through representatives, in the planning of the healthcare services, the development and consideration of proposals for changes in the way those services are provided, and the decisions to be made affecting the operation of those services (DoH 2008b: Section 2a).

There have been two further developments in the last two years. They are the establishment of LINks and the growth of Practice Based Commissioning. LINks (which replaced CPPIH) is a network of interested people and groups who scrutinise NHS activity in an area, and report to the OSC. Selected LINks members can visit and inspect NHS facilities. Practice Based Commissioning is where a group of GPs and other health professionals can put proposals for new community-based services to the local PCT, If the PCT approves it will fund the ventures (DoH 2008b). Both developments are explained more fully below. The Health of Commons Health Scrutiny Committee

felt that there had been unnecessary disruption with the establishment of first the CPPIH and then LINks, and that simply improving the old CHCs could have served the same purpose. It is interesting that many people involved with PPI still talk with fondness of the old CHC system, which continues to exist in Wales and Scotland (Board of Community Health Councils, Wales 2010; Community Health Partnerships, Scottish Executive, 2004).

Overview and Scrutiny Committees have gathered experience and developed their role. In most authorities they now consider Social Care as well. Initially they tended to be 'reactive', commenting on plans put forward by the NHS, but now they are involved in making suggestions, initiating new proposals and becoming involved in the forward planning of health provision (DoH 2009). OSCs at first did not have officers with experience of health issues, but they have now developed expertise and done some very useful work. The final piece in the jigsaw, so to speak, is the increasing importance of commissioning in the NHS. This is defined as follows:

Commissioning in the NHS is the process of ensuring that the health and care services provided effectively meet the needs of the population... It is a complex process with responsibilities ranging from assessing population needs, prioritising health outcomes, procuring products and services, and managing service providers (DoH 2009).

When the NHS market was established, the emphasis was on the PCTs and the GPs negotiating with the Acute Trusts to purchase hospital care. The process has now moved on to incorporate primary care, which is growing in importance (NHS 2010). Not all primary care is necessarily delivered by the NHS. There has been a process of merging acute trusts so as to provide more effectively complex specialist care, while at the same time moving as much care as possible out of large acute hospitals into community facilities (NHS 2010). The official guidance states:

Practice based commissioning will lead to high quality services for patients in local and convenient settings. GPs, nurses and other primary care professionals are in the prime position to translate patient needs into redesigned services that best deliver what local people want (DoH 2009).

In other words it represents what is needed/wanted at a grass roots level. Detailed guidance to GPs published in 2006 states proposals will only be considered if a business case is established. The criteria for assessing business cases will include:

whether the specific needs of population groups such as disabled people (including those with learning difficulties or mental health needs), people from Black Minority Ethnic communities (BME), the differing needs of men and women and of the diverse age groups, different faiths and sexual orientation of individuals and groups accessing services have been taken into account; patient and stakeholder support. (DoH 2006)

Thus there is an incentive, if Practice Based Commissioning (PBC) is to work, for the G.P.s to have evidence that they have consulted the public, particularly 'hard to reach groups' (DoH 2006). A document published by the Department of Health in June 2009 identifies good practice, including an example of how COPD services were redesigned locally in Easington. These are all examples of where G.P.s have organised projects in the community and drawn down, or 'unbundled' funds from the PCT to do so (DoH 2006). Examples given include:

1. The COPD project in Easington which helps patients to "self manage" the condition and thus avoid unnecessary trips to hospital.
2. A community palliative care service which allows patients to stay in their own homes rather than be admitted to hospital in Bournemouth and Poole.
3. A community glaucoma service in Liverpool.

The objective appears to be to enable patients to access treatment and support where possible in the community. This is particularly attractive in areas which are not near acute hospitals. As noted above more sophisticated methods and higher standards seems inevitably to lead to fewer specialist acute hospitals, and the converse of this is that hopefully people visit them less frequently but access more services locally (Robbins 2006). This is sometimes a difficult concept to explain to patients who have been used to visiting a local hospital. There is now an incentive for GPs to involve the public, particularly "hard to reach" groups if they wish to engage in PBC. Where GPs have joined together to draw down funding for joint facilities or schemes, they have established 'Practice Based Commissioning Boards' (PBCs). These may then set up a mechanism to obtain the views of the public. In County Durham there are arrangements in the West of the County and in Easington. Here there is 'Shadow PCB Board' now called the MAB, 'Monitoring and Advisory Board' which advises the PBC on the views of patients and the public (Durham PCT 2008).

The Department of Health and Strategic NHS Policy Development

One of the major documents which set out current NHS thinking is 'Our Health, Our Care, Our Say' published in January 2006. This set out a new direction for health and social care within the UK (DoH 2006; p7). Its stated objectives were; 'better

prevention services with earlier intervention, giving people more choice and a louder voice, doing more to tackling inequalities and improving access to community services, and more support for people with long-term needs' (DoH 2006). These are to be achieved by; 'Practice Based Commissioning which will provide more local services and will provide better value for money, shifting resources into prevention, more care undertaken outside hospitals and in the home, better joining up of services at the local level, encouraging innovation (in primary care we will assist this process by introducing new "local triggers" on public satisfaction and service quality), and allowing different providers to compete for services (DoH 2006).

There is a substantial section on local involvement, 'Ensuring our reforms put people in control'. E.g. At the same time as giving people greater choice and control over the services they use, there is also a need to ensure that everyone in society has a voice that is heard. When people get involved and use their voice they can shape improvements in provision and contribute to greater fairness in service use. (DoH 2006: para 7.4)

There is progress that we can build on. Some organisations in the NHS, local government and the voluntary, community and private sectors have engaged users and citizens in a systematic and robust way. However, these are not the norm. We want to see all parts of health and social care open and responsive to what people feel and prefer (DoH 2006: para 7.7)... Commissioning is the process whereby public resources are used effectively to meet the needs of local people. The voices of local people will be vitally important in improving this process. Public involvement is part of our wider strategy to facilitate high-quality commissioning and, in particular, to make joint commissioning a reality (DoH 2006)

Practice Based Commissioning receives much attention in this document. It is interesting to note how public involvement is seen as a measure of performance management. The NHS published 'Real Involvement', (2008), which is a guide to how NHS organisations should implement section 242 of the 2006 Act. This sets out the NHS policy on involvement. The Principles of Local Accountability and Involvement are set out in Part 1, Section 2. NHS involvement practices should be: 1. Clear, 2. accessible and transparent; 3. Open; 4. Inclusive; 5. Responsive; 6. Sustainable; 7. Proactive; 8. Focused on improvement (DoH 2008).

The last three, 5, 6 and 7, are perhaps the two that merit further investigation. One would expect all public bodies to observe the first four. (Whether they actually do is another debate!) The NHS, however, is aiming to establish long term relationships with the community which will build trust, and not simply consult people when a proposal has been made. Instead it wishes to engage in a dialogue with people, seeking to explain why changes are necessary rather than simply announcing they will happen. The NHS appears aware it has previous. Past practice has often presented the public with what appears to be a fait accompli, a proposal with no other alternative on a 'take it or leave it' basis (DoH 2008). This has bred distrust of the whole process amongst the public, and the NHS appears to recognise this. In fact the introduction to the publication is remarkably candid:

While nationally there are many examples of innovative practice, there is still little evidence that involvement is a mainstream activity alongside other policy and performance requirements. ... There is scant evidence to show that involvement activity is stitched into all the strands of NHS organisations' work, including their decision-making processes; of how organisations have listened and responded to what users have told them; or of how health services have been shaped according to the needs and preferences of users. .... We also know that the NHS is not always sure about when it needs to involve users and clear about whether involving users is the same or different to consulting them. ...World class commissioning ... reflects the shift of involvement to the forefront of the policy agenda and establish it as one of the key developmental challenges for NHS organisations (DoH 2008: 10).

Public Involvement is mentioned as being particularly important as part of commissioning. The main reason for involvement, from the NHS's perspective, is set out as point 7, 'Focus on Improvement'. This is not always clear as far as the public is concerned. The loss of an old and much loved institution does not always appear as an improvement. Lord Darzi commented in his interim report in 2007 that:

We need to reassure patients and the public that change is necessary and that it will improve the care they receive. ... We should be clear from the outset that no major service change should happen except on the basis of need and sound clinical evidence.... and that consultation should proceed only where there is effective and early engagement with the public, clear evidence of improved outcomes for patients, and resources available to enable new facilities to open alongside old ones closing (Darzi 2008).

The consultations which generate the most noise and are often the most contentious are those to reconfigure services. The public do not always understand clinical issues. They are usually far more

concerned about access and the loss of status for a particular town if it no longer has a hospital. Consultation needs explanation and dialogue (Darzi 2008). Nevertheless it is still essentially a reactive process, as distinct from the planning of future provision. In Part 1, Section 4 of 'Real Involvement' the report sets out the principles of involvement in commissioning. As described earlier, commissioning is about planning future NHS activity, and also evaluating what is most effective. Thus the Report acknowledges:

User involvement in the commissioning process is not well established and presently it is more likely to occur in designing services than in assessing needs or evaluating services. For example, one or two user representatives may attend a commissioning meeting, but there are many other decisions that precede or follow this stage. Much more thought needs to be given as to how best to involve users throughout the commissioning cycle. (DoH 2008: Section 4, p.96)

This is perhaps the part of Public and Patient Involvement which is least well developed. It is means planning what the NHS should do in the future, rather than reacting to what it is doing now. Unfortunately the aspect of the NHS which is most prominent in people's minds is hospitals, and the most prestigious people consultants. The comments of Lord Godber in 1948 have proved true (BMJ 1979). Involvement means whether hospitals stay open, and the campaigns which attract the most interest are those about hospitals.

Complex System of Public and Patient Involvement

At the end of the first decade of the new century, and almost ten years after the passing of the 2001 Act, a complex system of public and patient involvement is now in place. This study does not seek to compare the different avenues to participation. They have different emphases and purposes, and arrangements are different in various parts of the country. As indicated, new developments in Practice Based Commissioning require local involvement. It is unclear as yet how effective this is. The current structure of PPI as outlined in this section can therefore be put into four broad categories:

Scrutiny: The work of the OSCs and LINks, which feeds into the OSCs. These bodies consider and if necessary criticise the activities of the NHS. By law the NHS must respond.

2. Partnership: Carers, patients and other interested parties work with the NHS to improve services. There are often groups to consider particular illnesses or conditions. Within this category can be placed individuals who are now taking a greater role to manage their own treatment or care, particularly those with long term conditions.

3. Forward Planning: The Commissioning role. PBC Boards, PCTs and to a lesser extent OSCs consider the future options. This is a role primarily for the PCTs, with local involvement such as practice based commissioning, since the Acute Trusts have to respond to what is commissioned. This role is developing.

4. Customer Feedback: With the increasing complexity and variety of NHS provision, those who commission care want to know whether that care is working and what improvements can be made. Public and Patient Involvement has a role here.

The situation of the Foundation Trusts, which have developed separately from other PPI activities, is less easy to define, particularly since they are still developing. Possibly they would be most easily placed in the second category, Partnership from a PPI point of view, although one of the aims of Foundation Trusts was to enable them to improve their financial management, particularly their assets, by becoming independent of the NHS framework (DoH 2005). PCTs, Overview and Scrutiny Committees and PBC Boards all have a part to play in the commissioning process. PCTs organise meetings and groups to try and ascertain what the priorities of the public for commissioning are (Health and Social Care Act 2001). The OSCs will consider commissioning proposals, although they do seem to spend most of their time reacting to developments within the NHS. The PBCs, and the networks they establish in the community, seem to be an attempt to engage in a dialogue with grass roots opinion (DoH 2003). Whether this will result in an effective mechanism for influencing service provision has yet to be established, and is the main subject of this research. It is probably fair to say, however, that the reduction of PCTs by over a half will have made their PPI procedures more remote and less accessible in some cases. It is certainly true that the number of avenues open to an individual wishing to 'get involved' is complex, and possibly confusing. It is understandable that PPI arrangements will evolve as the NHS develops and changes, but the frequent changes of recent years appear to be an admission that the process is not yet deemed to be right.

A Brief History of the Easington Area in East Durham

The Municipal Corporations Act of 1835 established elected councils in towns. Local administration in the counties was conducted by JPs and Quarter Sessions. Later sanitary districts were established, and in 1888 elected County Councils, with 59 County Boroughs in England and two in Wales (Hobhouse and Wright 2008; Parker 2009). The jigsaw was completed by the act of 1894 which created elected urban district, rural district and of parish councils.(The latter had existed

for a long time and their position was now regularised). In the East of County Durham there was the Seaham Urban District Council and the Easington Rural District Council, extending from Seaham in the north to the borders of Harlepool in the south, and to the Trimdons and Wheatley Hill in the West (Bulmer 1978; Brown 1990; Smith 2010). It contained many large industrial villages, such as Murton, Easington Colliery, Shotton, Blackhall, Thornley, Wheatley Hill and Horden, but no major town. (The construction of Peterlee did not begin until 1949). Although there was a coastal railway line linking Sunderland, Hartlepool and London, and the main A19 road (known locally as 'The Turnpike'), East-West communications were not good. There are still no direct communications between many villages. Colliery villages were traditionally self-contained with most people working locally and often bitter rivals. The main need for communications was to get coal out, so many railway lines concentrated on mineral traffic (Brown 1990; Smith 2010).

Durham County Council treated Easington as an 'excepted district' for education, and the area remained very self-contained and isolated. In 1974 the reorganisation of local government following the Redcliffe-Maud Commission merged Seaham and Easington into the new District of Easington (Brown 1990; Smith 2010). The new town of Peterlee, which was now nearing completion, had a population of over 20,000(although many moved in from other parts of the District). It was run by a Development Corporation which was wound up in 1979 and its assets, mainly housing, transferred to the new council (Philipson and Stevenson 1988). Thus by 1980 the District of Easington had a population of over 90,000 and two major towns, Seaham and Peterlee. Quite a difference from the old Rural District, but it still remained very isolated (Philipson and Stevenson 1988).

The badge of the District of Easington Council included a miners' lamp, a wheat sheaf and a ship to symbolise the three main characteristics of the area, mining, agriculture and seafaring (Seaham is the only port in County Durham). In 1980 mining was still the dominant industry, employing over 10,000 men. 1,400 people were still employed in the industry in 1993 when the last pit, Easington Colliery, closed (DETR 1998; Smith 2010). The new industries which had been brought into Peterlee also faced difficulties, with textiles severely hit by foreign competition. Although, engineering continued to survive, attempts to bring in new 'hi-tech' industries largely resulted in call centres in Peterlee and Seaham. A new out-of-town retail centre, Dalton Park, has been built at Murton, and the infrastructure at Seaham substantially improved with relocation of the docks, a new shopping centre, and a new access road, the A183. Peterlee has also acquired a new college, and the secondary schools are being rebuilt, although plans to redevelop the town centre seem slow in reaching fruition (DETR 1998; Smith 2010).

Much of this new development is the result of Government aid, in Seaham as a result of EU funding (Jones and Evans 2008; Smith 2010). The public housing stock, which numbers almost 9000, was in a bad state, partly the legacy of much council building before the war, with almost 90% non-decent. Following strenuous efforts to improve its performance, the company which manages the housing, East Durham Homes, has now achieved government funding to put this right, which is a major boost to the district (CLG Committee 2010). The decline of the coal industry was a severe blow to the District. A raft of statistics in the 1980's and 1990's indicated problems in all areas. Peter Townsend's report on health and deprivation in 1987 (Townsend, et al. 1987) cited Wheatley Hill as the unhealthiest ward in England. Poor statistics of educational achievement led to the establishment of a Tertiary College in the District in 1984 (Townsend, et al. 1987; Phillimore and Beattie 1994). The coalfields taskforce report, Making the Difference (1998) showed that in all the ex-coalfield areas surveyed, GCSE passes grade A to C were lower than the national average, with Durham in the lower half of the league table. 'Real' unemployment, which includes sickness benefit and early retirement, was rated at 25% in Durham, the highest of the eleven ex-coalfield local education authorities surveyed (DETR 1998).

Deaths from circulatory disease, cancer and respiratory disease are higher than the national average, as are rates for smoking, obesity and teenage pregnancies. Easington also vied with Hull for the title of 'obesity capital' of the country. Premature death rates and the high numbers of people with limiting long-term illnesses completed a gloomy picture (Gordon and Walker 2010). The publication in 1999 of the statistics for the 'Index of Multiple Deprivation' by the Social Disadvantage Research Group of Oxford University showed Easington as the forth 'worst' area of deprivation in the country. (Hackney in London was number one). These statistics were used by the Government to determine allocation of grant aid, such as the Neighbourhood Renewal Fund. These figures were used by the council, and the Coalfields Communities Campaign, a lobby group organised by local authorities, to lobby for additional resources. They had some success, as did the PCT (ODPM 1999).

Durham Regional Health Indicators

In recent years, rates of educational achievement have improved, and the latest figures (2004) show that the Easington area is no longer the worst in the County. Housing developers now want to build in the area, and recently want to build new supermarkets (ODPM 2004). These are all optimistic signs. Despite these recent improvements, health indicators for the area are still poor. The final report of the Easington PCT in 2006 (Easington PCT 2006) alluded to the fact that indicators for respiratory, heart and mental health disorders were much higher in Easington than the national average, as were rates of obesity and smoking. 11,000 people were registered as permanently sick or disabled, and cancer death rates were also higher than the national average (ODPM 2004). The Easington PCT had been established in 2002 and focussed attention on the health issues in the area. It worked closely with the District of Easington Council. PCTs were reorganised into larger units in 2006, and the Easington PCT was incorporated into the new County Durham PCT (CLG 2009). Following this the District of Easington was incorporated into the new unitary authority of Durham in 2009. Both developments were very unpopular locally (CLG 2007). A further side effect of the reorganisations is that it is now much more difficult to obtain statistics relating specifically to East Durham. Before the introduction of Primary Care Trusts in 2002, Easington had suffered from a lack of focus from the NHS which had previously centred on hospitals. Easington was on the periphery of three hospital areas, Hartlepool, Sunderland and Durham, and was perceived to miss out on resources as a result (Roberts 2009). When the new PCTs were established one was established for Easington, which was roughly coterminous with the District of Easington Council area. Well-known local people were appointed to the Board. Two were District Councillors, one an ex-miner, one a previous mayor of Peterlee and a local schoolteacher. As a result relationships with the local authorities and the public were good (Eastington PCT 2006). An energetic PPI organiser was appointed with support staff, and she instituted a large scale programme involving people in discussing local issues and supporting carers. Area Health Forums were established, along with Groups to focus on long-term conditions and support carers (Eastington PCT 2006). The final report of the PCT published in 2006 noted that organised consultation events had been organised for

The Darzi Review, The Big Project, Urology Review, (shifting provision from Durham to Sunderland), The Urgent Care Centre (A pioneering venture in Peterlee, later replicated throughout the County), The Falls Service, The Estates Strategy, Mental Health, Heart Disease and Cancer, Children Centre And the Reconfiguration of the NHS. (Easington PCT 2006) Because of its local connections and strong public support the new PCT was able to lobby vigorously for extra resources for the area since it was underfunded compared to more prosperous parts of the country. On the health indicators identified, funding was estimated to be at 80% of what was required. A campaign supported by the local M.P. and politicians achieved its goal and the additional funding was promised (Easington PCT 2006). However, it should be noted that shortly afterwards the local PCT was abolished and incorporated into County Durham. The fact that these additional resources intended for East Durham were now part of a larger organisation is now a source of local resentment (Easington PCT 2006).

Understanding the NHS within a Post-Fordist Context

As discussed, there has been a considerable movement within contemporary policy which illustrates the importance of grassroots partnership work between NHS services, local communities and service users (DoH 2006). This is illustrated by the success and failures of public patient involvement within the Easington and County Durham PCTs. Hence, effective management approaches to public health need to be explored in relation to integrated services at both a local and regional level. Sociological management theory was originally defined within the work of Max Weber. Weber defined organisation structure through the notion of hierarchy, where promotion was on merit, and each position had clearly defined duties as a ‘bureaucracy’ (Weber 1947; Du Gay 2000; Miner 2007). Writing in early 20th century Germany, Weber based his ideas on the efficient organisations created by Bismarck which followed military lines. This is later defined as ‘Fordism’, a model of management deriving from the ‘scientific management’ of Frederick Taylor. ‘Fordism’ refers to a large mass-production organisation employing a strict ‘division of labour’. This produced a large number of major manufactures (an example being the USA and UK car industry) which in turn developed a model of management that underpinned the concept of early 20th Century capitalism (Handy 1999; Wood and Wood 2002). Yet, as Hoggett (1991) suggests contemporary organisations have evolved into far more complex structures due to globalisation and should be conceptualised through the notion of ‘post-fordism’. This is due to their complex nature where rigid bureaucracy along Weberian lines is no longer viable, and has to be replaced with a decentralised system with an emphasis on outcomes rather than rules. The NHS was traditionally seen as a hierarchical

organisation in the Weberian and Fordist mould.

The welfare state also assumed the form of a bureaucratic pyramid...The bureaucratic rules served the bureaucracy first and foremost; elderly, students, the unemployed, and the sick were obliged to behave like officeholders in the Weberian sense rather than as individuals with distinctive life histories. The system focussed ever more on institutional self-maintenance and stability rather than on the effective delivery of care. (Sennett 2007).

Many in the NHS might think Sennett's critique unfair, but in order to confront these criticisms there have been moves recently to make the service more flexible and responsive to patients (NHS Choice 2010). More patient involvement is a consequence of this. Nevertheless, control, particularly over funding, is still in the hands of centre management. This approach has been largely criticised within the sociological literature. Sennett (1998; 2007) argue that although the old hierarchical bureaucracy which became the model for large corporations was an 'iron cage', nevertheless workers were able to make sense of it and their place within an organisation (Sennett 2007) . Sennett identified a sense of "self worth" in public sector workers, who although badly paid felt they were serving the public good. 'The National Health Service ....gave them a positive, institutional place in British society' (Sennett 2007). In the more disorganised post-fordist society, however, these certainties are no more. Sennett (2007) and Drucker (1992; 2008) argue that although the Fordist model has changed into a more devolved one (post-fordism), there is nevertheless strong central control, particularly of finance. Sennett argues that the new 'liquid modernity' (Sennett 2007) does not necessarily bring more freedom as its apologists maintain.

Nevertheless, it should be noted that the NHS is envied by many other countries which have private insurance systems either fully or in part. The NHS is much more able to keep costs under control than these systems are where the insurance companies and practitioners can charge higher prices (Bolton 2004). The United States is perhaps the best example, but Germany, which has a system of state-sponsored health insurance, has now had to reduce the availability of some treatments. Recent work on the NHS has looked at the change from a professionally run NHS, where major decisions were left to the professionals, to a more market –orientated managerial system, where issues of financial accountability and measurement of effectiveness become more salient (Henderson 2001; Klein 2006; Martin et al. 2010).

Particularly significant changes have included the imposition of new arrangements for financial accountability and the measurement of 'effectiveness'; the 'marketisation' of structural arrangements between those who provide welfare services and those who pay for them; the 'marketization' of relations within service organisations; and attempts to change established relations between service providers and consumers (Exworthy and Halford 1999).

From the point of view of public and patient involvement, the changing relationship between patients and service providers is of interest. Commentators have given different explanations for the change. One is ideological – that during the 1980's Thatcherite ideology deliberately sought to weaken the power of NHS professionals in order to favour private interests and reduce public spending on the NHS (Exworthy and Halford 1999; Klein 2006). In fact the Act which introduced the 'purchaser-provider' split was not introduced until 1991, in her twelfth year in government.

Several commentators have commented that in fact NHS spending actually rose during this period (Hills 1998). Private contractors did not play a major role in clinical services, and privatisation was mainly confined to catering, cleaning and laundry services (Exworthy and Halford 1999; Klein 2006). It was not until the New Labour era post 1997 that private contractors were able to provide some clinical services such as MRI scanning, and serious attempts are now being made to introduce the 'purchaser provider split' to services such as community health, which is noted in 'Your Care, Your Say' (DoH 2006). This meant that a Primary Care Trust would commission services from a separately managed and still publicly owned organisation managing areas such as nursing (DoH 2006). There would then be scope to transfer these services to a privately managed body if the public one did not perform (Darzi 2005). Such a model has already been applied to housing – where most repairs and maintenance services are now 'contracted out'. It seems clear that the ideology of the Third Sector is rooted within the notion of efficiency underpinned by post-fordist models of management developed in the private sector. Furthermore, 'Our Health, Our Care, Our Say' specifically refers to the expansion of 'Third Sector' organisations in health and social care services (DoH 2006).

Models of Management

In order to simplify the complexities of management theory Charles Handy has developed a model based approach to the structural aspects of contemporary organisations. Handy (1999; 2009) identifies different cultures of organisations in his work. He draws on the work of Roger Harrison (1972) to identify four

ideologies, or cultures. Handy feels that the word 'culture' conveys more of a feeling of a pervasive way of life or set of norms, rather than just a set of ideas. The four are:

1. The Power Culture: Everything goes back to a central power source. The organisation can be described as a 'spider's web'. Good examples are some Trade Unions, where the General Secretary is the focus of power, and media organisations such as the Murdoch Empire. The fact that in such organisations things only change when the boss says so is indicative of how they work.
2. The Role Culture: This is based on the classic idea of a 'bureaucracy' as described by Max Weber. It works on the basis of logic and reality, with set procedures and roles. Such an organisation will be inflexible, but specialisation and technical expertise are necessary. It has to have a simple and clear goal. Examples of such organisations are the civil service, and, in the past, large car and oil companies. The NHS used to fit this pattern, but has made attempts to move away from this approach.
3. The Person culture: The structure or organisation exists to serve and assist the individuals within it. This would be an organisation composed of professionals such as barristers. It fits the old model of an NHS hospital where the registrar was subordinate to the consultants. Handy comments 'It is the culture most in tune with current ideologies of change and adaptation, individual freedom and low status differentials....but ...it is not always the appropriate culture'.
4. The Task Culture: Such an organisation is flexible, and able to re-structure itself to meet new changes and challenges. It is often called a 'matrix' and can be described as a net. IT and advertising can be described in this way. These organisations are innovative and able to deal with a rapidly changing situation. It is this model which is being used to define the concept of integrated health practice, which is at the centre of contemporary NHS services (Handy 1999; 2009).

This Task Model can be applied to the managerial approach emerging in the NHS, and other publicly owned organisations (Hudson 2004). Rather than a top-down management approach to the NHS (see Handy's Role Model), services become fragmented but also integrated. This would mean that services can adapt on a local level in order to deal with the complexities of modern health care. Furthermore, integrated networks would be made up of public and private sectors. The idea of devolving objectives to social enterprises is attractive, so long as they have the resources and expertise to achieve them. They have to be properly accountable too. A third sector organisation could become just as inefficient or nepotistic as the public or private sectors, and value for money in the public sector is something most would agree about.

In a free market, however, such small organisations would be vulnerable to being absorbed into much larger ones, which might not necessarily have community roots or control. If all provision fell into the hands of one private provider, the NHS or any other organisation would find it difficult to bargain with them. There is some evidence that small local based housing associations, for example, have merged into much larger organisations with little contact with local authorities or communities (NAHA 2004). Some local authorities have also had problems where all care homes are managed by one provider. If community contact and accountability are valued this is a worrying development (Hudson 2007). Should provision of a service such as health care or social housing be seen differently than retailing groceries for example, which is now mainly in the hands of a few large companies? The provider/purchaser split will only work with a diverse array of providers who are accountable to their community.

How do these developments influence public and patient involvement? If devolution of services is to small providers which are locally based this could give substantial opportunities for grass-roots involvement (Florin and Dixon 2004; Baggott 2005). If on the other hand health care is commissioned to large scale private companies, the likelihood is that these will see patients as customers, and will value feedback from them as consumers of services. This will be in their interest if they wish to regain contracts, but is unlikely to afford local people much direct influence on how the service is provided (Hudson 2007; Baggott 2005) Yet, in order to develop Handy's integrated approach to include public/patient involvement, a measurement of success can be defined by the classic work of Sherry Arnstein. Arnstein who investigated the citizen involvement programmes which were set up as part of the 'Great Society' welfare programme organised by the Johnson administration in the 1960's. In 1969 she constructed 'A Ladder of Citizen Participation' (Arnstein 1969: 216 – 224; refer to Illustration 1). It has degrees of participation, in the manner of a Weberian continuum. The ladder shows a progress from 'non-participation' to 'tokenism' to actual 'citizen power', and is a useful tool for identifying actual practice (Arnstein 1969). An issue with this schema, however, is that the terms used to carry moral overtones. 'Manipulation' has connotations of deviousness, and 'tokenism' of deception, whereas 'citizen control' would appeal to left-wing thinkers, but

perhaps not some others (Arnstein 1969).

Whether participation is judged as successful depends on what it sets out to do in the first place, and 'citizen control' might not be desirable in clinical matters. In the health context, for example, 'citizen control' might be the objective for a particular project, such as improvements in a particular cancer treatment, but not for the overall direction of regional health policy (Arnstein 1969). However, although an integrated (task) model, which includes affective patient/public involvement, is preferred in theory, commissioning, as distinct from provision of services will continue to be managed publicly, at the time of writing by the PCT, although future arrangements are uncertain. It would be their responsibility to ensure proper public involvement. Again they could see it as a way of ensuring customer feedback, so as to better monitor their contractors, as distinct from a strong public voice in how services are provided (Florin and Dixon 2004; Baggott 2005). (Refer to Illustration 1: Arnstein's Ladder of Citizen Participation).

The Whole Systems Approach and Local Health Service Management

Research in the north-east, conducted by Bob Hudson, was developed in order to understand the practical consequences of these models with reference to the devolved and integrated styles of working in the NHS. As noted above this approach is recommended in 'Our Health, Our Care, Our Say' (DoH 2006; Hudson 2006; 2008). He completed a study of an Integrated Team Working in the Sedgefield area of Durham in 2006. This looked at a project involving Sedgefield Primary Care Trust, Sedgefield Borough Council and Durham County Council. These three partners established five locality-based, co-located from line teams across the Borough, each consisting of social workers, district nurses and housing officers. This project is a practical example of devolution down to a non-hierarchical team. The project meant professional boundaries and hierarchies were broken down. Hudson (2006) notes that it had the effect of producing faster responses since people talked to each other rather than go through lengthy procedures. Greater trust also developed between different professionals. Hudson does note, however, that there were organisational and professional barriers to be overcome as well as ominously described 'political dilemmas'. What is important is that the project delivered on the ground. Easington PBC Board is currently considering two Integrated Care Initiatives in the Easington area for Mental Health and Long Term Conditions. The Draft Scoping Documents have been prepared in January 2010, and feature in the empirical work of this study. (Durham PCT 2010) Although the practical details of implementation have been highlighted during the consultation, it is too early to comment yet on their practical consequences. In a paper produced by the Care Services Improvement Partnership (2004) Bob Hudson looks at some of the theoretical issues of 'whole systems working' (Hudson 2004). He notes that practitioners have identified what they call 'wicked issues'. These are problems which are hard to identify but also do not fall under the jurisdiction of any one agency or department. Health Inequality is often described as such an issue. Anti-social behaviour is another. Such issues require integrated working (Hudson 2006). He uses an 'onion diagram' to illustrate what he means. This has been produced by Department of Education and Skills to illustrate the 'Every Child Matters' reforms in 2004. Children's needs are complex and rarely fit neatly within one set of organisational boundaries, and the categories around which services are organised are overlapping, fluid and in some cases blurred (Hudson 2005; 2006: refer to Illustration 2: Hudson's Onion Diagram)

The Department of Health would like to apply the same approach to unplanned hospital admissions. The Community Services White Paper of January 2006 talks of the need to encourage:

all health partners to work together in a system-wide approach to developing urgent care services including better care for patients with long-term conditions, shifting care from acute hospitals to the community, promoting better public health, integration with social care and improving access to GPs in-hours. (DoH, 2006, p90)

This is an example of 'Interagency working,' or 'whole systems' as Hudson prefers to call it. It is not always easy to work in such an unpredictable and changing climate. As Hudson (2004) points out, the emphasis is now on shifting resources from the acute sector to the community, whereas at the same time Acute Trusts have tied themselves into PFI deals. This could mean still paying for a hospital which is no longer used or even demolished. Practice Based Commissioning is now a major vehicle for public involvement, but runs parallel to involvement schemes organised by PCTs and by the Foundation Trusts (Hudson 2004; Robbins 2006). At the same time Local Authorities are strengthening their scrutiny function and LINks is establishing itself. Navigating ones way through all this is complicated for the patient or member of the public, and also difficult for the NHS to manage if it is to be effective.

The concept of services being focussed on the patient or client, rather than simply being managed in a top-down way, does, however, emphasise the importance of the patient and public involvement

(Hudson 2005). The patient and the public will have to be one of the main judges of success of programmes if traditional performance evaluation mechanisms are less easy to implement in a joined up system (Hudson 2005). Resulting from this work we can see an NHS which is a more flexible structure than before, with more emphasis on integrated working with other agencies (some of which may be third or private sector). At the same time there is considerable attention to achieving value for money as more demands are put onto a publicly funded service with people living longer and equipment and drugs costing more. Thus effective measurement of outputs and performance is now given high priority, and this is one objective behind the whole idea of actually putting services out to tender, or considering it as a way of improving performance. It is interesting to consider the consequences of adopting techniques of the private sector to improve efficiency within the NHS (Cooper, et al 2010).

Conflict within the NHS

The brief survey of the literature indicates a real tension at the heart of the NHS. The demands on the system are increasing all the time, yet funding is constrained. At the moment the system commands widespread public support, and it is in the interests of the Government to ensure that this remains, particularly if additional resources are required from the taxpayer to finance it. The government wants to keep tight control of the finance and control costs. It only has to look across the Atlantic to see what happens where there is not this control. At the same time, however, the Government recognises that if health is to improve, particularly as people live longer, it is essential that more resources are devoted to health promotion and the prevention of disease rather than simply acute provision. This will mean more flexible working and integrated working with other agencies. It will also mean involving the public, particularly with long-term care and health promotion. More flexibility means more devolution to local services.

The NHS seems sincere about its desire to involve patients and the public, and also remarkably candid about its shortcomings in the past. The conflict seems to be between the need for control, particularly of finance, and the need at the same time to devolve power downwards to the local level. The NHS frequently states that an aim of involvement is improvement, and the patients and the public will only judge such work a success if they can see visible signs of improvement as a result of their efforts. As Darzi notes, they may not think withdrawing or reorganising a particular service as an ‘improvement’.

Proper involvement requires a dialogue and considerable effort. In the next section the methodology will be discussed. This will outline the effectiveness of using triangulation to collect data on PPI within the NHS.

Methods

In order to evaluate the effectiveness of public and patient involvement within the NHS, the research has developed a methodology by means of triangulation. The methods used within this research primarily employed a qualitative approach in the form of interviews and document analysis; however, a quantitative element was also employed. The quantitative element was used in order to assess health inequalities within the North East region, with a particular focus on County Durham. The study is separated by three stages of data collection. Stage one refers to quantitative data which was obtained from a dataset produced by the Department of Community and Local Government. Stage two developed a document analysis of minutes from the MABs from County Durham Primary Care Trust to assess the impact that patient and public participation has on the development of services. The final stage used case studies by interviewing 15 people: five members of the PBC Board, five from the MAB or Shadow Board, and five from GP Forums which ‘feed into’ the MAB. This was to assess participants’ perceptions of success relating to patient and public participation within Easington as organised by the PBC Board, and whether this influenced the decision making of the Primary Care Trust.

Longitudinal Measurements of Health Inequalities within the North-East of England

Stage one of the analysis analysed longitudinal measurements of government health indicators. This developed a macro quantitative approach to this research in order to assess how successful the NHS has been in reducing health inequalities within the North-east and in particular the Durham area (De Vaus 2002; Bryman 2008). The data was obtained from the Department of Community and Local Government and was used to determine specific areas of health inequalities within the region. The study evaluates regional data on areas of health and well-being and compares this with national averages. This is secondary data which has allowed an approximate longitudinal measurement of 10 years. Unfortunately, because of the restructuring of local councils into one unitary authority in the Durham area,

only data from 2008 is available for County Durham. Data specifically referring to Easington is no longer available. County Durham data has been used in combination with the North-east regional data in order to understand longitudinal trends. The data analysis also illustrates data from neighbouring areas such as Sunderland and Middlesbrough in order to reinforce regional longitudinal health trends. This study specific he focuses on the domain of health deprivation defined within the Indices of Multiple Deprivation (Galobardes et al. 2007).

It should be noted that there were certain limitations when using this national indicator dataset (De Vaus 2002; Bryman 2008). Firstly, as discussed, there was a lack of information about the area of Easington and data was only available relating to a wider area of County Durham. As Easington is one of the most deprived areas of County Durham, the statistical analysis gained from this dataset will present an optimistic approach to health inequalities within the area. Secondly, as data was only available for County Durham for a one-year period, general health inequalities have to be examined at a regional rather than a local level. Furthermore, many of the national indicators within this dataset (in total 198) have only recently been developed and data on these indicators have yet to be collected. Hence, due to this the data analysis was restricted to mortality measurements in order to assess general health; teenage pregnancy trends in order to assess population growth; and suicide rates in order to access knowledge on mental health and well-being within the region.

Document Analysis of Practice Based Commissioning Board and the Monitoring and Advisory Board

The document analysis is based on the minutes from the Practice Based Commissioning Board and the Monitoring and Advisory Board which took place each month over a one-year period in 2009 (Prior 2003; Bryman 2008). The Practice Based Commissioning Board is a professional board which consists of general practitioners, practice managers, and other health professionals. It is at the Practice Based Commissioning Board where decisions on health management and strategic development take place which specifically affect local health services. A Monitoring and Advisory Board has been established (previously known as the 'Shadow Board') to represent the views of patients and the public. This consists of members of the community, patients and users of services within the Easington area. In order to develop a patient involvement within services it is these boards which are at the centre of this community health partnership. Hence, any suggestions and concerns are passed from the Monitoring and Advisory Board to the Practice Based Commissioning Board in order to be incorporated within any health care discussion/decisions. However, the Practice Based Commissioning Board is somewhat limited in the extent to what decisions it can make since it makes recommendations to the PCT which currently controls health funding. If the PCT agrees funding it can be 'unbundled' for locally managed projects.

In order to assess the effectiveness of patient and public involvement within Easington health care services a document analysis took place in order to assess what issues were discussed at the Monitoring and Advisory Board, how and if these were passed on to the Practice Based Commissioning Board and subsequently did this have an impact on the development of local services within Easington (Prior 2003; Bryman 2008; Hammersley 2008). In order to evaluate the success of this process the document analysis attempts to establish if there is any evidence which supports the Primary Care Trusts claim that public patient voices were incorporated within it strategic developments. Hence, the focus of this form of analysis was to discover if the mechanisms that have been established by Durham's PCT have successfully integrated the voices of local communities within their services (Prior 2003; Bryman 2008; Hammersley 2008).

Qualitative Interviews: Members of the Community Engaging In Patient/Public Involvement in Easington Health Care Services

The final stage of analysis developed a quantitative approach to collect data on the perceptions of public/patient involvement in Easington health care services. Qualitative case study interviews were used in order to investigate the perceptions of patients who had been involved in the Monitoring and Advisory Boards (Gilbert 2004; Hammersley 2008; Bryman 2008; Vennesson 2008). The interview stage was to investigate if participants who had been involved in these boards felt that the public voices were being represented at a senior level within the Primary Care Trust. The interviews used a semi-structured approach in order to obtain specific information on participation, but would also allow participants to expand on any points that they felt relevant to this study (Gilbert 2004; Bryman 2008; Vennesson 2008; Whittaker 2009). The interviews probed not so much as to whether these things are actually happening, but whether the enthusiasm and will is there to make them do so, and what blockages they experienced during this process. Fifteen people were interviewed in April and May 2010. They were drawn from three groups, The Practice Based Commissioning Board, the Monitoring and Advisory Board and the GP Practice Forums (which

are intended to feed their views into the MAB). A senior manager was also interviewed who dealt with involvement at the PCT to ascertain their perspective. The backgrounds and motivations of the people interviewed were diverse. Although the study attempted to achieve a 'balanced' sample this was constrained by practical issues. Several of the PBC members, for example were too busy to be interviewed, and the number of GP Forums functioning in the area is limited (although LINks has begun an initiative to increase the number.)

The members of the Monitoring and Advisory Board fell into two categories. Two participants, including the chair, worked for 'stakeholder' organisations in the local community, and represented them on the Board. The other three were volunteers with a background in health and voluntary bodies associated with health. All had been with the board since it was established in 2007 as the Shadow PBC Board (re-named MAB). The members of the Practice Based Commissioning Board consisted of two GPs, two practice managers, and one specialist nurse. One of the practice managers had been instrumental in establishing the PBC Board, and was chair. All these people were employed either directly or indirectly by the NHS.

The members of the GP Forums were all volunteers. These are bodies of patients which report back to the GPs about concerns of patients and suggest ideas for improving the Practice. These were established by the old Easington PCT although it is possible for GPs to continue to set them up, and LINk is at present encouraging them to do this. The Easington PCT also set up 'Health Forums' which are slightly different. They had a small budget, received administrative support from the PCT and were able to support various health-related initiatives in their area. It is the policy of the new county-wide PCT to phase these bodies out. Some have already ceased to meet in any case. Sometimes they also 'double up' as a GP Forum in villages where there is only one Practice such as Blackhall. The Chair of one of these bodies was interviewed. The others were members of GP Forums, two from Peterlee and one from Seaham. It was not possible to get a wider cross-section because in some parts of the District either GP forums have not been established or they have ceased to function.

All were involved in a large range of other community activities, such as Parish Councils, Churches, other NHS bodies such as Foundation Trusts, and community associations. They were all people who were used to committees and meetings. All were either retired or not working because of illness. All were asked the same questions, although not all of them applied to each interviewee. The questions were open-ended, which gave considerable scope for comments and observations from those participating in the study. As a result the survey gave a clear view of what participants saw as the aspirations and goals of involvement in the NHS (Gilbert 2004; Bryman 2008). The responses data was grouped into themes. During the interviewing process all the participants agreed to take part in the interview stage. At no point did any of the research participants drop out or withdraw from the research (Gilbert 2004; Bryman 2008; Vennesson 2008). The ethics of the study was considered in great depth and full ethical procedures were followed. Ethical approval was obtained through the National Health Service and the University of Sunderland.

By triangulating methods of research, such as quantitative secondary data, document analysis and qualitative semi-structured interviews, the study has produced reliable data to determine the significance of patient/public involvement in service processes, where information is passed from one body to another within the NHS. The key focus of this research is to expand on the level of involvement that members of the community feel they have within their local health services. The following section will present the quantitative data obtained from the Department of Community and Local Government on health inequalities. This will be followed by the document analysis and qualitative data representing perceptions of participants involved in both the Practice Based Commissioning Board and the Monitoring and Advisory Board. This will develop the policy and theory discussions of the previous sections with the raw data collected within this research.

Results: National Health Indicators

The data findings are divided into three sections, quantitative data analysis, document data analysis, and qualitative data analysis. Section 3 will commence with a quantitative data analysis of national health indicators with reference to regional and local issues of health and inequality. Although national performance indicators in health are now not made available for the district of Easington, it is still possible to measure health trends within the north-east of England in comparison to the UK national average. Furthermore, it is still possible to place Durham within this measurement. This does not give us the level of analysis needed to highlight health inequalities specifically for Easington however it does allow access to wider information on health inequalities within the North-east and within the Durham area in general. The

study pinpoints five areas of statistical analysis comparing health rates within England with that of the North-East and Durham. Data comparisons made between England and the North-East will be examined longitudinally over approximately a 10 year period. The data themes will be organised into general mortality rates, cancer mortality rates and circulatory diseases. This will give an indication of health trends within the North-East region in comparison to that of the national average in England. This will then develop into an analysis of teenage pregnancy rates (below the age of 18) in order to give some indication of socio-economic depravation in the area. Finally, this will conclude by looking at suicide rates in order to give an indication of mental health and well-being within the area in comparison to the national average within England. The section will conclude by discussing the significance of these findings in relation to service improvement with specific reference to the importance of integrated patient/public voices within service accountability.

Mortality Rates within the North-east Region

Health inequalities within the north-east of England have been well documented over the past three decades (Townsend et al. 1979; 1987; Phillimore and Beattie 1994). Within the indices of deprivation areas in the north-east of England are reported to experience some of the highest levels of poverty, unemployment, educational failure and health deprivation within England and Wales. The Labour government (1997 to 2010) claimed to make considerable improvement within this region. This has been suggested to be partly due to the development of Primary Care Trusts with their aim to effectively manage health problems within local communities. However, when examining current statistics on mortality rates within the region (see Illustration 3), the data indicates that although mortality rates have decreased throughout the country the north-east is still considerably higher than the national average.

Within England mortality rates in 2002 were at 663 per 100,000 compared with 751 within the north-east of England. By 2008 England's mortality rate had fallen to 575 per 100,000 compared with the north-east's 657. As we can see although mortality rates have dropped within the north-east, data from 2008 indicates that the North-East is still consistently higher than the national average (see Illustration 3). As discussed longitudinal data for East Durham is no longer available due to the reorganisation of the district, however Durham's 2008 data allows the study to make some comparison in combination with England's national average and the North-East regional data. The data reveals that not only is Durham's mortality rate considerably higher at 663 than England's national average (575,) in 2008 but also the north-east average which is at 657. Surprisingly, this data reveals that mortality rates within the Durham area have only just reached England's national average mortality rates of 2002 which were at 663 per 100,000. (Refer to Illustration 3: All-age mortality rate per 100 000 population).

Circulatory Disease Mortality Rate within the North-east Region

In order to investigate further, the study compared regional circulatory disease mortality rate with England's national average (see Illustration 4). This compares longitudinal data from 2002 to 2008 of people under the age of 75. Illustration 4 reveals a similar trend to previous data, as the national average in 2002 for England was at 103 deaths per 100,000 which dropped to 71 deaths in 2008. In the north-east of England in 2002 circulatory mortality death rates were at 123 which dropped considerably to 81 in 2008. This shows a significant improvement, however it also reveals that circulatory disease death rates are 12% higher within the north-east of England in 2008 than the rest of the country. Yet death rates increased again when comparing figures for Durham, as in 2008 cancer mortality rates were at 87 per 100,000 which are 18% higher than the national average. Again, this highlights that although the mortality rate for circulatory disease has improved, within Durham death rates (at 87) is still considerably higher than the national average of England (at 71) and the north-east (at 81 per 100,000). (Refer to Illustration 4: Mortality rate from all circulatory diseases per 100 000 population at ages under 75 ages)

Cancer Mortality Rate in the North-east

When examining the mortality rate of people with cancer, both the North-East as a region and Durham are considerably higher than the national average. By referring to Illustration 5 the data indicates that in 2000 deaths through cancer in the north-east was at 150 per 100,000 which were significantly higher than the national average of 127. By 2008 this had dropped to 134 in the North-East compared with the national average of 114 in England per 100,000. Again this data highlights that mortality rates within the north-east in 2008 is still above the national average mortality rates of 2000. When comparing the data from cancer mortality rates in Durham there is a slight fall to 131, however this is still higher than the 2000 national average in England (Refer to Illustration 5: Mortality rate: cancer rate per 100 000 population).

Conception Rate of Under 18 Year-olds in the North-east

Within the literature Easington has been referred to as

having one of the highest teenage pregnancy rates within the country (Durham PCT). In order to investigate this on a regional level the data indicates that although teenage pregnancy rates have dropped throughout the country, this fall took place within the 1990s and has stayed relatively even throughout the 2000s. As Illustration 6 indicates in 1998 the north-east of England recorded conception rates of teenagers (below the age of 18) at 54 per 100,000 compared to the national average of 45. In 2008, within the North-East this dropped to 50 compared with a national average of 41 per 1000. Interestingly longitudinal data has been made available for the Durham area from 1998 to 2008. As we can see Durham's teenage pregnancy rate is slightly lower than the North-East's, as in 1998 conception rates were at 52 and dropped to 49 per 1000 in 2008. Although compared with regional data teenage pregnancy has improved, within Durham pregnancies in 2008 have not dropped to the national average of 1998. (Refer to Illustration 6: Conception rate of Under 18 year olds females per 1,000).

Suicide Mortality Rate

Mental health rates within the North-East of England, in particular within Easington area, have been reported to be a significant problem for local services (Glover 2002). When examining data on mental health issues although the government has set targets in order to measure mental health rates within England, unfortunately the data collection has not yet been completed. In order to give us some idea about levels of mental health and well-being in the region, this study has analysed suicide rates. Comparable with the previous data analysis, in the North-East region suicide rates are generally higher than the national average and are consistent over an eight year period. The data reveals that in 2000, 10 people per 100,000 committed suicide within the north-east. This is compared with the national average of England at 9. By 2008 this had dropped to 9 people per 100,000 committing suicide within the North-East of England compared with a national average of 8 people. This data is consistent with data from 2008 in Durham where 9 per 100,000 people were recorded having committed suicide. Again, suicide rates have dropped within the North-East, but these figures for 2008 show that Durham has just achieved the national average of 2000. Although suicide rates do not give us a definitive measurement of mental health and well being within the region, it does give us an approximate indication. (Refer to Illustration 7: Mortality rate: suicide and undetermined injury rate per 100 000).

Health Depravation in Durham

These data findings present strong evidence that, although health issues have improved within the region, the North-East of England is generally a decade behind the national average of England in relation to health depravation. Furthermore, in the data available in the Durham area general mortality rates are actually higher than north-east mortality rates. As the academic literature within medical sociology has indicated health inequalities are not just about individual lifestyles but are often rooted within the culture of particular local areas (Williams 2004). In order to overcome health inequalities within the north-east, and particularly in Durham, there will not be one solution, but multiple solutions which are culturally specific to a given area (Lupton 2003; Williams 2004). As Hudson (2004) points out in his whole systems model in order to develop effective services an integrated approach must be developed. Integration happens at every level of operation from policy development, through to integrated services and finally in the improvement of partnerships between practitioners and communities (Handy 1999; Hudson 2004). In order to have an impact on health inequalities within areas like Easington a particular strategy needs to be developed on a local rather than a regional or national basis.

With this in mind in order to understand health inequalities within areas of the North-East a commitment to public and patient involvement within the health services must be implemented. Furthermore, to develop an effective model of health management integrated services and partnerships between organisations and local communities must be developed efficiently (Arnstein 1969; Hudson 2004). Although the Whole systems approach has been recognized by the previous government, both in research and policy (DoH 2006), engagement at a grassroots level must not be tokenistic. The data findings within this section have revealed longitudinal evidence of structural inequality in relation to areas of health within the north-east, in particular the Durham region. The following sections will focus on how these structural inequalities of health are being tackled from a grassroots approach through patient and public involvement within the Easington area. This will examine the level of commitment and resources that Durham Primary Care Trust has devoted in developing a successful partnership between patient/public groups and service development in the Easington area, focussing on the work of the Practice Based Commissioning Board. This will examine any qualitative changes which might have an impact on health management within local communities and examine the success of Public/Patient Involvement initiatives within the Easington area.

Evaluating Communication Processes between the Practice-Based Commissioning Board and the Monitoring and Advisory Board

Section four will report on the findings of the document analysis of the Practice Based Commissioning Board (PBC) and the Monitoring and Advisory Board (MAB). The general focus of this analysis was to examine how patient and participant voices, ideas and concerns were collected and recorded by the Practice Based Commissioning Board (PBC) and then implemented by the Primary Care Trust (PCT). The document analysis examines the minutes from Monitoring and Advisory Board (MAB) where public concerns were first voiced and then follows the process through to the Practice-Based Commissioning Board (PBC) where public concerns and ideas are discussed by practitioners and health managers in order to improve and develop services. However it should be noted that although using the MAB as a conduit to transmit knowledge of initiatives to the wider community is highly desirable, it is not public involvement in the sense of ideas being communicated to the PBC, and thus to the PCT, through the mechanism of the MAB. The role of the MAB is for:

Sourcing the views of the wider community of Easington on needs/quality of current service to influence the Commissioning decisions for service re-designs and feed outcomes back to the Groups (2009: Durham PCT)

This draws comparison to the Government paper 'Real Involvement' which states that involvement should be 'focused on improvement' and 'proactive'. Hence, the object of this study is to see to what extent this is happening, and if not, what are the barriers to it and to suggest how improvements could be made. This looks at the respective minutes of the PBC and the MAB to ascertain how effective the MAB has been in producing initiatives which have then influenced the PBC and lead to identifiable results. The composition of both these bodies has been outlined previously. The PBC consists of GPs and Practice Managers, the MAB representatives of Practice Forums and other community organisations.

Establishing the New Practice Based Commissioning Board and the Monitoring and Advisory Board for County Durham Primary Care Trust

The new PCT has currently one non-executive Board Member who lives in East Durham, a person who had extensive business and managerial experience, but was not involved in the community locally the way the previous Easington Board Members had been (Durham PCT 2007-2008). There was a public involvement manager for East Durham who also dealt with the Sedgefield area. Because the new Trust covered the whole County public involvement events now focussed on the whole county, and consequently did not include so many people from East Durham as formerly (Durham PCT 2007-2008). The Health Forums continued to meet, although some have now disbanded because of lack of support. The resources devoted to public involvement in East Durham are certainly less than before, although this is not to disparage the enthusiasm and commitment of the PCT staff involved.

Following the transfer of Easington PCT to the new County Durham PCT in September 2006, the amount of Public Patient Involvement (PPI) activity in East Durham diminished. The Practice Based Commissioning Board for East Durham was established by the area GPs in 2006. In 2007, following an initiative from the Head of PPI for the Easington locality, the MAB was established (East Durham PCT 2007-2008). This would consist of representatives from the health forums, GP Practice Forums where these existed and other stakeholders to advise the PBC on its commissioning decisions. The Easington Public Patient Involvement (PPI) Forum, which was still then functioning (CPPIH did not stop until March 2008) appointed a delegate at their July 23rd 2007 meeting following an invitation from the Head of Public Patient Involvement (PPI). East Durham Trust, a community development trust which represents the voluntary sector in East Durham, took a prominent role. (The Chief Executive later became chair). The MAB held its first meeting on October 12th 2007. The MAB drew up the following terms of reference:

Role/Objectives of Advisory body to the Easington Practice Based Commissioning Board representing patient/public views

1. This will be achieved through attendance at PBC Board meetings by the Chair of the MAB or his/her representative.
2. To ensure patient safety and quality are considered in all commissioning decisions.
3. Sourcing the views of the wider community of Easington on needs/quality of current service to influence the Commissioning decisions for service re-design and feed outcomes back to the Groups.
4. Provide or elect representatives onto Practice

Based Commissioning Board Disease specific Steering Groups.

5. Identify recurring themes from available data e.g., PALS report, patient surveys etc., and signpost these to the PBC Board to influence the commissioning decisions.

Membership

1. Patient, public and user representation will be fluid and linked to the demands of the commissioning intentions of Easington Practice Based Commissioning Board at the time. Other members will include PALs, PCPE, PBC Board representative, Public Health

A list of groups to be represented was also established. This included the Health Forums, GP Practice forums, East Durham Trust, the PPI Forum, the local authorities and a large number of community groups, including groups representing patients and carers (Durham PCT 2007-2008). After the inevitable period of 'bedding down' for a new organisation, the MAB sent its Chair regularly to the PBC Board which met monthly. The PBC organises two additional meetings each year with the members of the MAB and other stakeholders. One is to secure views by the MAB on its plans, and the other is to hold a dialogue between Clinicians from the Acute Trusts serving the area, the GPs and the patients and wider public. This study considers the minutes of the MAB from March 2009. One meeting, in May 2009 was a workshop discussing how the MAB could move forward. The joint commissioning meeting was held in November, and the meeting between clinicians, GPs and other stakeholders, the PBC Conference 'Moving Services Closer to Home' in February 2010. There was not a MAB meeting in that month. The PBC has also published two newsletters in December 2009 and January 2010, and intends to continue to do so.

Analysis of Document Minutes

The PBC minutes are available from the beginning of 2009. Items relating to the wider community and the MAB in particular have been identified. At each meeting there was a standing item for a report from the MAB (or Shadow Board as it was at first). The Chair, or in his absence the vice-chair, attended. There were problems in the year because the vice-chair unexpectedly died and the Chair had no cover if he could not attend. A new Vice-Chair has now been appointed. The Chair of the MAB (or Shadow Board as it then was) initially reported on the process of establishing it and devising procedures. The two issues it was specifically involved with were promoting transport links to the acute hospitals, and involvement in the Chronic Obstructive Pulmonary Disease (COPD) programme. The COPD programme was one of the PBC Board's 'flagships'. It was a programme of respiratory screening carried out in the community to identify patients who might need treatment. The PBC Board had initiated it because it was extremely expensive to refer patients to hospitals for both screening and treatment, and a proactive screening programme would not only improve health but reduce costs. It was mentioned in an NHS publication in July 2009

The transport links referred to the East Durham Hospital Link. This is an on-demand minibus service established by the PCT to take patients and visitors from the area to Hartlepool Hospital. It was set up as a result of public pressure but is not well used. The MAB is involved in publicising it. There was also discussion at the PBC about the reorganisation of local government which took place in April 2009 when the District Council was abolished and a Unitary Council established. Whether links could be established with the new community engagement mechanisms to fund joint projects was discussed. There is an impression from the minutes that some members of the PBC Board do not fully understand the purpose of the MAB or what it does since time was taken explaining its function.

The MAB (or previously the Shadow PBC) minutes were available from March 2009. (For ease of transcription the author shall refer to it as the MAB throughout.)These are written by an officer of the PCT who is designated to work for the PBC Board. These have been divided into three categories for the purpose of analysis; Dealing with internal matters; receiving information from the PBC Board and NHS generally; and making recommendations to the full PBC Board

Dealing with Internal Matters

A workshop was arranged in May2009 to discuss the role of the MAB. Out of this arose an Action Plan. Members' skills and community connections were recorded, and an induction pack for new members produced. It was agreed that one of the roles of the MAB was to evaluate services and report back to the full PBC so they know how effective they were. There was concern that some of the Health Forums and Practice Forums were not sending representatives to the MAB, and they were asked to do so. The Board were also informed about this research project. It was agreed that members should publicise the work of the MAB by talking to other community groups so that their views could be fed back. The newsletter would provide information. MAB members could contribute to it, and distribute it. During the period from January 2009 onwards, the following issues were raised by the MAB Chair at the full PBC Board:

1.Access to the new Healthworks site at Easington

(patients having to travel long distances)
2.The Integrated transport system to take patients and visitors to local hospitals.
3. The new Area Action Partnership (a community involvement initiative launched by the County Council) and how this could improve health in the area by levering in additional resources.
4.Marketing and promoting new initiatives in the area such as the hospital link bus, food coops and social prescribing.
5.The COPD initiatives in the area.
The COPD initiative (Chronic Obstructive Pulmonary Disease) is an initiative of the PBC for which they have already won national recognition and the role of the MAB is essentially one of promoting and publicising an initiative which has already begun (Buckingham et al. 2008). The hospital bus link is an initiative piloted in East Durham in 2008 funded jointly by the County Council and the PCT. The population of East Durham is scattered through large industrial villages, transport links are poor, and there is a tradition of low car ownership amongst older people because they used to work locally, and had low incomes (NHS 2009). As noted earlier Easington is on the edge of the catchment areas for three acute hospitals, Hartlepool, Durham, and Sunderland. The link is an attempt to deal with this problem for people visiting hospital either for treatment or to visit. The main problem has been low take-up because people do not know about it, and the role of the MAB has been to publicise the initiative. It is of course, expensive, and high usage is needed to justify it. Thus these initiatives are examples of the PBC using the MAB to publicise and support initiatives which it is already involved in.
Receiving Information
The MAB discussed the COPD project and the East Durham Hospital Link. They also listened to presentations on patient advocacy, social prescribing, preventing home fires, Quality Innovation, Prevention and Productivity (QUIPP), Mental Health, the new commissioning arrangements for PCT community services, and integrated care initiatives on Mental Health and Long Term Conditions. These last two are radical innovations, and could lead to inter-agency working between the NHS, social services and other agencies to deliver long term care in the community. These were initially brought to the Board in January, and are to be discussed further. The Board was also informed of an initiative to develop the Peterlee Health Centre. Members of the board have become involved in this.
These items took a considerable amount of the Board's time. The last three, (the Integrated Care Initiatives and the new Health Centre) could be major developments in the provision of local services, and do involve Board members. It is too early at the time of writing to evaluate their success or otherwise. Several of the others do not seem to have led to any further progress or involvement by Board members. For example, Board members volunteered to become involved in the social prescribing project, but there appears to be no progress so far. These other agencies may be anxious to demonstrate that they have consulted, but the purpose of coming to the MAB is to involve its members in activities which will benefit the health of the local community. It is not for other agencies to come and talk so they can report back that they have consulted the public, which is often a requirement.
Items Where Recommendations Have Been Made
The reason for the establishment of the MAB was so that it could endorse/influence proposals which the PBC made to the PCT. These proposals would then have more validity as they would have popular support and approval. The MAB should also report issues to the Board where services were not functioning properly so alterations/improvements could be made. This could be considered the most important function of the MAB in terms of Public and Patient Involvement. There were four items where there was an input from the MAB. The first was the response to the PBC's strategy which had been explained to the MAB in September 2008. The MAB felt older people were not given enough priority and GPs should have records of people with, for example, heart conditions in their area so they could keep a check on them.
The Hospital Link was discussed, and because of the representations of the MAB the PCT had commissioned the East Durham Trust (an umbrella organisation for community and voluntary groups) to promote the service, and usage was now increasing. A further significant issue was prostate cancer. A campaigner came to the Board concerned about lack of availability of treatment for prostate cancer. The Board made representations on his behalf and as a result progress has been made. Finally the MAB gave its support to efforts to upgrade the Peterlee Health Centre, and a campaign is now under way to achieve this.
In theory the views of the MAB should be taken into account when the PBC makes commissioning decisions. For ideas to come to fruition, however, the PCT must accept the recommendations of the PBC so that funding can be released. A local decision, to develop Healthworks (a community health promotion facility) at Easington Colliery, was made by the Durham PCT and the local authority without consulting either the PBC Board or the MAB, although they did

hold consultation meetings locally with the public. Neither body would necessarily have objected, but they do not appear to be 'in the loop'. Successful initiatives such as the COPD screening programme, have been initiated by the PBC Board and supported by the MAB, but these have involved the PBC Board putting in funds from GPs.

It should also be noted that two issues where the MAB has achieved some success, the East Durham Hospital Link, and improving prostate cancer treatment have both involved representations to other parts of the NHS (the PCT and the Acute Trusts) rather than to the PBC to be part of a commissioning decision. Both, however, could be described as 'quality assurance' issues, where deficiencies in services have been brought to light and as a result the service has been improved. The issue of a new Health Centre for Peterlee has not yet reached the stage when a proposal for funding has been reached. The initiative will come from the GPs who use the centre, but they may need to secure funding from the PCT, and also contacts for the other services to be provided there. The proposal will need the approval of the PCT. There will probably be a role for the MAB here, but this stage has not yet been reached.

A further event, which is not part of the minutes, but which should be noted, was the Easington PBC Annual Conference, held on February 25th 2010, and replacing the MAB for that month. This gathered together representatives of the three Acute Trusts which serve the East Durham area, Sunderland, Darlington and Durham, Hartlepool and Tees, the members of the PBC Board and members of the MAB. The author attended the event. Such a meeting of Acute Trust clinicians, GPs and members of the public is unusual, and gave individual patients and GPs the opportunity to discuss the availability of treatment locally. Durham PCT did not send a representative, which was unfortunate. Holding an event like that was a major advance in local involvement.

Recent Development in Patient and Public Involvement

This data covered only a short period of time, and it is probably fair to note that the MAB, which was initially established in October 2007, had considerable teething troubles becoming established, so it has only recently matured. The background to Patient and Public Involvement in Easington is also relevant. The Easington PCT, which existed prior to September 2006, had a very vigorous PPI programme. The new County-wide body tends to focus on county-wide issues, and does not appear to hold meetings in Easington. There are events in Durham, for example, but no assistance is provided for transport, so few people from East Durham attend. LINks is in the process of establishing itself, but again has not had many events in East Durham, although more appear to be happening now. It would appear that many activists see the MAB as the only avenue for expressing their views.

The interviews with the MAB members and with the members of GP forums will investigate this further. To conclude, from the material analysed, the MAB is playing an important role in representing the views of patients and the public, and the PBC Board is very innovative with such initiatives as the meeting between clinicians, GPs and the public. It is problematic, however, as to how effective the process is at delivering results, and if not, where the obstacles are. It should be remembered that the PBC is limited in what it can achieve by the Primary Care Trust. At present it is the Primary Care Trust which can 'unbundle' funds to the PBC to develop local services. Thus the PBC might support an initiative, but it does not necessarily happen. It is to the advantage of the PBC to demonstrate that it has the support of patients and the wider community before putting an initiative forward. If it can demonstrate a need, and support from the wider public, it is more likely that the PBC will take notice. The next section develops this data by analysing participants' perceptions of this process in relation to patient/public participation in Durham's health services.

Perceptions of the Monitoring and Commissioning Boards

The previous section identified the role that the Monitoring and Advisory Board (MAB) and the Practice Based Commissioning (PBC) Board contribute to Patient and Public Involvement. This section will present qualitative data of people involved in both the PBC Board and the MAB in order to collect in-depth knowledge on the processes and perceptions of people engaging with patient/public involvement (PPI). This will examine why participants became involved in the process; perceptions on how successful the Monitoring and Advisory Board has been in terms of service improvement; and what participants feel needs to be done in order to improve patient and public involvement in health care services. The following interviews will consider the perceptions of those involved with the MAB as to how far these objectives are being achieved, and what the problems and difficulties are. The interviews will probe not so

much as to whether these things are actually happening, because the data has shown that at present they are not happening to a full extent, but whether the enthusiasm and will is there to make them do so, and what blockages they encounter.

Reasons for Involvement

The literature on involvement does not really address the issue of whether patients or customers in large organisations actually want to be involved. Thus 'Our Health, Our Care, Our Say' (2006) admits that involvement has had its shortcomings, but expresses the aspiration that all parts of health and social care should be responsive to what people want and prefer, and adds that 'When people get involved and use their voice they can shape improvements in provision and contribute to greater fairness in service use' (OLR 2006: para 7.4) How this can be achieved is not addressed systematically. All the members of the MAB expressed a strong belief in involvement. The most common response was 'To make a difference'. Although one member explicitly stated 'I believe that you should not complain if you are not prepared to do something about issues and problem'. Another aspect which several respondents mentioned was a desire to ensure that treatments and practices were effective.

I had a career in biomedical science, and I am particularly interested in point of care testing, and whether it can be carried out in Primary care. I want to make sure it is done properly.... I strongly believe in public involvement, and the MAB seems to be the best way to do it (Participant)

As was noted above, the reorganisation of the NHS and local government in the area had reduced other avenues for participation. Involvement in the GP Forums appeared to be almost accidental. Two had joined because asked to by the GP and another because his wife was involved. Their motivations, however, were all similar. They wanted improvements in the health services in their area. The initiatives had generally come from the practices. The participants all wanted to do something in their area. Another reason was the strong belief that the patient had a unique insight into his/her particular situation. The clinician might know about the symptoms and nature of the disease or condition, but only they know what it was actually like and what they needed. As noted by various theorists (Sennett, 1998, 2006, Drucker 1992) the NHS appears to be following the pattern of a strong central control system relating especially to finance, together with devolution to various different organisations on the ground, and public involvement is a way of both helping these operate and ensuring they do the job properly.

I do not like leaving everything to the professionals – they can make mistakes. You know more about your own disease and particular situation. Although the doctor may know about clinical symptoms – the patient is a person not an object. (Participant)

The reasons given by the members of the PBC Board were slightly different, but related to the same point. They certainly felt it made their job easier, and enabled them to be more effective. Furthermore, the PBC Board members wanted more power locally.

If you do not do it, it makes things harder, more expensive and less efficient... I felt that GPs should be involved in the commissioning cycle, and the first part of that is engaging with patients. GPs and patients should work together in partnership. Patients should be at the heart of the process. (Participant)

I have recently become a member of the Board. The system we had before (Easington PCT) initiated the process of Practice Based Commissioning. I thought the previous fund holding system had worked well. Initially there were two 'clusters', North and South. The old system of Fund holding had offered opportunities for service design, such as local delivery of diabetes care. The present system does not actually give any funds locally to do this, and depends on the PCT granting them. I would like to be able to design things locally. (Participant)

There was also a desire to find out if treatment was working properly, and to obtain 'feedback' from patients and the public.

We hope to get benefits from involving patients..... I suppose it is a form of market research. We want to know whether services are doing what they should. (Participant)

There was certainly an ambition and enthusiasm to take on the organisation of things locally. This was in line with the ideas coming from the Department of Health 2006, although there was also a hint of recognition of the possibilities of disorganisation, disagreement and uncertainty (Langton 1990, Hudson 2006). The big problem, which all of them pointed out, was that at present GP surgeries do not have the resources for innovation. Funds have to be 'unbundled' from the PCT. At the moment this does not always happen. They were keen to point out things that had happened, when resources were available.

I helped identify patients to become members of the Practice Forum, and set up support groups for Diabetes and COPD. I also promoted the Expert Patient Programme and set up a CHD Group – which a patient now chairs. Patients with long-term conditions need to work in partnership with the health professionals in the NHS. (Participant)

It is interesting that the new Government (May 2010) has stated 'We will strengthen the power of GPs as

patients' expert through the health system by enabling them to commission care on their behalf. We will give GPs greater incentives to tackle public health problems' (The Coalition 2010). This has been developed further, of course, in the White Paper of July 2010.

What Involvement Should Be Doing: Ideas and Examples

Examples of practical involvement were sought – both what had actually happened, and what interviewees thought was possible. In particular, the study was aiming to find out if involvement was a necessary part of the effective devolution of power down to locally – based organisations. All respondents thought the experience of patients was important, and that an important function of involvement was to relay this information to the professionals. Patients could also support each other.

The expert patient programme is very important. You learn to manage your own illness. You have to take a positive view, think about what you can do rather than what you cannot. I encouraged someone else who was complaining about his situation by pointing out that I was worse than him, but I managed to do things. (Participant: Practice Forum Member)

Members of the PBC (the health professionals) saw it more as enabling them to do their job better.

It (involvement) should look at proposed plans, to consider whether they will work from the patient point of view ..... People rarely say "take this away", but they do say that things can be improved. Information about services which could be "pushed out" into the wider community. Involvement is also an information resource for the NHS e.g. it tells us where people are. (Participant)

Several people (from all three groups) used the phrase 'what works and what doesn't' or words to that effect. There was a strong view from some members of the MAB, and to a lesser extent the GP Forums, that a function of involvement was to scrutinise and probe the NHS. This could be seen as an extension of the idea of finding out what works and what does not, although local government also has this role through scrutiny committees.

It should make sure that people ask questions – find out what is happening and keeping them informed. Some people are too used to saying that is "your job" and deferring to authority. These people do not ask questions. Involvement therefore should be probing and questioning of the NHS. Local people should be aware of what is being done in their name ... It should be giving the opinion of what patients in the area want the PBC Board to commission. Unfortunately not all GPs have forums to enable these opinions to "filter up". I wonder if they actually want it to happen. (Participant)

A GP expressed a similar view. He does not mention the word 'scrutiny', but he is talking about constructive criticism, what is sometimes known as 'consensual scrutiny' in local government parlance.

The service is set up by doctors and other health professionals. Involvement enables them to explore all aspects and identify areas where improvements can be made. The NHS spends a large amount of public money and should always be looking for ways of improving quality, value for money and innovation. (Participant)

Taking forward the idea that the MAB should scrutinise and probe, nearly all the members interviewed had the idea that it should also be a pressure group or lobby, pressing for improvements or new facilities

The process gives patients a stronger voice to speak to consultants and other professionals. E.g. the Fire Brigade should be informed if a patient has oxygen in the house ... The process of mobilising the public into getting involved is critical. Schemes such as befriending and using volunteers to install fire alarms do this. The volunteers should do additional things to professionals – not replace them.....Volunteers listen to public opinion – such things as transport. A commercial firm would pay for this information. (Participant)

The MAB had helped lobby for the 'East Durham Hospital Link', a bus service to local hospitals. In other words the process of encouraging volunteer involvement establishes a network, which hopefully feeds into the MAB indicating what health facilities people both want and need. This information can be fed back into the MAB which will carry it forward. A GP Forum member expressed it eloquently.

It is beginning to happen. When there were smaller PCTs people began to feel they had a "voice" and got used to this. The bigger organisations are now beginning to appreciate the importance of "voice". The Expert Patient programme was started by the smaller PCTs. The process cannot be stopped – top down and bottom up. People expect to be heard. The patient is now more recognised as a person. Choice gives people more influence over their own treatment and they expect a voice. (Participant)

The smaller PCTs, which were more community-based encouraged people to feel they could influence things, and the larger ones cannot ignore this. No one thought that it was the role of the MAB to tell the professionals what to do. One GP Forum member summed it up rather well, and many of the others interviewed echoed what she said.

It (the MAB) should not be telling GPs and other

professionals what to do. They have expertise – and know about the incidence of disease and clinical information. Patients know how their individual condition affects them. E.G. There may be a high incidence of diabetes but we need to know the best way for patients to control this. GPs need to know the actual effects on people. With long-term conditions people have to manage their own illnesses. The GP has to listen to what sort of help/support patients need. This could well be a nurse or some other type of practitioner. Diabetes might need a team but does not necessarily have to include the GP. Doctors need to know what sort of support people want/need. (Participant)

Involvement had a further dimension when volunteers were in a position to control or influence resources. Thus the volunteer who chaired the Health Forum which still had access to funding **commented:**

These small projects can save the NHS money. Lights will prevent falls, and hip replacements. Community organisations can prevent loneliness and depression. Many organisations promote physical fitness. Funding is also spent locally. There is less community involvement now with a larger council and PCT. (Participant)

This enthusiasm for being able to control resources, which meant that you could actually see some result for your efforts, was shared by members of the PBC Board. One commented:

If a local practice had a budget it could provide additional local services. At the moment proposals are put to the PCT, and a large number are turned down. The present arrangements are locality rather than practice based, and some practices are keener to innovate than others. (Participant)

So overall the view is that involvement improves services by adding the unique viewpoint of the patient. It is also a form of constructive scrutiny, which also leads to improvement. Many interviewees, however, felt that their involvement would be more effective if they had some handle on resources to ensure ideas were carried through. Handy's ideas on ecology (1999) seem relevant here. How an organisation is structured influences the behaviour of the people in it. When they are given some influence, particularly over resources, their enthusiasm increases.

The respondents then gave examples of what they thought successful involvement was, which illustrated the ideas they had articulated above. Some members of the PBC Board gave examples of health promotion schemes which had worked because the public had been involved, either helping deliver them, or promoting them in the community. This is an example given by one GP.

The "Get Active" scheme has been promoted through public involvement. A weight management scheme was very successful, but funding was limited. When the PCT was more locally based it was far easier for the public to be involved. (Participant)

The 'Expert Patient Scheme' was also cited, particularly by the lay members interviewed. This is currently promoted by the PCT, although funding is due to be reviewed in 2011. Another example which was given was 'social marketing' programmes. These are aimed at promoting healthy behaviour such as smoking reduction and cessation. People who want to improve their health are invited to come to groups where they discuss their problem with others and are encouraged to do something about it. 'Social Marketing' is further explained in an article in Nursing Times. A DoH spokesperson told the magazine research suggests that 86% of people think that the government should intervene to prevent illness by providing information and advice, but 89% of people think individuals are responsible for their own health. This illustrates the need to find new ways of empowering people to make the choices themselves. 'Social marketing is rooted in a deep understanding of what people think and how they act, and can be a powerful tool for bringing about behavioural change. Finding new ways to motivate people to lead healthier lives is vital to making improvements in public health.' (Lomas 2009).

Social Marketing can employ a range of techniques, including videos and posters, but to be effective it needs one-to one interaction between volunteers who are sympathetic to the person who wants to change their behaviour. The volunteer who was Chair of the Health Forum which had (until next year) access to funding, was proud to list the projects his group had promoted. They included promoting flu vaccination, fitting smoke alarms, providing lighting for the elderly to reduce the risk of falls, and promoting various activities organised by community groups to reduce loneliness and promote fitness. Projects needed financial help (although most also raised resources themselves), but none could have functioned without volunteers – to carry out the survey of elderly people's properties, for example. They all had a positive effect of health, either preventing accidents and illness or promoting good health, physical and mental, through exercise and social activity. Another success for involvement was about consultations for new local health schemes, such as health centres or GP surgery improvements. The interviewees thought this led to improvement in service design. They noted, however, that this successful involvement did not always extend to the wider NHS organisation.

The requests of the GP Practice Forum have improved the telephone system for patients. There are now out of hours and Saturday morning appointments. Overall the system works well, but does not seem to influence the wider NHS. (Participant)

Several respondents, particularly the members of the PBC Board, thought the establishment of a planning system for the PBC Board, where consultants and members of the public were involved in drawing up the PBC Five year plan was a significant advance.

The members of the MAB came to annual planning meetings for the local PBC plan. Good to involve the public, and for their views to feed into the plan (Participant: Member of PBC Board).

To summarise there seemed to be several clusters of ideas about what successful involvement was. These include; involving the public in planning new services, improving the actual service and facilities in GP surgeries, helping to run healthy activities for people, working jointly with the NHS on health promotion schemes including social marketing, and setting up and running patient support groups. There is certainly enthusiasm from all the participants to do more locally, and to work in the integrated way suggested by the Department of Health and Hudson (2006). There does seem to be frustrations, and difficulties, with funding and with PCT liaisons which seems to reveal a hint of Hudson's reference to the 'Edge of Chaos' when developing integrated services.

The Role of the MAB

The data appears to confirm the enthusiasm and the necessity for involvement which is devolved from the NHS. This has been suggested in the NHS's own literature as well as described by Drucker (1992) and Sennett (2007). But the MAB and Practice Based Commissioning are not necessarily the only or the best way to do this, so the respondents were then asked how they saw the MAB fitting into this process. The situation in Easington has been described above, and previous avenues for participation have ceased to exist. It could therefore seem natural that volunteers would see the MAB as their new 'voice'. Interviewees who were not members of the MAB were asked whether they were aware of the MAB, and how effective they thought it was. It is important to remember that many of the examples of successful involvement described above do not necessarily refer to the MAB, but to structures which were established before it was set up.

As expected all the members of the MAB knew what it was. Two members of GP Forums knew nothing about it. Of the others, one was a member, so she had, and another knew about it, but not much about what it did. The PBC members had all heard of it, but except for the Chair did not know much about what it actually did. The existing MAB members all thought it had taken a long time to get established, and had gone through what one described as a long 'gestation' period. One thought there should be better liaison with the PBC Board, and better feedback. Another was **blunt:**

So far it has not been useful. It cannot be effective unless it knows what the PBC Board is doing and what the new thinking is within the NHS on a range of issues.. It needs to be informed and to question and challenge. Issues seem to be repeated again and again. (Participant)

All those who were aware of its activities thought that it was now 'getting its act together'. The Chair of the PBC Board commented.

The MAB is now moving out of its "gestation" phase and hopefully into an "action" one. The MAB needs a programme of work. It should be aligned to the PBC's programme of work e.g. if a priority is mental health the MAB needs to work in parallel with it. It should be working with a local user group. The MAB should ensure that these local groups are effective. (Participant)

Several of the MAB members were pleased with this development. The MAB has now adopted an 'Action Plan' to monitor the activities and plans of the PBC Board.

I am now learning more about it. I have a vague picture of what it does. A forward/action plan would make it easier to understand. The networking is valuable – find out about other people and groups. Issues get raised – e.g. Cherry Knowles. (Participant: Stakeholder Member of MAB)

The MAB now seems to be making progress. It feels as if we are genuinely being listened to. Some NHS officials appear to be nervous about public involvement. (Participant: Stakeholder Member of MAB)

The MAB together with the PBC Board had to design their own structures in an uncertain situation. In some ways these are the 'professional and organisational' barriers which Hudson identified in Sedgefield (2007) he noted that trust and relationships have to be built up, and this does take time. There was some ignorance by the PBC Board members too as to what the MAB actually did.

I am not sure what they are doing or how much the PBC Board are using them (although developments are in train). I would like to see patients involved in service development e.g. COPD to comment on it and publicise it. (Participant: Practice Manager)

I think Patient and Public Involvement is a good thing, but I do not know how effective the MAB per se is. I am not sure how effective it is, nor am I aware of any

successful activities which it has done. (Participant: local GP)

Another PBC Board member, however, had a much clearer view of the MAB's role,

The MAB represents the views of "stakeholders" and patients to the PBC Board. The Easington area is used to having no money and therefore establishes initiatives which do not cost much. (Participant)

She felt the MAB had pursued a constructive role so far. To conclude, one of the GP Forum Members, who also sits on the MAB, gave an optimistic view of its future prospects.

The MAB is on the cusp of becoming useful and now has the potential of being a prime mover within the local NHS. It does need a local "base" to inform it. It has now formulated a plan which monitors the PBC Board plan. The MAB can now work with them to make it work. The Doctors are now more enthusiastic..... The MAB can be a catalyst to make things happen. (Participant)

There seemed to be a range of awareness of the MAB and what it did, but although members acknowledged its shortcomings, there was a general enthusiasm to improve it and make it work. No one suggested any other system. Several respondents noted that mutual suspicions and barriers were now breaking down. The GPs in particular now accepted the role of the MAB more. There does sometimes seem to be failures in communications between the GP Forums and the MAB, but they also comment that they are not communicating with any other areas of the NHS either.

Improving the Process of Involvement

Where the respondents were aware of the Forward Plan they all thought it was a good idea. There was a feeling that in the past the MAB had gone over the same ground more than once, and needed to move forward. There was also a desire for better feedback from the PBC Board to the MAB. This was mentioned by several respondents from all three categories. The issue of the PBC Board and the MAB having more resources was mentioned by several respondents:

There needs to be widespread ownership of the action plan and feedback from the GPs. Investment from the practices is also important. There has to be financial backing [from PCT] for suggestions and interventions. (Participant: MAB Chair)

There needs to be devolution of a budget to the PBC or another body, possibly established as a social enterprise. If a local practice had a budget it could provide additional local services. At the moment proposals are put to the PCT, and a large number are turned down. The present arrangements are locality rather than practice based, and some practices are keener to innovate than others. (Participant: GP, Member of PBC Board)

The MAB needs to continue and be strengthened. There needs to be an exchange of information. The status of members of the MAB needs to be raised. It needs more resources. Sharing minutes and a representative from each Board attending the others' meetings would improve information flow. (Participant: Member PBC Board)

The Chair of the local health Forum which still had power over an admittedly limited budget, put the case for resources in a different way.

Abolishing the local Health Forums, which could actually do something in the community, was a retrograde step. The NHS invites comments from people, but is better at telling people what it is going to do than listening to them. (Participant)

Another GP Forum Member stressed the need to produce clear results in order to establish credibility. The MAB needs to "pick up" on a topic and pursue it. People like to see quick results. As regards how the MAB should work if things went according to plan, one GP Forum member had a very clear view.

There is a need for more people with expertise to be involved, E.g. the DNA (Did Not Attend for appointments) issue. Information from Patient Forums is needed. Examples of good practice can then be "fed upwards". Patient Forums need to be more involved with the MAB. Information from them could be collated. The Forums could also benefit from interaction with each other. They would then know about wider trends and developments elsewhere, and not feel isolated. This would energise the MAB. (Participant)

Interviewees were also asked to comment as to how far they felt involvement influenced the wider NHS outside their own Practice and area. The general feeling was that people were much happier influencing their own surgery and practice, where they could see concrete results. For example, two GP Forum members expressed views which others also held:

There is a danger that people at the bottom may only tell the higher-ups what they want to know, rather than the "whole truth". I am not really aware of a system. It is much easier to identify lower down staff than consultants when making complaints. It is easier to deal with "lower down" rather than "higher up" things. (Participant)

The wider NHS organisation is told about what is going on at the grass roots, but does not seem to take much notice. It is much easier to involve people with their GP. E.g. putting up screens to tell people when their appointments are so that hearing impaired people do not miss them. (Participant)

Another Forum Member was more positive. I have quoted her above – she felt that the wider NHS was

beginning to appreciate the 'voice' of patients. The PBC Board Members noted that the formal mechanism for involvement was the PCT, but this did not always seem to work very well. Three PBC Board Members gave their comments.

The information is "sent upwards" through the Chair of the PBC Board. This information could be shared throughout the NHS as in the days of the Primary Care Collaborative [An arrangement when GPs from different parts of the country used to meet and share good practice]. Face to face meetings are better than websites. For example, information about heart attacks [Post Coronary Medication, secondary prevention]. A successful campaign in East Durham reduced deaths by 60%. This information should be shared. There is no "joined up thinking" about PBC. We need a collaborative so individual areas do not have to "reinvent the wheel" and can benefit from the good practice of others. (Participant)

Two other PBC Board members seemed to indicate that the NHS's practice was still what Handy would have called 'The Role Culture' or the traditional Weberian bureaucracy (Weber 1947), rather than the more devolved structures identified by Hoggett (1991), Drucker (1992), and Sennett (1998, 2007). They want participation and involvement, but seek to impose it from the centre rather than let it 'evolve' locally.

One has to get the PCT to agree to a proposal. It is very bureaucratic – too many layers. There is also a lack of clear answers. In a perfect world information would go up to the PCT to influence their decisions. The PCT often appears to think it knows best. (Participant)

The NHS generally is very keen on local involvement. At the moment the mechanism is through the PCT, and it depends whether the PCT accepts ideas. New ideas will not work unless funding is available. (Participant)

The MAB members felt that it was necessary to have a 'success story' to show that involvement in commissioning worked, and thereby convince the wider NHS.

Information flow is in the hands of the statutory sector. More specific information will make it easier for campaigns to go ahead. One success with "unblock" the process. Newsletters from participant organisations can be sued to publicise issues. (Participant: Chair of MAB)

Several others stressed the importance of better feedback. These comment summed up their feelings: 'There does not seem to be any feedback. Would make people more interested if there was.' Overall there was a feeling that the system could work. What was needed was better liaison between the PBC Board and the MAB, and properly informed work so that a proposal was accepted by the PCT. Then there would be clear evidence that the process worked. A PBC Board Member summarised the feelings of many 'The PCT needs evidence (including that there has been PPI) together with proof of outcomes. It the PBC can do this PCT will take notice.' (Participant)

The study also interviewed a senior NHS manager responsible for involvement in the County-wide PCT. (The new County-wide PCT had been mentioned by many respondents, so it was fair to listen to their point of view.) She is not directly involved with the MAB:

There are various different forms of involvement in the NHS, both at the local GP level and also on a County-wide basis through the PCT and LINks. I think we have to be clear about what PPI should be doing. We (the PCT) want to get clear and accurate information about how well services are performing and how they could be improved. This involves survey work, and volunteers can be involved here provided they are properly trained.... We should be clear about outcomes. If we are organising patient support groups we must target and identify the best people to be on them.... There is often a desire to achieve something tangible, such as a new building and local activists are often enthusiastic about this. (Participant)

Two points come from this, Patient and Public involvement is a mechanism for ensuring quality control, and the whole process of 'patient support' is managed from the top. This is rather different from local involvement schemes designed to improve health and progress support for people with long-term illnesses, in which the MAB volunteers have expressed interest. However it should be noted that these viewpoints are not more or less worthwhile, they are just different.

Discussion

It should be remembered that this study is not simply about whether involvement in the NHS is desirable, but specifically whether involvement through Practice Based Commissioning is effective. As the NHS Manager pointed out there are other mechanisms for involvement in the NHS, and this study has not considered them or compared them with involvement through Practice Based Commissioning. As the senior NHS manager remarked, there are a large number of mechanisms in the NHS whose aim is to involve people. If what is required is evidence of the effectiveness of treatment, then survey methods can be established, and these could involve volunteers. Local Authorities can provide scrutiny particularly

when services are reconfigured. The role of the MAB and Practice Based Commissioning seems to be more than this. If it worked effectively it would mobilise local people, patients and voluntary organisations to work in partnership with GPs and other health professionals locally to deliver a better localised NHS, with the emphasis on promoting better health and preventing illness. Some treatments could be taken out of hospitals and delivered in the community. Examples would be 'stop smoking' or 'weight management' programmes, or diabetes and COPD clinics. Health professionals provide the expertise necessary, but local people and organisations can publicise the schemes and involve the people who need to be reached. Some progress in reducing health inequalities has been made, but despite the efforts of the various agencies, health inequalities in the North-East persist, with all the indicators showing lower standards with that of the national average. This study makes this clear. The way to reduce these health inequalities are the sort of community-based projects to promote better health with which the MAB has been involved.

It is clear that the PBC and MAB want to organise more services locally. This would not only make care and treatment more readily available to those with long-term conditions but also make health promotion programmes more accessible. But to do it requires resources. As explained above, funding needs to be 'unbundled' from the NHS. People spoke with enthusiasm of the various arrangements of the old PCT and District Council where they actually had influence over how resources that were spent locally. Having this influence encourages and mobilises volunteers. How this progress can be advanced is considered in the conclusion.

Conclusion

This study is not simply about whether involvement in the NHS is desirable, but whether involvement through Practice Based Commissioning is effective. As the NHS Manager pointed out there are other mechanisms for involvement in the NHS and this study has not considered them or compared them with involvement through Practice Based Commissioning. The end of the locally based Primary Care Trust and District Council certainly reduced the opportunities for local involvement. The new County-wide PCT and the LINks organisation are trying to widen opportunities for involvement in the area, but when the research was conducted these did not appear very salient or accessible for the people interviewed.

The enthusiasm and commitment of all those concerned was very apparent and in many ways humbling. There is a reservoir of voluntary effort and commitment which the NHS can tap into. People want to volunteer, and want to feel that they contribute to the NHS. But they also want to be taken seriously, and feel that what they are doing is having some effect. If they feel that their involvement is tokenistic and being organised simply so that the NHS can claim it is involving people they will not want to continue.

The previous analysis has shown that a more market-based NHS, as identified by Exworthy and Halford (1999) will result in a more diverse and devolved system. Other commentators, notably Handy (1999) have commented on the modification and 'loosening' of the traditional Weberian idea of a bureaucracy, although as Sennett points out (2007) this does not necessarily mean loss of central control of what is happening. The work of Bob Hudson shows both the benefits and the problems of devolving authority to the 'front line' by breaking down organisational and professional barriers and to secure 'inter-agency working'. His conclusion is that it is effective and a success once the barriers have been overcome. The Community Services White Paper of 2006 encourages this approach, although Hudson also comments that the system will operate at 'the edge of uncertainty' and can be stressful for those involved. Current developments indicate a desire to cut costs and devolve decision-making down to the front-line. This will necessitate different professionals working together more, and, from the NHS literature, a wish to involve the community and volunteers. At the same time there is the conflict, identified in much of the literature, between devolution of decision-making and the need to keep strict financial control. There could be conflict between professionals and those seeking a more market-based approach, and between professionals and volunteers and voluntary bodies. This study indicates that there is enthusiasm to make Practice Based Commissioning work through involvement at a local level, although at present there are barriers, mainly financial. The PCT appears reluctant to delegate, although the proposals in the White Paper (NHS July 2010) may produce more delegation. How this works will be interesting.

Some may simply wish to improve the way their local GP surgery is run, or have a say in how health facilities are organised in their particular village or community. It was clear that the Health Forums with small delegated budgets, where there was an effective chair, could bring substantial benefits to their specific areas, particularly if they worked with other bodies such as Parish Councils. Abolishing them appears to

be a retrograde step as far as involvement is concerned. It sees that for various reasons some GP Practices do not have Forums. Clear evidence is not available as to why this is, but if the NHS wants to encourage involvement at a grassroots level then it needs to pursue a policy of encouraging them to be established (possibly by offering administrative support). Information supplied by County Durham LINks (co Durham LINks 2010) indicates that Forums are functioning for about half the GP practices in the County.

As the senior NHS manager remarked, there are a large number of mechanisms in the NHS whose aim is to involve people. If what is

required is evidence of the effectiveness of treatment, then survey methods can be established, and these could involve volunteers. The people interviewed, however, did not mention activities of this nature. They all wanted to be involved in the provision of services at a local level. Some wanted to improve the service at their local surgery. Others were involved where the focus was on dealing with patients with long-term conditions, and programmes to prevent people having to go to hospital such as COPD. There was also a willingness to become involved in projects promoting healthy lifestyles, such as weight management and alcohol reduction.

The professionals interviewed would like to develop more community-based projects, aimed at providing community treatment, such as weight management and diabetes, but felt they were not getting access to the necessary funding. These projects could involve community volunteers in a social marketing role. The volunteers all wanted active involvement in the improvement of services. They did not seem very interested in survey work, or developing policy. Bodies such as LINks and the Overview and Scrutiny Committee carry out these roles.

The Monitoring and Advisory Board organised seminars to consider its wider commissioning role, about to which acute trusts patients should be sent, which involved discussions with GPs and consultants. The people interviewed in this survey, however, did not see this as a major part of their involvement. There is evidence that Practice Based Commissioning can mobilise local people, patients and voluntary organisations to work in partnership with GPs and other health professionals to deliver a better NHS locally, with the emphasis on promoting better health and preventing illness. Some treatments could be taken out of hospitals and delivered in the community. Examples would be ‘stop smoking’ or ‘weight management’ programmes, or diabetes and COPD clinics. Health professionals provide the expertise necessary, but local people and organisations can publicise the schemes and involve the people who need to be reached. It is clear that the PBC and MAB want to organise more services locally. This would not only make care and treatment more readily available to those with long-term conditions but also make health promotion programmes more accessible. But to do it requires

resources.

It has been observed that the hospitals in the North-east are of a high standard, but health is poor compared to the rest of the UK. This study makes this clear. The way to reduce these health inequalities are the sort of community-based projects to promote better health with which the MAB has been involved . As explained above, funding needs to be ‘unbundled’ from the NHS. People spoke with enthusiasm of the various arrangements of the old PCT and District Council where they actually had influence over how resources were spent locally. Having this influence encourages and mobilises volunteers.

Recommendations

At the time of completion of this work the Coalition Government’s proposals for the NHS have been published (The 2010 White Paper, ‘Equity and Excellence, liberating the NHS’). This makes far-reaching proposals about GP commissioning, which will need to be carefully considered. This research considers the current arrangements. ‘Involvement’ can be a vague term, and is always something which is considered virtuous, rather like ‘fairness’. It needs to be much more precisely defined. It could be possible to construct a continuum in the manner of Arnstein, with ‘passive’ involvement at one end, and ‘active’ involvement at the other (refer to Illustration 8: Involvement Continuum).

Passive Active

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Involvement Continuum

‘Passive’ involvement could be filling in surveys, or attending meetings which explain what is happening. The study stresses that it is better than no involvement at all, and it is a role many people would wish to have. Involvement of this nature is already organised by the PCT and LINks.

Active involvement means actually being involved in the delivery of a service, with the end point being volunteers actually running the service. As with all continuums, they are intended to measure what actually happens, and in real life involvement activity could be placed at some point on it. The problem with words like ‘Active’ and ‘Passive’ is that they have

moral or even political overtones. The majority of people will want to be involved in a 'passive' way and organisations such as LINks are trying to establish large networks of people who can be consulted on health issues. The PCT also wants to do 'market research' to find out how effective services are. This large scale involvement will be at the left-hand end of the continuum.

The people interviewed in this survey would seek more active involvement through the sort of health promotion and illness prevention programmes identified above. They would be placed on the right hand side of the continuum. Not everyone would go at either end. Some people would be more active than others. It is simply a tool of analysis. Many health professionals welcome this involvement, and the problem at present is lack of access to resources for such projects. As noted in the research, however, many health professionals are not involved in practice-based commissioning which involves the wider community, and half of the GP practices in County Durham do not, as yet, have patients' forums. Research needs to identify why this is the case.

Practice Based Commissioning is more developed in other parts of the country. In Northamptonshire a group of 350 GPs commission together, and have reduced the number of people sent to hospital for back pain by a fifth by providing more physiotherapy locally (Seiger 2010). This is the same approach as establishing the COPD programme in Easington. It reduces hospital admissions and the money saved can be spent locally. It is clear that the programmes which the volunteers are most involved in are those designed to promote health (such as anti-smoking campaigns), disease prevention or care of the long-term sick. All of these are activities at present funded by the PCT, but the White Paper reforms propose transferring public health back to local authorities, and some of these activities could be part of it. This will make commissioning more complex. Promoting these programmes, however, is an effective way to reduce health inequalities.

There is little evidence of direct involvement by patients or the public in the major aspect of commissioning which is deciding to which hospital patients should be sent. If this is delegated to GPs, they will probably need professional help. Thus there is ample scope for the NHS to expand what the study has designated 'active involvement' in the fields of health promotion, disease prevention, and the management of long-term conditions. Medical opinion is almost universally agreed that this would reduce the number of people needing to go to hospital and would help to reduce health inequalities. It will require resources, but is cheaper than admitting people to hospital. Little or no evidence was found that the public and patients want, or have the expertise to be involved in the more clinical decisions as to which hospital patients should be sent or what treatment should be commissioned.

The new arrangements in the White Paper may make it more complicated to commission the activities where volunteers are involved, since some will be funded by local authorities and others by the GPs. Nevertheless this is an aspect of health policy which needs careful examination as to how it will fit into the new arrangements. Local involvement is accepted as desirable by nearly all health policy makers. The new commissioning arrangements could give more opportunities for it, but much careful work needs to be done working out how this will happen. Yet, it should be noted that too much haste could damage existing initiatives without providing anything better.

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Illustrations

Illustration 1

Arnstein's Ladder of Citizen Participation

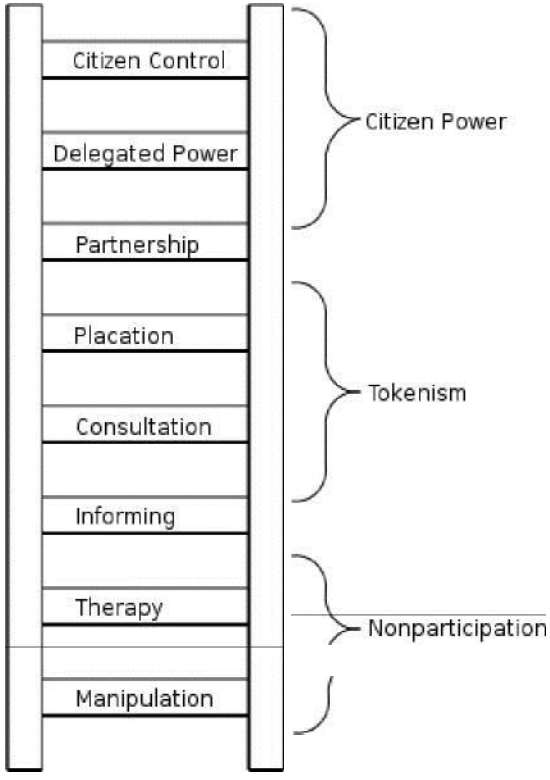


Illustration 2

Hudson's Onion Diagram

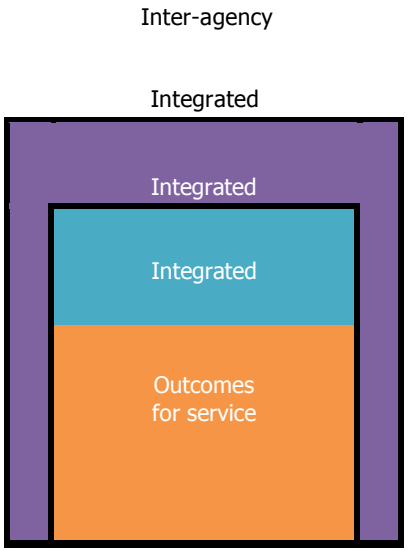


Illustration 3

All-age mortality rate per 100 000 population

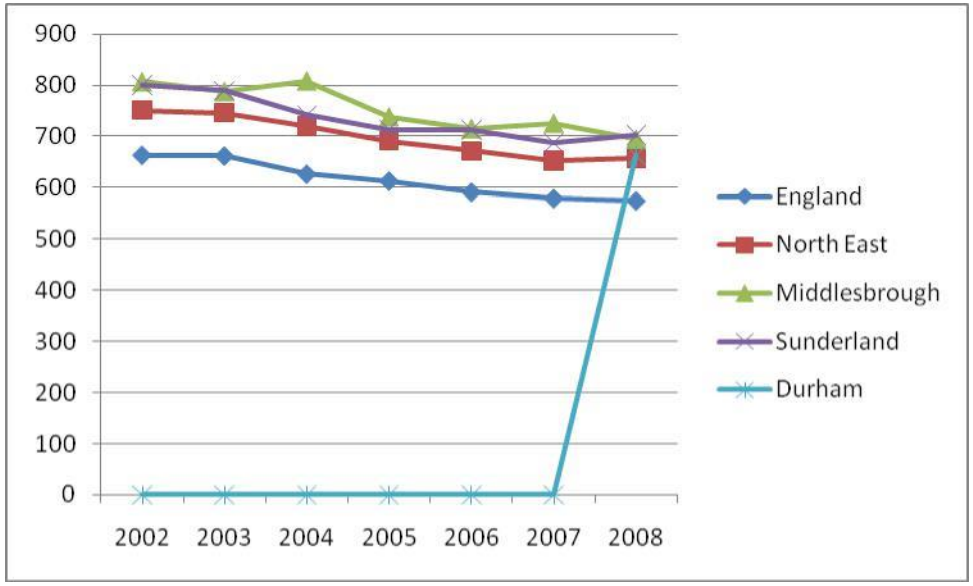


Illustration 4

Mortality rate from all circulatory diseases per 100 000 population at ages under 75 years

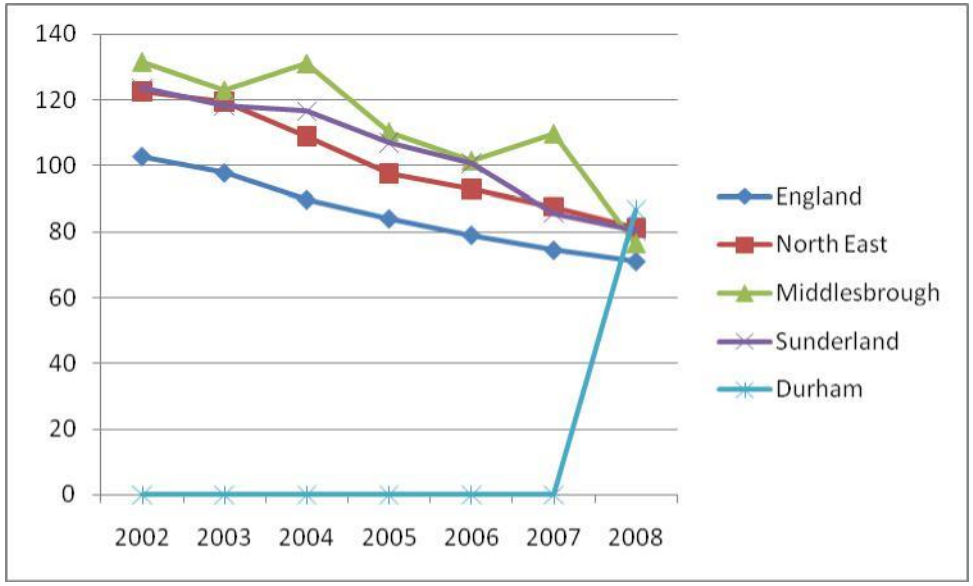


Illustration 5

Mortality rate: cancer rate per 100 000 population

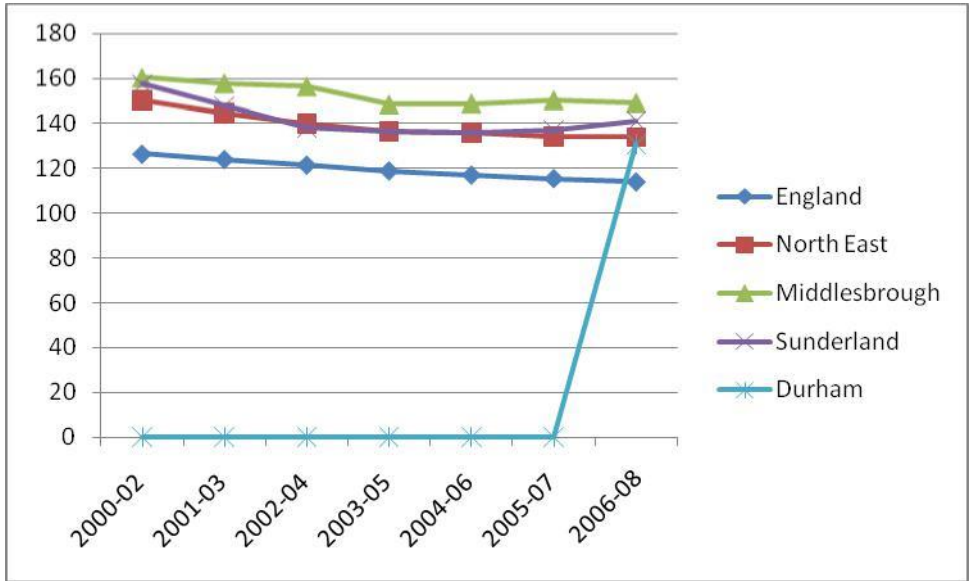


Illustration 6

Conception rate of Under 18 year olds females per 1,000

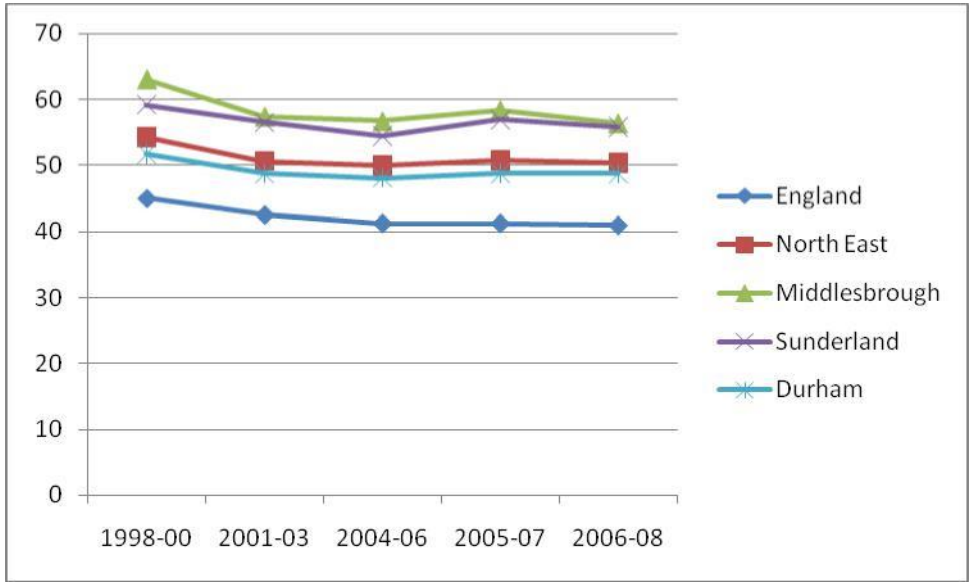


Illustration 7

Mortality rate: suicide and undetermined injury rate per 100 000

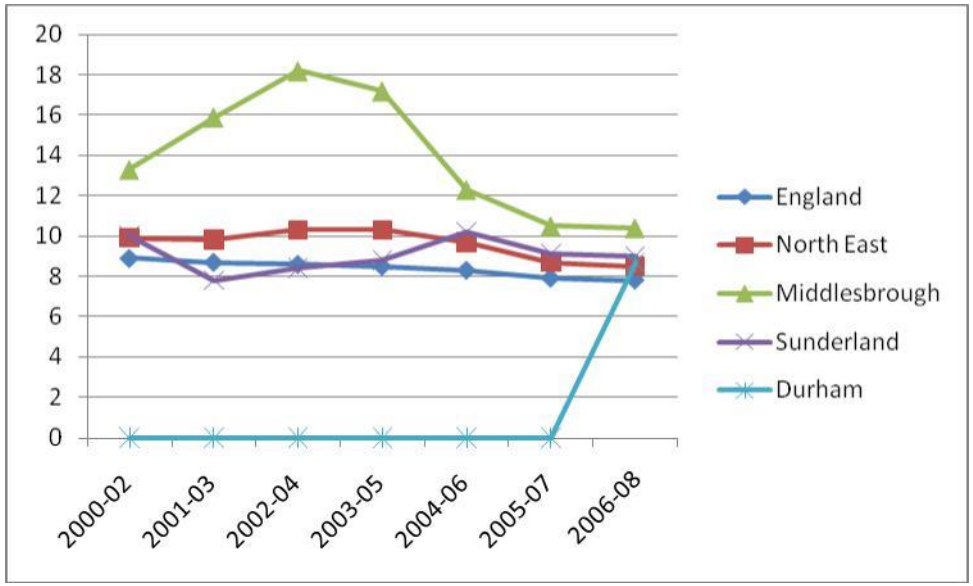
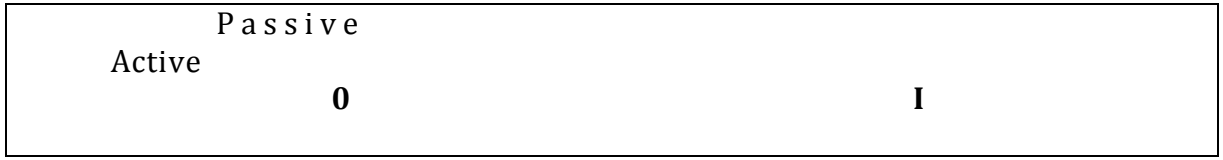


Illustration 8

Involvement Continuum



Involvement Continuum

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