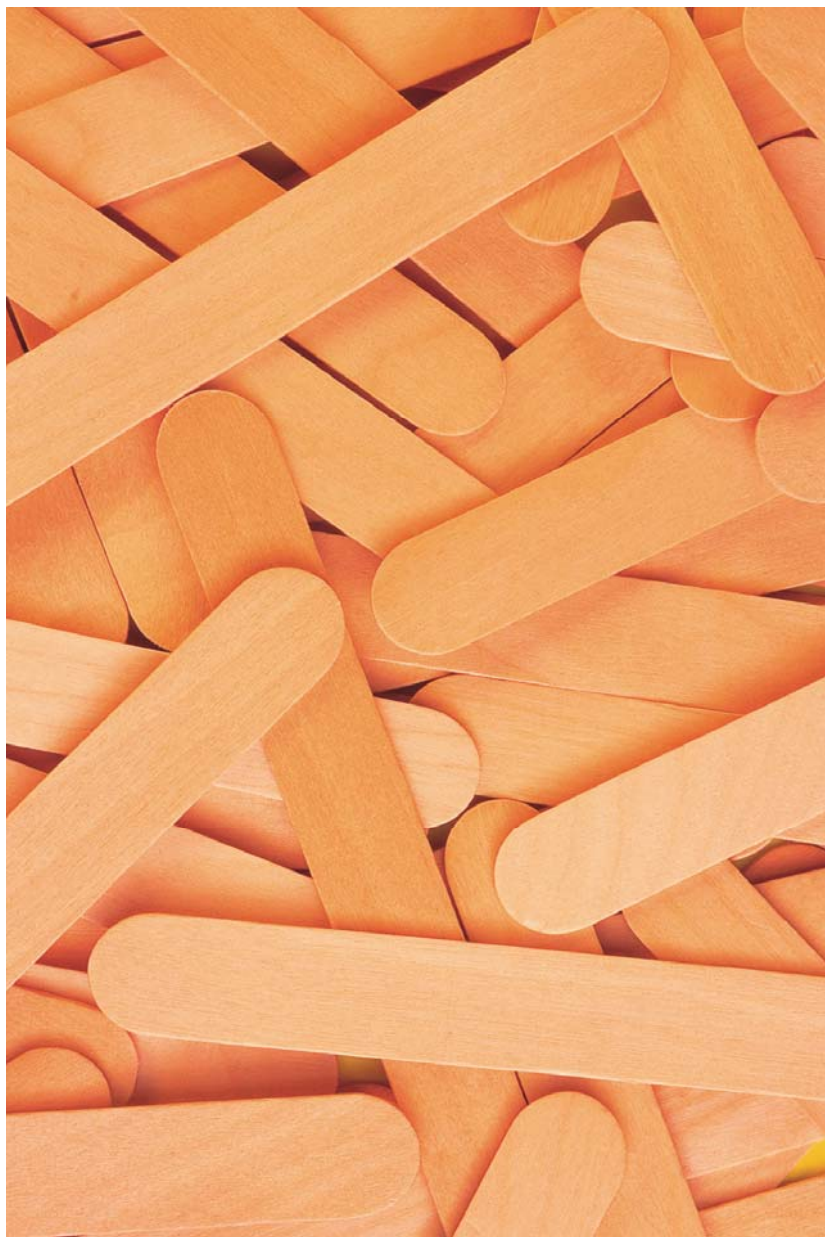


Innovation in the Public Sector

Publin Report No. D12-2
UK case study WP4

Developing Patient-Oriented Education Systems for Diabetes

By Paul Windrum and
Pascale de Berranger



This document is a working paper produced by the PUBLIN research project. PUBLIN is part of the Programme for research, technological development and demonstration on "Improving the human research potential and the socio-economic knowledge base, 1998-2002" under the EU 5th Framework Programme. For more information, see www.step.no/publin/.

PUBLIN

MMUBS UK Report:
Developing Patient-Oriented Education Systems for
Diabetes

By Paul Windrum and Pascale de Berranger

Manchester Metropolitan University, February 2005
Published by NIFU STEP, Oslo, Norway 2005

INDEX:

1.	Introduction	3
2.	Policy Level and Wider Context	4
2.1	The Healthcare system in the United Kingdom	4
2.2	Drivers of change in the NHS	5
	2.2.1 Demographics	5
	2.2.2 Increase in chronic diseases and long-term conditions	6
	2.2.3 Consumerisation	7
	2.2.4 Public trust in expert opinion	7
	2.2.6 Patient empowerment	8
	2.2.5 Privatisation and New Public Management	9
	2.2.7 Shortage of healthcare professionals	10
2.3.	Current Structure of the NHS in England and Wales	10
2.4.	National Institute of Clinical Excellence (NICE).....	12
2.5.	National Service Framework	12
3.	Service Level Innovation: Patient-orientated Diabetes Education	13
3.1.	Background	13
3.2.	Salford City and Salford PCT	14
3.3.	Critical incidents	15
3.4.	The innovation process	19
	3.4.1. The beginning of the process	19
	3.4.2. Initial scoping exercise	19
	3.4.3. The objectives of the patient-orientated education programme	22
	3.4.4. Development of two alternative education programmes	24
	3.4.5. Maximising material within a short period	25
	3.4.6. Addressing the diverse needs of local users	26
	3.4.7. Content: imparting key messages and building self-confidence	26
	3.4.8. Mode of delivery	27
	4.3.8. Strengthening the link between diagnosis and education	28
3.5.	Piloting and test instruments	28
3.6.	Future issues	29
4.	Discussion	30
4.1.	Initiation	30
4.2.	Design and development	32
4.3.	Selection, diffusion and utilisation	34

4.4.	Evaluation and learning	35
4.5.	Other issues	35
5.	Conclusions and Policy Prospects.....	36
	APPENDIX 1	42
	APPENDIX 2	53

1 Introduction

The MMUBS case study analyses the birth, development and implementation of a novel innovation within the NHS: patient-centred diabetes education. This innovation is multi-faceted. Indeed, it is best not to think of it as a single innovation but as a set of interrelated innovations. These include conceptual innovations, systemic innovation, policy innovations, and administrative/organisational innovations, as well as service and service delivery innovations. Some of the innovations occur at the policy and service levels. Others cut across the policy and service levels. Notably, the concept of patient-centred diabetes education cuts across all hierarchical levels. It represents an important break from the traditional, paternalistic model of health service provision and delivery. In the new conceptual frame, the individual patient is the central focus and services are to be tailored to the individual's needs, and delivered at the local level.

The shift is associated with a radical structuring of the NHS that has occurred in recent years. The objective of this is to create a primary care-led NHS that is responsive to local needs. In addition, a set of key UK policy agencies / enforcing bodies, the National Institute for Clinical Excellence (NICE) and National Service Framework (NSF) standards, have been established to evaluate needs, set and enforce standards of care. Within these, the development of patient-centred diabetes education services are identified as a priority.

These bodies are experimenting with a new approach to policy learning in order to arrive at an effective set of standards for diabetes education. This departs from the traditional model of governmental standards-setting by *de jure*. Instead, a pseudo market for innovation has been established. This supports the development of local, bottom-up innovations in services and service delivery. As a consequence, a number of alternative education services ('service packages') are currently being developed in the UK. While the basic understanding (or 'science') of the condition, of diet, and of exercise, are not contested, important differences exist between the alternative service packages being developed and tested. These include significant differences in content, in styles of education, and in modes of delivery. The report examines the key factors that lead to the generation of this variety at the service level.

The research methods used by the MMUBS team are of particular interest. Through action research methods, the team has gained unique, and intimate, access to innovation processes occurring at the service level. It has been possible to examine, at close hand, the development of a diabetes education programme currently being trialled within Salford Primary Care Trust (hereafter 'Salford PCT') in the North-West of England. In addition, we have conducted interviews with key policy-makers. This has enabled us to gain clear insight into the dynamics of policy innovation as they unfold.

The action research approach enabled us to examine 'critical incidents' that occurred along the pathway of an innovation process. Not only do these key events play a crucial role in determining the character and relative success/failure of an innovation, but it also helps enormously in identifying the different dimensions over which an innovation process occurs. The particular features that are pertinent in this case study are the diffusion and translation of policies into action at ground level, organisational learning by Primary Care Trusts (PCTs), the implications of education innovations for staff skills and competences, and the management of change.

2 Policy Level and Wider Context

2.1 The Healthcare System in the United Kingdom

The National Health Service (NHS) was created shortly after the second world war, in 1948 by a Labour government. It aimed to ensure access for all, irrespective of income, to healthcare of the highest feasible standard. To this day, it is almost entirely funded by national public taxation (98%) and is the largest organisation in Europe.

All healthcare, apart from charges for items such as prescriptions, eye checks and dentistry, is free and available to all UK citizens who need it. In practice, however, most non-critical interventions are subject to long waiting lists. Those who can afford it are increasingly turning to private healthcare insurance in order to bypass the waiting lists.

Most medical facilities, such as hospitals, are currently owned by the state (although this is changing). However, not all of the people working within the NHS are state employees. Most family doctors - General Practitioners or 'GPs' as they are known - and their employees are independent contractors. This goes back to the formation of the NHS in 1948. In order to ensure the new NHS succeeded, it was necessary to set up contracts with the (then) private sector GPs.

Conflicts between central and local bodies are not new. Indeed, they have often been seen as a natural occurrence in an organisation built upon fairly paternalistic assumptions about the nature of medical authority and patients' ability to care for themselves. Still, central intervention and direction has increased significantly since the early 1980s.

The initial structure of the NHS was characterised by a very high degree of local autonomy and discretion for medical practitioners. Over time, though, various reforms have sought to increase the accountability of practitioners to central government. The 1974 reorganisation saw significant changes, with Area Health Authorities set up to coincide with local authority boundaries, and Health Districts that constituted a new tier under the Area Authorities. Teaching hospitals were integrated into this unified structure, and Family Practitioner Committees and Community Health Councils were created in an attempt to promote 'consensual management decisions'.

A second major reorganisation began under the second Thatcher Conservative administration in 1982. This sought to simplify and tighten the NHS structure. Area Health Authorities were abolished, District Health Authorities becoming the basic planning unit. At the same time, initiatives were implemented to open up the NHS to private sector firms, and to improve managerial performance through the adoption of private sector management practices. The changes wrought were fundamental and non-reversible in many respects; not only in terms of fundamentally changing the balance of power between central and local authorities, but also the basis of discourse within the NHS – from predominantly clinical criteria to criteria that are predominantly based on economic efficiency. In 1991 a set of new reforms led to the creation of an 'internal market' in which GPs were given independent budgets and district health authorities

competed against each other for service contracts from these independent budget holders.

The third, most recent, major reform exercise directly impacts upon the service innovation analysed by this report. The reforms began in 1997 under the current Labour Government and are part of a wider reform of all public sector services. While the first Labour administration abolished independent GP budget holders, the latest reforms are in other respects a development of the previous Conservative reforms. At their heart lies a greater role for the private sector in delivering state-run services, and the establishment of 'standards of practice' that are to be met by healthcare professionals. A programme of changes, under the title of 'Shifting the Balance of Power', was initiated. The Prime Minister, Tony Blair, took personal charge through a special review committee. The plan was drawn up by five action groups, headed by health ministers and comprising 100 health professionals. The main aim is to redesign the health service system around the needs of the individual patient, making the service more patient-friendly, while tackling the causes of illness with prevention strategies. The key stated goals are:

- to reduce variations in quality of, and access, to services, and
- to reduce health inequalities, especially in primary care.

Despite significant changes brought about by the programmes of reforms, the Prime Minister is keen to point out that access to free healthcare, regardless of position or wealth, is a timeless principle that will be preserved.

2.2 Drivers of Change in the NHS

A number of welfare issues are shaping the way in which health is tackled in the UK, and in western Europe more generally. These lie at the heart of the changes being made to the NHS in England and Wales and precursors to the service innovation studied here. These include demographics, an increase in chronic diseases and long-term conditions, consumerisation, patient empowerment, public trust in expert opinion, the privatisation of services and the introduction of and New Public Management in the NHS, and a shortage of healthcare professionals

2.2.1 Demographics

Changing birth patterns, together with a general decline in mortality rates, have led to an increasingly ageing population and a commensurate rise in total health costs in the UK. In 1971, 13% of the total population were over of people over 65. This rose to 16% in 2003. Forecasters suggest that one in ten of the population will be 75 or over by 2030.

The greatest problems stem from the over 80s, as they represent a major cost to the NHS. They currently represent 4% of the total population but their number is growing faster than the over 65s. At the same time, the number of young people is set to be

around 20 per cent lower than it was 20 years ago (Bosanquet, 1999). The working age population will also fall in size when the so-called baby boomers move into retirement, as a relatively smaller number of people have been born since the mid-1970s (ONS, 2004).

Under a transfer of payments system, a shrinking work force is required to pay ever higher taxes to cover this ageing population. Yet the tax burden cannot be increased without limit. The problem is compounded by the rising cost of medicine - it costs substantially more to provide good quality health services, and earlier detection means the pathway of treatment is longer. The question is 'can the NHS continue to exist?'. Its continuation will probably be tied to changes in the age of retirement. Further, the working population may need to increase their savings and cover part of their own health costs through private insurance, as is the case in the United States and in some EU countries (such as the Netherlands). Unfortunately, savings amongst the current working population are *falling* and they are not investing in private health insurance schemes. Further, poor returns in stock markets over the last decade mean private and company pension schemes are not meeting expectations, compounding the problems for newly retired workers.

2.2.2 Increase in chronic diseases and long-term conditions

There are currently 17.5 million people with long-term medical conditions in the UK, of which 8.8 million are chronic. This is due to the growth in obesity (leading to a growing incidence of diabetes and heart disease), lack of exercise, poor diet, smoking, and rising alcohol consumption. Multiple long-term conditions make care particularly complex, and a small number of patients and conditions account for a disproportionate amount of health care use. Indeed, the majority of GPs visits are related to chronic disease, and more than 60% of hospital beds are occupied by people with chronic diseases.

Early and effective treatment is thought to be the way forward, coupled with preventive measures to avoid or delay the onset of illness. This requires two things:

- 1) a long-term view rather than short-term political expediency, and
- 2) a holistic approach with associated integrated services across primary and secondary care that allow patients to gain control over their condition.

The irony is that recent changes in the organisation and structure of the NHS has produced an array of new public and private sector institutions which actually makes the achievement of (2) more difficult. An important finding of our research in the area of diabetes is the bewildering number of bodies that exist. The links between these bodies is unclear to patients, and indeed to a number of the health care professionals that we interviewed! This is why some suggest that UK patients need to fit within an existing set of fragmented systems, rather than a set of services being integrated around their needs.

The stated goal of (1) is laudable but unlikely to occur in the near future. The 2005 General Election serves to remind us that the NHS remains a prominent political issue and, in turn, a highly politicised institution that alters whenever governments with different ideological perspectives gain power.

2.2.3 Consumerisation

It is often suggested that the public's expectations of the NHS are ever increasing. At the same time, it is suggested, users have become highly sophisticated and demanding, so much so that they are now 'customers' and no longer 'patients'. This has given rise to a new relationship between health practitioners (GPs, hospital doctors and consultants, and nurses) and users; one that is more akin to private sector services. The public is no longer willing to behave as submissive patients, and are more likely to litigate when errors are made.

The change is said to be driven by a number of factors. One factor is a shift in attitude, partly driven by the influence of the USA (where litigation is now common practice). Another factor is the growth of the internet as a source of medical information. The reason for the internet's popularity is easy to appreciate. Here is an opportunity for people to go beyond their GP and gain information about conditions and treatments when they want, and from many sources (Cumbo, 2001).

In practice, strong caveats need to be placed on these notions of consumerisation. Our research indicates that it is not universally applicable. In Salford we found that the majority do not view themselves as customers, or wish to become empowered customers. Instead, they are more than happy to remain passive recipients of medical services that are determined by their GP and other medical practitioners. In other words, they prefer to remain traditional 'patients'. This reflects the economic and social demographics of the residents within Salford. They are invariably poorly educated and economically disadvantaged. Further, their age means do not tend to be internet users, or have an interest in gaining access or learning how to use the internet. Hence, they are informationally disadvantaged as well. As we shall see, this has important implications for the design and delivery of a patient-orientated education programme at the service level. New programmes not only need to identify effective ways of transmitting knowledge, they are also faced with the (even more daunting task?) of trying to change users' basic beliefs and expectations – i.e. changing people who would rather be taken care into people who prefer to take care for themselves, and who would rather rely on GPs and hospital staff to given them knowledge rather than look for it themselves.

2.2.4 Public trust in expert opinion

Health practitioners (GPs, hospital doctors and consultants, and nurses) are far less respected in society than they once were. There is a growing realisation that what is considered to be the basis for good health today can change over time. Indeed, the rate of scientific and clinical discovery is so fast that it is hard for any individual to stay at the leading edge of knowledge - health advice is subject to change. But rather than viewing this in a positive light – i.e. as a necessary consequence of improving medical understating over time, the general public (and key elements of the popular media) increasingly question the validity of the knowledge and competences of health practitioners. At its worse, this leads to a questioning about whether we should even take the advice of a health expert, given that 'it is bound to change in the future'.

A number of well-publicised cases of malpractice (most notably the Shipman case) have further eroded the public's confidence in the health sector, and more particularly the General Medical Council (GMC) which regulates the medical profession.

2.2.5 Patient empowerment

Closely linked to (2.2.2) and (2.2.3) is the notion of individual 'empowerment', whereby the customer takes on responsibility for the management of his/her condition. Consecutive governments have been keen to place greater emphasis on the responsibility of individual 'health service consumers' to take greater care of their own health. The shift from 'passive patient' to 'empowered customer' is illustrated by the proposal, put forward in the late 1990s, that smokers should be refused cancer treatment if they failed to quit smoking (the public outcry that ensued meant that this proposal was never actually put into practice).

As yet, there is no political consensus about the appropriate balance between societal and individual responsibility. The current government withdrew the 'Patient's Charter for England' – a list of rights and entitlements drawn up by the previous Conservative government in 1991 - and replaced it with a new document, 'Your Guide to the NHS', which emphasises patients' responsibility to look after themselves.

On the face of it, individual empowerment appears to be a positive move. But it presumes that patients have the knowledge and understanding to actually make informed choices. This ignores possible tensions between clinical emergency and people's capabilities. Users face serious problems in terms of understanding new medical evidence. Are they expected to have the time and capabilities to read all the latest papers published in medical journals? Are they expected to develop their own medical knowledge to a degree where they can do this? Are they supposed to be able to discriminate between the quality of the information they currently hold and new information? After all, the non-immutable nature of medical knowledge (2.2.4) is thought to be linked to a decline in public trust in the medical opinion of healthcare professionals. Would not the general public lose confidence in their own capabilities when faced with the need to radically update their own knowledge? This is closely linked to the service innovation studied in this report. The diabetes education programme seeks, amongst other things, to impart patients with the knowledge required to manage their own illness. This is in line with government policy. However, apart from the issue of ability, we have already noted that this requires a willingness on the part of the patient to *become* empowered. We addressed this issue during interviews with patients and found that in many instances this willingness was not present.

Could it be that patient empowerment is a rhetorical means of shifting responsibility from government to the patient? Is the consumerisation of users being used by the State to offset its own responsibility, given its inability to solve the demographics problem? The rationale for patients having a role to play in their own welfare clearly stems from problems associated with an ageing population and the increasing prevalence (and costs) of chronic conditions such as diabetes. Yet the fact remains that empowerment does not represent a cheap option. Indeed, it is very likely that any system based on empowered, informed patients will be more costly in time and

resources than a paternalistic system (which itself is costly!). A key issue in the development of a patient-orientated education programme is the need to meet very tight resource constraints, while at the same time building patient empowerment and independence. Alternative programmes have treated the trade-off differently and, as a consequence, look very different. Further, the success of rival programmes will to a large extent depend on how this trade-off between effectiveness and efficacy has been treated (see 3.4.3 below).

2.2.6 Privatisation and New Public Management

The ‘crisis of the State’ in the 1970s, combined with changing demographics (2.2.1 above) pushed the search for greater efficiency gains in healthcare in order to reduce the increasing financial burden placed on the State. The increasing significance of health as a key political issue is illustrated by the appointment (for the first time) in 1997 of a Minister of State with specific responsibility for public health.

As noted already, there has been a significant change in the attitude of central government to the NHS since the early 1980s. This is notable in 3 respects:

(1) A significant review (and continued questioning) of the boundary of state and private sector provision. This trend effectively started under the Thatcher government where there was a move to significantly ‘pull back the boundaries of the State’. Privatisation policies increased the number of pay beds, encouraged the management of NHS hospitals by private firms, uneconomic hospitals were closed, residential NHS accommodation was sold, private sector auditors introduced, and ancillary services contracted out. As well as boosting the private medical sector (most notably BUPA), it has opened new markets for firms providing a variety of non-medical services. Currently, 10% of people have private health insurance in UK. In addition, 220,000 people paid for their own treatment in 2004. While the first Labour administration sought to rein back aspects of the private sector when it came to power, the issue has bounced back to the forefront of the current government’s policy drive. It even appears to be considering the reintroduction of independent GP budget holding.

(2) The introduction of private sector management practices in the public sector. The search for greater efficiency with public sector health provision by national governments has led to the introduction of new tiers of middle management using management practices and styles taken from the private sector, and an institution-wide restructuring of public sector agencies. Much has been written about New Public Management (NPM).

(3) The desire for greater direct control by government. Managers within public sector organisations, and the NHS in particular, are expected to meet targets specified by bodies commissioned by central government (see section 2.4 on NICE). There has been an important change (and continuing tensions) in the relationship between the government and health practitioners, underpinned by a shift in real power. Under the new NHS structure, power is maximised at the top while responsibility for implementation is minimised. By contrast, responsibility for delivery is maximised at the local level while power has been minimised. Health practitioners are now more akin to skilled service workers, responsible to managers, than independent experts.

2.2.7 Shortage of healthcare professionals

A falling behind of public sector pay, the erosion of public sector professionals' status, and the loss of independence as government exerts greater direct control, is a common story across UK public services. So too is the difficulty of attracting quality staff and professionals. In health, an increasing number of GPs now choose to opt out of the NHS altogether and to work solely in the private sector. Similarly, many trained nurses are choosing not to work for the NHS. They are either shifting to the private sector or abandoning nursing altogether. There is a major shortage of healthcare professionals, with associated tensions and pressures at service delivery level. Solutions have been sought in attracting foreign doctors and nurses on short-term contracts while expanding the numbers of nurses and medical students in UK universities. So far, the policy is being undermined by poor retention rates.

2.3 Current Structure of the NHS in England and Wales

In April 2002, the government introduced the new the NHS structure in England and Wales. This is presented in Figure 1 below.

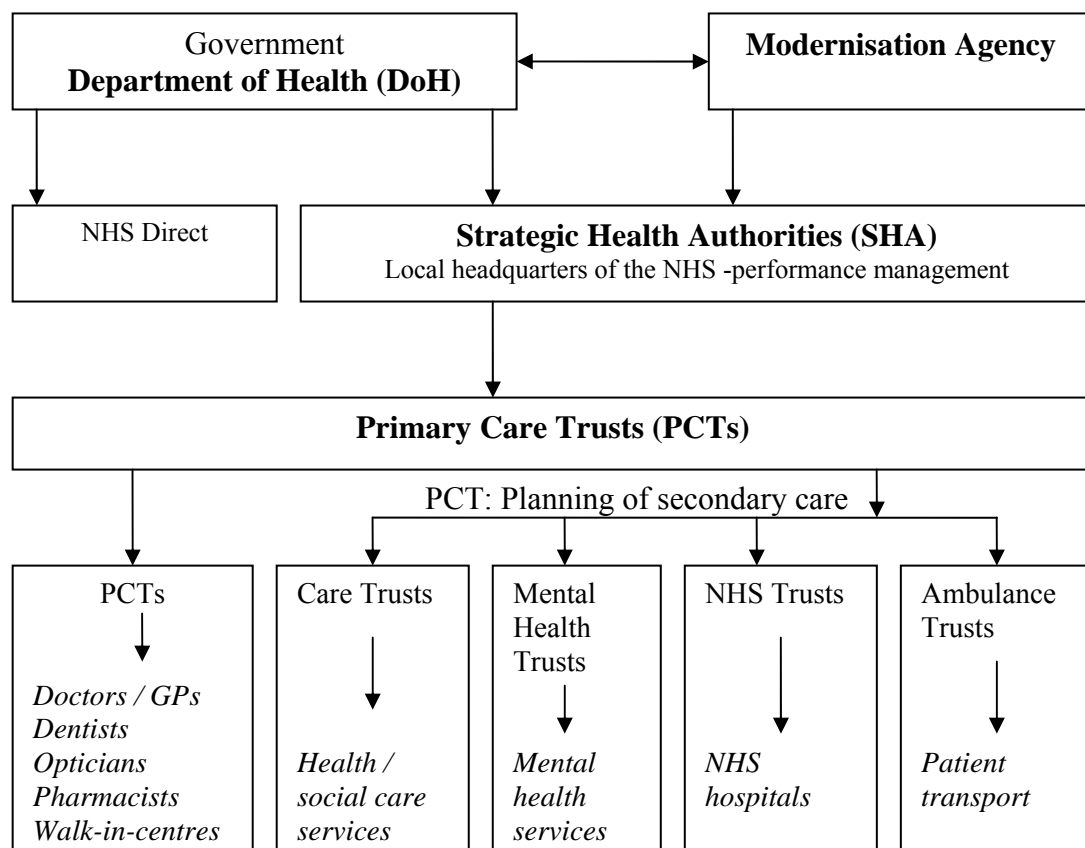


Figure 1.

The new structure represents a major organisational innovation in the way health care is delivered in England and Wales. In particular, there has been a shift of emphasis away

from secondary care (or the acute health sector) to the primary care, in order to create a 'primary care-led NHS'.

The stated aim of the new structure is to facilitate the implementation of central government policies that:

- 1) reduce variations in quality of, and access to services, and
- 2) to reduce health inequalities while
- 3) ensuring that the structure of the NHS and the delivery of services focuses on making the service more patient-friendly while tackling the causes of illness with prevention strategies.

The new structure reflects the strong rhetorical push to focus services around the needs of the individual patient. This is supposed to be achieved through greater stakeholder engagement, patient empowerment, the use of lay people, systematisation, cross-disciplinarity, and the breaking down the barriers between the professions).

An important organisational innovation was the establishment of a specific division within the Department of Health to lead a programme of research and development, with a strategy designed to make decision-making in the NHS research-based. Heading the changes is the Modernisation Agency (formed in April 2001) which ensures that new policies are implemented. They support NHS clinicians and managers in their efforts to deliver improvements to their services. The Agency has the power to reward or punish NHS organisations, based on their performance. Strategic Health Authorities manage the NHS locally and are a key link between the Department of Health (DoH) and the NHS. They were set up to develop strategies for the NHS, to ensure that national priorities (see NICE (2.4) and NSF (2.5) below) are integrated into local health service plans, and to ensure that local NHS organisations are performing well.

The new structure embodies a major shift in power within the NHS. On the one hand, decision-making, funding allocation and responsibility for service delivery has been devolved to the local level through the creation of Primary Care Trusts (PCTs). On the other hand, there has been a significant shift in power towards to centre, notably in the specification of NHS-wide standards by NICE and NSF, and their implementation and enforcement under the Modernisation Agency.

PCTs - the focus of this study - are umbrella bodies responsible for managing health services locally and all practitioners offering primary care services (e.g. GPs, dentists and opticians). The rationale for creating PCTs lies in the current government's belief that these institutions are best placed to understand local needs and, hence, ensure that these needs are met. PCTs control the allocation of funds awarded annually by the DoH, and are now receive some 75% of the total NHS budget. In addition to the organisation of primary care services, PCTs are also responsible for secondary care organisations (i.e. hospitals, mental health services, and ambulance services). This is a radical change. Under this newly reformed system, secondary care organisations are no longer responsible for their own budget allocations but are dependent on their local PCT.

A number of initiatives were put in place in order to facilitate policy-making and policy learning, and to ensure enforcement once in place. In particular, the National Service Framework (NSF) was created in 1995, the National Institute of Clinical Excellence

(NICE) in 1999. It is important to note that these initiatives have greatly evolved since their creation, through a cyclical growth and review process.

2.4 National Institute of Clinical Excellence (NICE)

In principle, NICE is independent of government, although it reports directly to the Secretary of State (the Minister for Health). It has been set up to provide national guidance and to support healthcare professionals, patients and their carers in decision-making about treatment and healthcare. Its remit is to advise NHS healthcare professionals about the cost and effectiveness of alternative treatments, thus bringing in economic considerations in addition to clinical ones. It is also introducing certain aspects of market services (e.g. levels of customer demand and costs) into the allocation of NHS resources. As such, NICE goes well beyond clinical medical judgements, which hitherto was the focus of medical practitioners.

NICE produces guidance on:

- the use of new and existing medicines and treatments (*technological appraisals*),
- the appropriate treatment and care of patients with specific diseases and conditions within the NHS (*clinical guidelines*), and
- on whether procedures used for diagnosis or treatment (that require entry into the body or use of electromagnetic radiation) are safe enough and work well enough for routine use (*interventional procedures*).

NICE guidance considers stakeholders' views: patients, lay carers, healthcare professionals and industry. These stakeholders can, in principle, appeal against decisions. It is important to note that, although independent of government, the main focus of NICE is towards government priorities. Currently, these are geographical variation in the availability of NHS services, and uncertainty over the value of these services. This suggests an attempt to reduce the costs of healthcare delivery. In December 2001, the Government issued directions that made it mandatory for health authorities to act on NICE recommendations, forcing change in a top-down fashion. Indeed, since 2002 the NHS is obliged to provide funding and resources for medicines and treatment recommended in technology appraisals (while no such obligation exist regarding clinical procedures). Clinical audit programmes have been put in place to record the proportion of treatment adhering to NICE guidance.

2.5 National Service Framework (NSF)

National Service Frameworks (NSFs) are long-term strategies for improving specific areas of care, and form an integral part of the Government's 'Modernisation Agenda'. NSFs set measurable goals within specific timeframes, and currently are introduced at a rate of one per year. NSFs are developed by the Department of Health (DoH) to increase consistency. Their ultimate aim is to reduce unacceptable variations in care and standards of treatment, using best evidence of cost and clinical effectiveness. Again, there is clear evidence of a shift towards national, systematic, evaluation-based evidence for policy learning and policy changes.

There are currently 7 NSF's. One of these NSF's concentrates on diabetes, the focus of our service level innovation. All of these NSF's have a generic set of goals:

- to set national standards and identify key interventions for a defined service or care group,
- to put in place strategies to support implementation, and
- establish ways to ensure progress within an agreed time-scale.

Each NSF is stakeholder-driven and developed with the assistance of an 'External Reference Group' (ERG) that brings together health professionals, service users and carers, health service managers, partner agencies, and other advocates. ERGs adopt an inclusive process to engage the full range of stakeholders' views. The DoH supports the ERGs, and manages the overall process.

3 Service Level Innovation: Patient-Orientated Diabetes Education

3.1 Background

The service innovation that we examine is a novel, high quality, *patient-orientated* programme of education for type 2 diabetes patients. It is the product of a collaboration between the Salford PCT Diabetes Education Unit and a group of education specialists at MMU. Diabetes is a very common disease. There are 1.4 million people with diagnosed diabetes in England, and its incidence is rising. This is a direct consequence of an ageing population - more than 10% of people over 65 are diabetic - and an increasing incidence of obesity. The vast majority (85%) of people living with the disease are diagnosed with type 2 diabetes. Patients with type 2 diabetes are able to produce some insulin but the levels are not sufficient to properly control their blood sugar levels¹. Through changes in lifestyle – notably, a healthy food regime and regular physical activity – type 2 patients can control their diabetes. In addition, some type 2 patients will need to take tablets to keep their blood sugar levels within the recommended range.

It is estimated that 1 million people in the UK have the condition but are currently undiagnosed due to a lack of screening. Type 2 diabetes tends to run in families and is particularly common amongst people of African, Caribbean and Asian origin. At the moment, the average age for developing the disease is 52 years old. The average age is falling, and some very overweight children are starting to become affected. Diabetes can have very serious consequences, these include heart conditions, loss of limbs and blindness.

¹ Type 1 diabetes patients are dependent on insulin injections.

3.2 Salford City and Salford PCT

Salford City

Salford City is a highly deprived area within Greater Manchester. Greater Manchester is a metropolitan region in the North West of England. Salford City has an area of 37 square miles comprising the town of Salford and a number of towns and semi-rural areas. The City has a population of 216,000 people.

Salford City has high unemployment levels, its inhabitants typically have poor educational backgrounds, and there is very poor quality housing and infrastructure in the area. There is a great deal of high density housing (built in the 1970s), of which over a quarter are rented public properties (versus 13.2% for England and Wales). Car ownership is 26.8%, very low compared with the national average of almost 40%. There are few sport and local recreational facilities and opportunities. The area is currently being regenerated with much needed European funding. The ethnic base of Salford is overwhelmingly white (96.1%). 2.3% of the population are diagnosed as having diabetes. As noted, the actual figure for people with diabetes is likely to be much higher. As elsewhere in the UK, a lack of screening means that many residents with the condition go undetected.

Salford PCT

Health care in Salford city is managed by Salford PCT. Salford PCT was established on the 1st April 2001 following the implementation of the new NHS structure. Its remit is to:

- assess the health needs of the local population
- plan and secure healthcare services
- improve the health of the community
- integrate health and social care locally.

The accountability for health care services rests with individual organisations operating under the PCT trust umbrella but ultimately rests with Greater Manchester Health Authority, which reports directly to the Department of Health and Social Care (see figure 1). This being said, for specific aspects of planning and performance management, PCTs themselves are directly accountable to the Department of Health and Social Care.

Salford PCT's remit is based on the strategic direction established by the Department of Health. It is responsible for the allocation of funds for all primary care services in Salford. The PCT comprises 140 family doctors in 68 practices. Salford PCT is unusual in that it also contains a district hospital: Salford Hope Hospital. Following the NHS policy reforms, Hope Hospital is no longer charged with the care of type 2 patients. Hope hospital has a number of leading UK experts in diabetes, one of which had a significant impact on the service innovation studied here (see 3.3 'Critical Incidents' below).

3.3 Critical Incidents

A number of critical incidents facilitated the development of the patient-orientated education programme. Figure 2 illustrates the ‘path’ of critical incidents leading to the innovation being created.

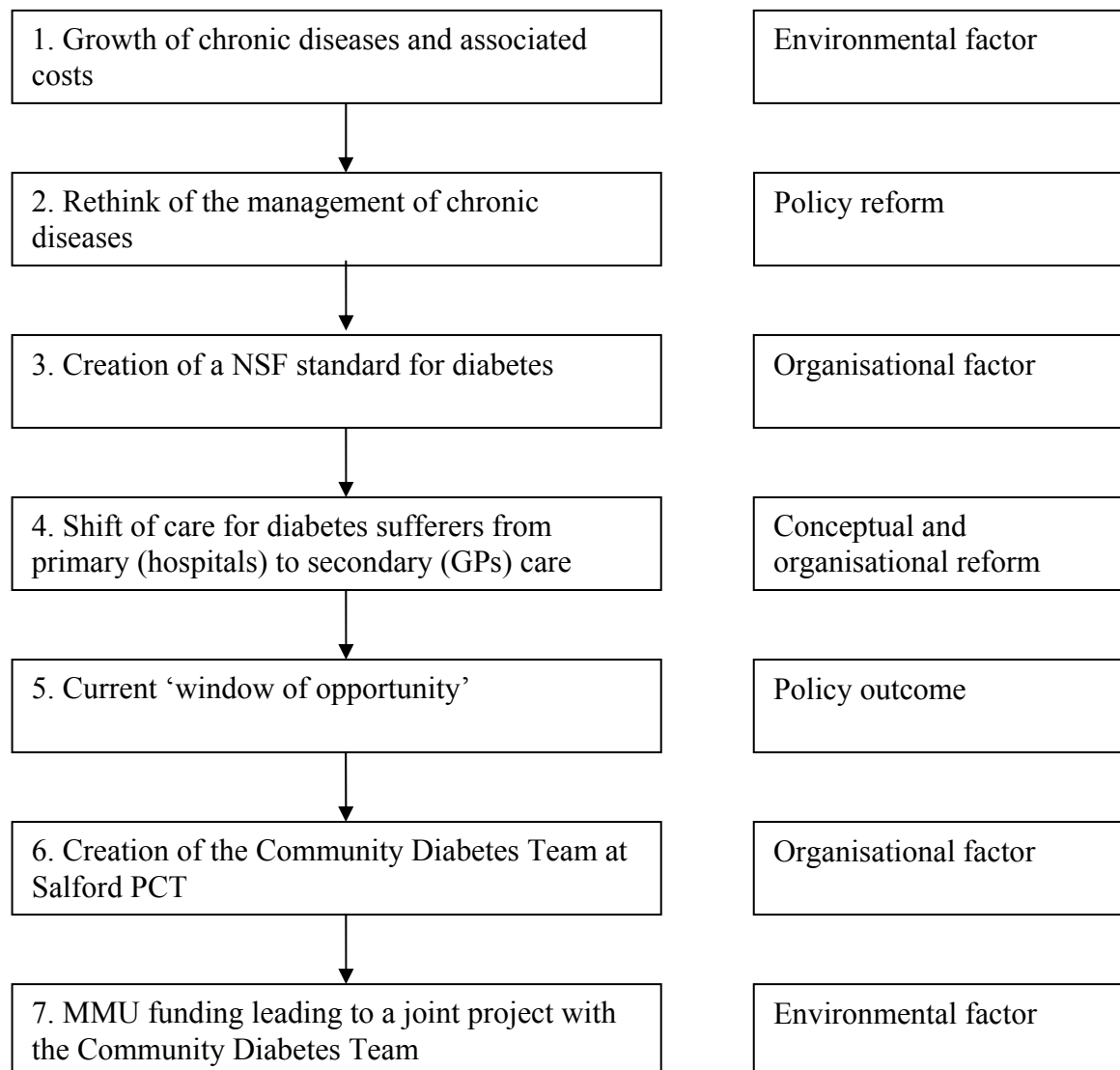


Figure 2. Critical incidents in diabetes education

The first critical incident is the general increase in chronic diseases in the UK, and of diabetes in particular. This puts considerable strain on the already stretched resources of the NHS. It has prompted the second critical incident: a significant rethink of the management of chronic diseases in the UK, leading to a push for an increased standardisation of care.

The NSF and NICE were created as part of the drive for greater standardisation. The third critical incident was the creation of an NSF for diabetes and the proposal for NICE guidelines were defined to achieve more cost effective, higher quality, and standardised care and management for diabetes sufferers. This is a radical organisational innovation. Previously, diabetes education was entirely conducted within hospitals and tended to be very unstructured. The quality of education varied enormously, as it depended on the knowledge of specialists and nurses in particular hospitals, on their skills as educators, and more pragmatically on their workload. In addition, the knowledge imparted tended to depend on what health care staff thought was necessary for patients.

The NSF for diabetes contains 9 standards. These range from screening, to education, to the detection of complications. The first NSF document, published in 2001, set out 'the vision'. This was followed, in 2003, by a Delivery Strategy document that set out the standards to be achieved over the next 10 years. In the same year, Dr Sue Roberts was appointed as National Clinical Director for Diabetes to oversee the implementation of the 9 NSFs. Dr Sue Roberts' role is interesting because it bridges structural barriers within the NHS. Dr Roberts has carried out a fact finding exercise at service level, and is feeding knowledge back to policy-makers, NICE, and the Modernisation Agency.

The fourth critical incident involved a further conceptual and organisational reform. In 2002, care for people with type 2 diabetes was transferred from secondary care institutions (i.e. hospitals) to primary care institutions (i.e. GP practices and community health services). It was argued that this would enable hospitals to focus on acute illnesses, while GP practices would deal with all non-acute illnesses. Importantly, while type 1 diabetes is classed as an acute illness, type 2 diabetes is not. Consequently, treatment of type 1 patients has remained the responsibility of hospitals while type 2 patients were transferred to primary care institutions.

The vast majority of patients are type 2. The change has placed a huge burden on primary care institutions since there has not been an equivalent transfer of money and other resources. In case study interviews with government officials it was suggested that the reforms have been driven by the need to ease the burden on overstretched hospitals, freeing resources for the treatment of more acute illnesses. At the same time, type 2 diabetes can be better treated at the local level. Yet, in interviews with primary care practitioners, it was pointed out that *all* areas in the NHS are stretched. In the UK there is, on average, almost 2000 patients per GP! It was also observed that the cost of treatment in the primary services sector is far less than in the acute services sector. Some of our interviewees suggested that the reduction of costs have been the key factor for the changes rather than improvements in the quality of care. As one interviewee put it, "it's health care on the cheap".

The transfer of responsibility has had a number of serious consequences. In addition to financial and resource implications, many GP practices do not have the experience, knowledge or skills to manage the care of type 2 diabetes patients. Training and educating practitioners is therefore as pressing an issue as the training and education of patients! Further, we found that many GPs that we interviewed are not willingly accepting the new responsibility. This in itself has serious implications for the delivery of quality services. Incentivisation is needed if the reforms are to succeed. In the opinion of the practitioners that we interviewed the development of high quality services is unlikely to succeed through top-down dictate alone.

The foregoing discussion highlights four key areas for research in public sector innovation in health education. First, the quality and the delivery of new services. Second, ways to deal with the increased stress on primary care resources. Third, the training of healthcare staff, and fourth incentivisation. Innovations in diabetes education will need to address each of these factors if they are to succeed. These four factors are in addition to the key factors highlighted in the earlier discussion of patients and their needs, of the need to successfully engage with the end-users, and the development of patient skills and capabilities that truly enable patients to become empowered. Clearly, the development of effective and efficient patient-orientated education programmes is a not an easy task!

Diabetes is a long-term condition, and patients need to make changes to their lifestyles in order to avoid the worst of its consequences for as long as possible. The key ways in which this is achieved are changes of diet, changes in exercise patterns, monitoring of blood sugar levels, and (if necessary) learning to take drugs. In practice, changing exercise patterns may be all but impossible for some sufferers (e.g. badly overweight and suffering from arthritis), so the focus tends to fall on diet. The other challenge faced by a patient-orientated education approach is dealing with the extensive cultural, economic, social and educational diversity that exists in the UK.

The fifth critical incident is the current ‘window of opportunity’ for the development and evaluation of new diabetes education programmes. The current set of NICE guidelines and relevant NSF standards are vague. They state that ‘education should be timely and on-going, patient-centred, multidisciplinary and aimed at empowering people living with the illness’. The stated aim of education programs is to reduce NHS costs by reducing (or at the very least warding off for as long as possible) diabetes-related complications (e.g. heart diseases, amputations, and liver damage). This loosely specified set of NICE guidelines and NSF standards for diabetes education is deliberate and is the product of a particular strategy for policy learning. The guidelines and requirements will remain loose until alternative education programmes have been evaluated. Thereafter, a more specific and prescriptive set of guidelines will be issued to PCTs, and a clear set of formal standards and targets will need to be met.

The sixth critical incident is the existence of a specialist education team in Salford PCT. This is exceptional in the UK. The creation of the Salford PCT Community Diabetes Team was prompted by a short-term payment to GPs for taking on diabetes patients (this is no longer paid). Salford PCT is unusual in that it includes Salford Hope Hospital. Fortuitously, the hospital has a number of specialists who are leading national figures in diabetes care and research. One of these specialists, Dr Robert Young, came up with the idea of pooling together the GP payments and setting up a dedicated education unit. Following tough negotiations with some GPs, a consensus was reached. The future of the Team was subsequently secured when the same specialist put together a successful bid for long-term funding from the DoH.

It is important to observe that this critical event was *not* a product of the organisational reforms that have taken place within the NHS. Instead, the Community Diabetes Team owes its existence to the activities of individual, local ‘champions’. These local champions are nationally respected experts in their field and hold positions of authority and influence at the local and national level. They recognised, and had the wherewithal and will to exploit, a particular opportunity when it arose.

The creation of the Diabetes Team means there is a single institution within Salford PCT that is responsible for the design and implementation of innovation within type 2 diabetes education. This confers the Team with a degree of autonomy from the other primary care institutions within the PCT (though this may present its own particular set of issues).

The personality of the Manager of the Community Diabetes Team, Jackie Steadman, is particularly important. She is well-known to the staff at Salford Hope Hospital, having been trained there. The Manager was free to choose her own multi-disciplinary team, and given carte blanche on the content and implementation of the education services to be delivered.

Ms Steadman has successfully built a team of highly competent specialists that include two specialist diabetes nurses, two dieticians, and two podiatrists. What is more, the team is critically aware of their own educational performance, continually seeking to improve the quality of education delivered, and extremely open minded with regards to experimenting with alternative educational practices from other fields. Indeed, prior to the new programme, the Team had revamped their teaching methods and content on a number of occasions. As one member of the Team put it, “there was a distinct feeling that they we were more concerned with ticking boxes than actually delivering ‘real’ education”.

The Community Diabetes Team started to look for other diabetes educators who were further along the path of patient-orientated education. There were two notable examples which they came across. Each had been developed by PhD students in neighbouring PCTs. One was in Liverpool, the other in Blackburn. These stimulated the Team to start modifying their own practices, if only in a piecemeal way. In 2003 the Team were approach by the group of specialist researchers at Manchester Metropolitan University (MMU) to work together on a new, patient-orientated programme for type 2 diabetes education.

The seventh critical incident was the funding of a project that enabled a team of education specialists at MMU to work with the Community Diabetes Team. The aim was to explore what a practical, workable patient-orientated education programme would look like, and to establish an effective and viable programme, given tight financial and other resource constraints, within Salford PCT.

3.4 The innovation process

3.4.1 The beginning of the process

The MMU team comprised Paul Windrum, Pascale de Berranger, Robin Johnson, and Ian Martin. The MMU team was interested to work within a primary care setting, and was keen to look at ICT-based solutions for access to information by diabetes patients. Dr Eileen Fairhurst, the Chairperson of Salford PCT put the MMU team in contact with Dr Young. Dr Young is a leading national figure in the field of diabetes in the UK and is based at Salford Hope Hospital. It was through Dr Young that the MMU team came into contact with the Community Diabetes Team at Salford PCT. This was the starting point of the collaboration. Following a number of initial meetings, it was agreed that the teams would work together in order to review and develop a new programme for diabetes education. Two separate LREC applications were drawn up and sent to the Salford and Trafford Local Research Ethics Committee in order to gain permission to conduct research in Salford PCT.

3.4.2 Initial scoping exercise

An extensive initial scoping exercise was performed by the MMU team. Research included detailed primary research as well as secondary research. Secondary research comprised a thorough literature review, focusing on academic research into principles of adult education, and on previous research on patient-centred education for other chronic illnesses. Non-scientific publications (in national newspapers and magazines and on the Internet) were examined in order to assess the style and content of general information on diabetes in the UK.

In addition, government documents and other key secondary sources were examined. These included government White Papers on reforming the NHS, on diabetes and diabetes care, NHS publications, the NHS Direct website, NICE website and NICE guidelines, NSF website and NSF publications, and the Diabetes UK² website. Other, lesser well-known sources were used, such as internet user groups dedicated to diabetes sufferers and carers, and nationally based websites based in Canada, New Zealand, and France. Material from the two diabetes programmes 'studied' by the Education Team were obtained.

These secondary sources were important in three specific areas:

- 1) background information on diabetes (e.g. statistics, trends, patient and practitioner vocabulary)
- 2) education specific documents (again much was to be learned about the vocabulary used and current views on alternative modes of diabetes education)
- 3) contextual understanding (e.g. relating to the precursors to the innovation, the public health landscape, major players in policy-making)

² Diabetes UK is a registered charity and the largest organisation in the UK working with people with Diabetes, funding research, campaigning and helping people live with the condition.

Detailed primary research involved the PUBLIN team conducting face-to-face interviews (23 in total) in order to gain an understanding of the views of key stakeholders, and of their roles in the innovation process. Some open-ended pilot interviews were conducted in order to obtain information on the general NHS landscape and on recent local and national policy changes. While waiting for LREC³ authorisation from the Salford and Trafford Local Research Ethics Committee⁴, pilot interviews were carried out in Gorton. Gorton is an area with similar demographics to Salford. The pilot interviews included 3GPs, 2 nurses involved in diabetes care at GPs surgeries, and 5 people living with type 2 diabetes.

In order to evaluate the key education issues facing diabetes patients, and the strengths and weaknesses of the previous education programme being delivered by the Salford Community Diabetes Team, 11 face-to-face interviews were conducted with patients who had attended education sessions during the previous 12 months. In addition to these interviews, the MMU team attended and observed 3 sessions of the existing education programme given by Salford PCT Community Diabetes Team. This primary research enabled the MMU team to appreciate the particular issues faced by patients, by educators in the Salford area, and provided the basis for an assessment of the strengths and weaknesses of the existing programme. This was the starting point for the collaborative development of a radically new programme.

The questionnaire used in these interviews is included in Appendix 1. The issues investigated covered by the questionnaire were:

- Knowledge about diabetes prior to diagnosis, information given at diagnosis, and immediately following diagnosis
- Different sources of information at initial diagnosis, and additional sources sought by patients prior to attending education sessions provided by the Community Diabetes Team
- Patients' evaluation of the information provided prior to attending education sessions
- The personal support mechanisms of recently diagnosed patients
- Information they had sought immediately after being diagnosed, the different sources used, and patients' evaluations of that information
- Why they attended the education sessions, and their initial prior expectations
- In-depth probing of the knowledge imparted about diabetes in general, and with respect to key topics, i.e. the condition; diet; heart, feet, eyes and other complications; medication; and monitoring
- Perceived strengths and weaknesses of the education sessions
- Patients' evaluations of the printed material provided in the education sessions
- Sources of further information used by patients since attending the education session, and the perceived quality of the additional information

The first key finding of the scoping exercise was that an ICT supported programme would *not* be suitable. This is due to a combination of age and the local economic and social demographics. As noted, the average age for developing type 2 diabetes is 52.

³ The authorisation to conduct interviews with patients.

⁴ In the UK, all research involving patients must have prior approval by the Local Research Ethics Committee (LREC). Two successful applications were made to the Salford and Trafford Research Ethics Committee for the PUBLIN project.

Given the generally poor educational backgrounds, social deprivation and economic poverty found in Salford, this means the vast majority of potential users do not have access to the internet, and do not have the financial means to obtain access. Consequently, in order to address the needs of patients within this particular region, the new programme needed to be supported by more traditional (non-ICT) media.

The second key finding was that images are a key learning format. Patients, sometimes with poor reading abilities, are more likely to access, understand and remember information that is presented through clearly structured images. It was found that these had greatest impact when combined with short, concise written messages. Generally, information communicated in detailed and long texts were not effective. Having said this, it became clear that some patients were comfortable with extensive texts, and also desired that these would be available. Consequently, an effective programme would need to take on board the preferences and needs of this minority group as well as those of the majority within the user group population of Salford.

Before turning to the more detailed issues identified by the scoping exercise, and how these are addressed by the new education programme, it should be noted that the MMU team found very large differences in the experiences of patients. Notably, with respect to how the news of their condition was broken to them, and the initial support which patients received from their local GPs and practice nurses. These ranged from very good initial counselling to the frankly shocking. One patient, who had been diagnosed 18 months previously, had not received counselling, or thereafter been invited back for consultation by her GP. This issue was beyond the remit of this research project, and so it could not be taken up further.

Another important finding was the very different reactions of individuals to the initial news. The immediate post-shock responses reported ranged from sinking into depression, to quickly seeking to take control and battling the condition, to complete denial. Some patients discussed how their attitudes changed over time, initially finding themselves in shock, sometimes followed by initial denial, then moving to acceptance, and then on to seeking to take positive action. Some, though, appeared to be less advanced, and two of the people interviewed were clearly still in a state of denial.

Probing into specific issues on the education sessions received, patients in the sample openly admitted weak knowledge about the condition. There was, for example, confusion as to what exactly diabetes is, and on the nature of sugars and sugar deficiency. Patients expressed more confidence in their knowledge of food and what healthy food was. Having said this, there was an expressed lack of understanding about what carbohydrates are, and the relationship between carbohydrates and sugars. Generally, there was a recognised need to do more exercise but there was a general admitting that little or no improvement had occurred. Only three of the patients interviewed stated that they had sought information from other sources in the period since the education session. Further, the vast majority stated that they had not subsequently looked at the printed material given during their education session.

The findings suggested there are problems in

1. retaining the information imparted during the education sessions
2. in building sufficient self-confidence of patients so that they are self-empowered individuals capable of taking control of their further education needs, and
3. in the quality of the hand-out materials (sourced from NHS and Diabetes UK) sufficient to get across key information and to reinforce these messages after the education sessions.

3.4.3 The objectives of the patient-orientated education programme

There exists a fundamental trade-off within the NHS. On the one hand, there is the goal of maximising service quality. On the other hand, service providers need to minimise the use of highly expensive, and extremely scarce, resources. This fundamental trade-off pervades all discussions within the NHS. The task facing the designers of a patient-orientated diabetes education programme is how best these opposing forces can be balanced.

Another key issue is how one understands, defines, and translates into practice the concept of 'patient-orientated education'. Closely related to this is the concept of 'patient empowerment'. How each of these concepts is understood affects the type of programmes that are developed. Importantly, very different understandings were found to exist amongst medical practitioners. This goes a long way to explaining the very different types of programmes currently being developed by different groups in the UK. Take, for example, the programme developed by a PhD student in Blackburn. It also uses a lot of visual materials, presumably because the researcher identified similar findings with regards to the impact of visually-based information. However, the media that was used is different to that developed by the MMU-Salford Team. Images in the Blackburn programme are placed on expensively produced posters which are then placed around the learning area. The MMU-Salford programme developed an *education pack* (details below) which easily replicated (i.e. all contents are held in WORD-format and can be readily printed out), and a copy of which is given away free to each patient who follows the course. Furthermore, the content of the two programmes differ significantly. The MMU-Salford programme directly takes on board criteria defined by the NHS, while the Blackburn programme does not.

The programme developed in Liverpool also differs significantly to the other two programmes. First, a large number of sessions are held over a two month period. This is impracticable for the Salford Education Team. This is not simply due to the cost of rolling out such a programme. There is a pressing need to dealing with the large backlog of diabetes patients in Salford (as there is across the UK), and the Education Team have a limited number of staff and a limited number of local locations in which they can hold meetings with patients. In other words, the constraints on resources of the Salford Community Diabetes Team are intense (as they are throughout the UK). The numbers of recently diagnosed patients, plus tremendous backlog in patients that have been diagnosed for a number of years, is daunting. The Team are at full stretch simply meeting these numbers.

In terms of content, the Liverpool programme devotes a significant amount of time to teaching patients formal techniques that build confidence and empowerment. Due to the constraints faced by the Salford Education Team, the MMU-Salford programme seeks to build these through implicit means. Notably, empowerment is developed as part of a learning process that takes place within *learning sets*. The process is encouraged to continue after the direct contact with the Education Team has ended. This is done within the specially designed education pack. The pack contains more detailed information that patients can access when they are ready, and provides many other sources of information, such as key websites, local diabetes groups, and so on. Thus, rather than seeking to deliver all material ‘up front’, as the Liverpool programme does, the MMU-Salford programme seeks to address the issue of ‘timeliness of information’ within a learning cycle that takes place over a long time period, while simultaneously dealing with the fundamental trade-off.

The objectives specified for the MMU-Salford education programme were that it

- improves the learning experience
- supports self-empowerment
- provides timely information, as and when users require it
- improves efficiency in delivery
- shortens the time between initial diagnosis and the education session

As noted, there are many different ways in which this could be achieved, and many different types of education programmes developed.

Prior to the project, the education package delivered to patients involved a *single* education session, lasting 2 hours, held at a location within Salford (typically a GP practice or a local public facility, such as a public library). The Community Diabetes Team was unhappy with aspects of the programme they had been delivering, and wished to improve the quality of material and the delivery mode. Importantly, the members of the team are extremely open minded with regards to learning about, and using, new teaching methods and materials, a fact readily seen by their past and continuing efforts to devise new materials and teaching aids. There are, however, major constraints that affect their degree of freedom. Notably, these are extremely tight constraints on staff time and resources, the availability of local sites in which to deliver the courses, and the organisational overheads involved in arranging meetings with patients. These practical constraints are common across the NHS. As a consequence, the new education programme needed to achieve another key objective:

- feasibility: a programme that could be delivered using existing staff and physical resources that are locally available

In order to achieve these objectives, the combined MMU and Salford teams addressed 5 core issues in the design of the new programme. These were

1. how best to deliver a large amount of material in a short time period
2. how to deal with a diversity of clients’ needs, great diversity in their educational background, and in their self-motivation or ability to ‘be’ empowered

3. how to design content that focuses on imparting key messages and at the same time building confidence
4. how to provide materials that support further reading and promote self-reliance and continuing self-education
5. appropriate modes for delivering the material, and of relating the material to the topics covered in the education sessions

How each of these issues was addressed in the project is discussed in sections 3.4.4 to 3.4.9.

3.4.4 Development of two alternative education programmes

In order to critically evaluate the strengths and weaknesses of a patient-orientated programme, it was decided to compare it with a good quality didactic programme. This provided a 'control group' of patients against which to assess the learning outcomes of patients following the patient-orientated education programme. The didactic education programme was rolled in January 2004 and run through to end of March 2004. The patient-orientated programme was rolled in April 2004 and run through to the end of June 2004.

The didactic education programme was a development of the programme already in existence. The new version took into account the findings of the scoping exercise in order to improve the quality of service. The changes were two-fold. First, there were improvements in the quality of materials used. Here materials developed with the MMU team were introduced in this programme as well as in the patient-orientated programme in order to eliminate this as a possible discriminating factor. Second, the mode of delivery was changed from 1 x 2 hour session to 2 x 2 hour sessions. Breaking the material up, and delivering it across two sessions would, it was believed, help to address concerns about cramming too much information into one session – the information overload problem. The cost of this was to double the number of sessions that needed to be arranged and staffing hours, increasing the demands placed on staff and on local resources. This stretched to the limit the resources of the Salford team.

The new patient-orientated programme was based on a very different starting premise. Indeed, it represents an important conceptual innovation in itself. This in turn led to innovation in the service and in the delivery of the service. As noted already, there are many possible meanings and interpretations of 'patient-orientated education' and, hence, there are many different types of programmes that can be developed. The starting point taken by the MMU and Salford team is that of patient-mediated learning. This is an adaptation of methods previously developed in higher education. In this case, medical practitioners do not didactically 'teach' patients. Instead they mediate discussions between patients on key areas of diabetes health. In this alternative method, the patients learn to become self-empowered, critical learners. They learn how to use and critically appraise information on diabetes, how to translate this information into their own individual circumstances, and learn about the multiple potential benefits of interacting with other diabetes patients. The latter range from having contacts that can help find additional sources of information, to gaining alternative opinions about new information.

3.4.5 Maximising material within a short period: supported, multiple sessions

Product, process and organisational innovation went hand-in-hand in the development of the new programme. A criticism of the old programme had been its attempt to deliver too much material within a short period of time. Given the fixed constraints on staff resources, a novel solution was needed to increase the ‘learning points’.

This was achieved by developing a new organisational structure in which the programme is delivered over three separate sessions, each last one hour, with each session supported by education material that is given to patients *prior* to their attending the session. Together, the material and the education sessions provide 6 learning points. This compares with the 2 separate learning points (the 2 x 2 hour sessions) in the alternative education programme.

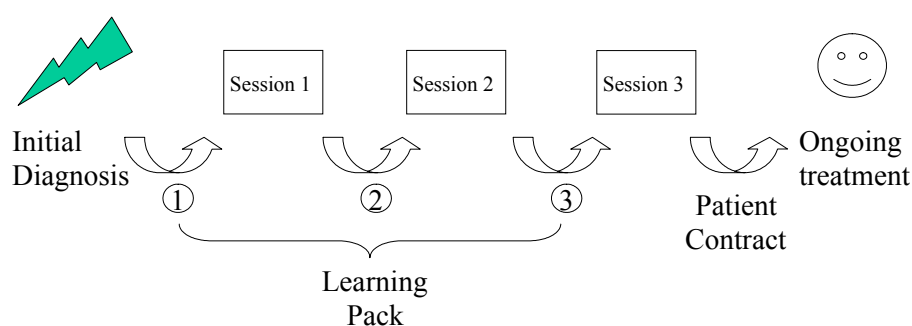


Figure 3

Effectively supporting the three education sessions placed a great onus on the quality of the education material. Hand-out materials were used in the other programme. These were leaflets and other printed materials published by the NHS, Diabetes UK and other sources. It was recognised that these would not suffice for the patient-orientated programme, however. This required tailored material that directly supported the content and the teaching style of new programme. The development of this supporting ‘learning pack’ was resource intensive. This development work was led and managed by the MMU team.

The new learning pack comprises 3 separate ‘units’. These are indicated as (1), (2) and (3) in Figure 3. As noted, each unit provides patients with all the material and information needed to support the session that follows it – i.e. this is the key resource for the mediated learning conducted in each of the three education sessions. The first unit (1) provides a general introduction to the new programme, it introduces patients to what diabetes is, how it can be recognised, and the medical complications that can arise. The second unit (2) provides extensive coverage of different issues in diet and exercise. The third unit (3) addresses medication and provides in-depth information on specialist issues, such as maintaining healthy feet and eye care.

The process does not end with the third education session. Patients return to their local GPs/diabetes nurses where they continue along their diabetes pathway. Through a

patient contract titled ‘My Action Plan’, drawn up between the Diabetes Education Unit and the patient, a link is made between the education programme and the local GP practice. The contract is in part a certificate of achievement for having attended the course, and in part an agreement (of good intentions) on diet, exercise etc that the patient takes back to their local GP.

3.4.6 Addressing the diverse needs of local users

There was great diversity of educational backgrounds and needs identified in the interviews with Salford patients. It thus became clear that this heterogeneity be taken into account, and directly addressed, in the patient-orientated education programme. In addition, the interviews indicated the need to deal with the changing needs of individuals over the course of their illness pathway.

An important aspect of a patient-orientated education programme and the policy changes made by the government are ways that encourage patients to take ownership, and enable them to learn at their own pace, and in ways that are most appropriate for them. While the average educational background of residents may be low compared to the national average, the interviews revealed a great diversity in the educational backgrounds and needs amongst patients in Salford.

The interviews explored in much detail the types of messages and formats that they found most effective. The findings lead the MMU team to deliver all material at *two levels*. The first level material is provided in a simple format with an extensive use of visual images. According to most of the patients interviewed, this was the best way of introducing the subject matter and making it memorable. The second level material provides much more detailed textual information and does not use illustrative images. This material is far more extensive and detailed. This caters for the demands of better educated patients. They stated that, while they were happy to initially read introductory material, they would later want to access more detailed information. This they had found very hard to find through their own searches (e.g. over the internet). While this type of patient was fewer in number, they still made up a significant proportion of the patients interviewed.

3.4.7 Content: imparting key messages and building self-confidence

The use of visual images and basic material in the pack was honed to impart ‘key messages’. These key messages, identified by the Salford Team, form the backbone for more extensive learning. For example, understanding the role of insulin in the body is a ‘key message’ because this is a basic building block for understanding what happens when not enough insulin is produced by the pancreas.

Various mechanisms are used in the packs in order to reinforce the key messages. These take three forms. One form is a quiz. These follow each major section in the pack. A second form is the self-evaluation exercise. This involves patients applying the new knowledge to their own situations, and asking them to consider how they can improve things by changing or altering their own behaviour. For example, after learning about different food groups and their impact on blood sugar levels, patients are asked to fill in an exercise listing everything they eat that day. Thereafter, patients are

asked to consider whether they consider their diet to be healthy in general, and whether the levels of carbohydrates, protein, sugar and fat in their diets are correct.

The third mechanism used is an open section, placed at the end of each learning unit, in which patients are asked to list a set of questions and/or queries on the material they have read. These are brought to the next education session. Having worked through the learning materials, and formulated a set of questions and issues to be addressed, the discussions at the education session are 'moderated' by the Salford Team.

The moderation of the learning experience is an important part of building confidence amongst patients and over the three sessions, patients discover that it is possible to become independent, self-empowered learners. As noted above, there is a second more detailed level of material on each of the key areas covered in the programme. This is given out at the end of the course. In addition, a list of key resources – from local groups to useful websites – is provided in order to stimulate further reading, promote self-reliance, and continuing self-education after the course has finished.

3.4.8 Mode of delivery

In the very early days it was thought that the internet could be usefully employed in order to deliver one or more web-based components. However, the scoping exercise made it clear that the demographics of patients in Salford - i.e. age, education and income - together with a lack of computer and internet access amongst the sample, meant that this would not be an effective use of resources. The MMU-Salford team instead turned to more traditional paper-based resources as these were more appropriate in this case.

The first novel innovation in delivery is the idea of supporting each session with a special 'pack'. This allowed for specialisation of all materials so that these were tailored made for the education team that delivers the sessions. By integrating home-based learning materials and formal, mediated sessions, patients have more opportunity to process and learn the material. Further, specialisation of sessions, and the provision of different levels of material in the pack (i.e. basic introductory information and more advanced information) increases the chances of keeping the interest of younger, better educated, and more independent patients.

The second novel innovation is the reorganisation of the delivery into 3 x 1 hour sessions. This provides an increased number of education points, and reducing information overload on patients who need to absorb a large amount of material. In addition, it offers significant scope for efficiency gains in staff time. Under the alternative programme, material is all condensed into 2 hours, meaning that staff from each specialist area need to attend every session. By contrast, the move from 2 to 3 sessions means the material can be divided into different specialist areas and staff from each area would only have to attend 1 hour each. This saves on staff time and the number of trips that each member of staff needs to make.

There is one important negative consequence on the move to 3 x 1 hour sessions. This is increased stress placed on the organisation of sessions, in particular the hiring of venues in which to hold the patient-mediated sessions.

3.4.9 Strengthening the link between diagnosis and education

The patient-orientated programme has a number of further benefits. First, because the first part of the education pack is distributed prior to the first education session, the time between initial diagnosis and the start of the learning process is reduced. Second, because the material is standardised, this ensures that all patients from all GP practices receive the same information early on. In the scoping exercise it became clear – from interviews with patients and practitioners – that there exist enormous differences in what patients are told by local practices, and the quality of the information that is disseminated.

Improving the quality of information delivered as early as possible may also assist in increasing the total number of referrals that actually attend the education sessions, and increase the percentage of particular types of patients – i.e. males - that attend the education sessions.

3.5 Piloting and test instruments

The two alternative education models were rolled out and piloted in 2004. The first to be piloted was the high quality ‘traditional’ model of formal teaching. This was from January to the end of March 2004. The patient-orientated programme was rolled in April 2004 and was run through to the end of June 2004.

A set of test instruments is used for programme evaluation by the MMU team. The objective is to evaluate the short and long-term impacts of the two programmes. Short term data was collected during 2004. The long-term data is being collected in 2005. All data will be evaluated in 2005.

The short term data comprises

- (1) a questionnaire to evaluate the immediate learning outcomes of the programmes
- (2) the percentage of males and females attending each programme
- (3) the ratio of referrals to ‘no shows’.

The long-term data comprises

- (1) a questionnaire to evaluate the long-term learning impact of the programmes
- (2) blood test data to evaluate the medical impact of the programmes
- (3) a questionnaire to evaluate the extent to which individuals have become independent, empowered learners.

3.6 Future issues

Transferring the delivery of type 2 education, from the primary to the secondary health sector, has placed an important burden on GPs and local practice nurses. When the set of NICE guidelines, and relevant NSF standards, on diabetes education are defined, GPs will be much more accountable and specific targets relating to care and education delivery will be in place, which so far is not the case. On the ground, innovation in education services is being hampered by a number of factors (besides lack of experience and knowledge). Three obvious factors are:

1. A lack of existing organisational structures
2. A lack of skills/ knowledge in GP practices
3. A lack of funding for new education services, and for research and development of new/improved services

While other standards have been devised (e.g. for eye screening) and detailed guidelines are being produced, no funds have been made available for this particular aspect of diabetes care. This creates a tension between increased demands being placed on GP practices and the real resources available to meet these new demands. So far, there are no rewards for compliance.

If a new coherent and effective patient-centred education programme is identified, there exist a number of important issues to be addressed.

1. Who will deliver type 2 diabetes education? If local GPs and practice nurses do not have the appropriate skills and knowledge, then provision will need to be sourced from alternative providers. One possibility is outsourcing to private sector education providers. An alternative model is provided by Salford PCT Diabetes Education Team. Similar public sector teams could be developed across the UK using pooled funds from the PCT level.
2. Will the empowerment of patients really occur? This clearly depends on more than learning about diet, symptoms, how to take medicines etc. Will further problems be created if greater empowerment actually occurs? For example, the demand for more expensive treatments (such as blood testing kits rather than urine test strips?). Also, it takes time and resources to guide people towards empowerment. This is *not* a cheap option! This an important issue for local GP practices that are already operating at the limits of their capacity.
3. Do patients generally *want* to be empowered? The changes have also meant a significant impact on type 2 diabetes patients themselves. This creates a number of issues. For example, existing, diagnosed patients were previously used to being 'passive recipients' of health care in hospitals. Now they are being expected to take control of their own education and of their continuing health care to a far greater extent than previously. It could well be the case that a number (many?) may actually *prefer* to remain 'passive'! Indeed, the MMU Team found occurrences of this attitude during interviews with local patients.

4 Discussion

In an order to define a common methodological framework within which to study innovation in the public sector, each of the PUBLIN case studies considers 12 research statements. We address each of these in turn.

4.1 Initiation

Statement 1: Public sector innovation at the service level is problem driven

Innovation studies claims that innovation is invariably a problem-solving activity. This is as true for the public sector as it is the private sector. Our case study supports the statement. The situation or environment which defines the problem may differ enormously between the two, but (to paraphrase Milton Friedman) ‘innovation is always and everywhere a problem-solving activity’.

In our case, patient-orientated education seeks to address a constellation of interrelated issues. First, the increasing prevalence of diabetes (a chronic illness) in the UK. Second, the increased costs (to the NHS) of treating the complications associated with diabetes. Third, the question of how best to deal with the issue and ensure a high quality of patient care (the forthcoming NSF and NICE requirements). Fourth, this is set against a context what we have called the ‘fundamental trade-off’ within the NHS. This involves a maximisation of service quality while simultaneously minimising the use of highly expensive and scarce resources.

Statement 2A: Performance targets are a driver for public sector innovation.

Statement 2B: Performance targets are a facilitator of innovation.

This case study supports statements 2A and 2B, but in a very specific way (and not as they were originally intended). Targets and directives are a key means of managing within the NHS. Further, the innovation we have studied is closely tied to the development of performance targets for diabetes education. Having said this, a distinction needs to be made between innovation that follows the implementation of performance targets, and innovation that occurs before targets are implemented.

The statements have in mind innovation that follows the implementation of performance targets. In our case, the innovation *precedes*, rather than follows, the implementation of performance targets in diabetes education. Indeed, a novel aspect of the policy making in this area (itself an important innovation) is that a ‘window of opportunity’ for innovation has been purposely designed within the policy process. The process of policy learning pursued in this area encourages local experimentation, and thereafter selects and pushes for standardisation on this basis of an evaluation of the alternatives that have been developed.

This novel process of developing performance targets encourages experimentation, providing an opportunity for radical innovations as a precursor to defining and drawing up the performance targets. However, the policy process does not encourage the continuation of radical experimentation at the local level once the performance

standards and targets have been defined. In fact, it discourages it. This is not to say that less radical, more incremental, innovation may not occur at the local level as different PCTs seek to implement the directives. However, it is clear that the principle behind the implementation of directives is that a tightly specified set of targets will be adopted throughout the NHS. It remains an empirical question whether or not much innovation will occur at the implementation stage, but it is likely that relatively little room will be left for radical innovation at the local level.

Statement 3: This innovation is “top-down” (i.e. policy-led) as opposed to “bottom-up”(i.e. practice led).

This case study highlights the way in which innovation can be a circular process rather than a unidirectional (*either* top-down *or* bottom-up) process. The service level innovation we have investigated has many aspects of a bottom-up practice-led innovation, i.e. it is a local initiative by two public sector institutions that brings together expertise in education and medicine in order to experiment with new models of education within diabetes. Yet, as just discussed, this local level innovation is closely tied to a wider national context. While it is not a reaction to the implementation of a set of specified performance targets and quality standards (it precedes them), the innovation is part of a wider process in which national targets and standards are being developed.

This highlights the extent to which the innovation process is an iterative and complex process. The statement, however, is shaped by a binary either/or assumption – it adopts a uni-directional perspective in which innovations are initiated, defined and driven either from above, or from below. In our case study it is not easy to draw a clear distinction and to label it as one case or the other. This is because the emerging standards in diabetes education at this particular moment in time are being shaped within a complex multi-level environment.

We would characterise the process in the following way. A top-down induced opportunity for radical innovation (a window of opportunity) is being created at the NSF and NICE policy level. At the local level, highly innovative programmes are being experimented with. Important differences exist between the programmes as different groups explore what a patient-orientated education programme actually is, what it looks like, and how effective it can be compared to more traditional, didactic education programmes. These local experiments provide the learning inputs for effective standards setting. Once the evaluation process has taken place, the nature of the policy process changes. Standards are then implemented and these are directives which the local level must adhere to. This process is represented in Figure 4.

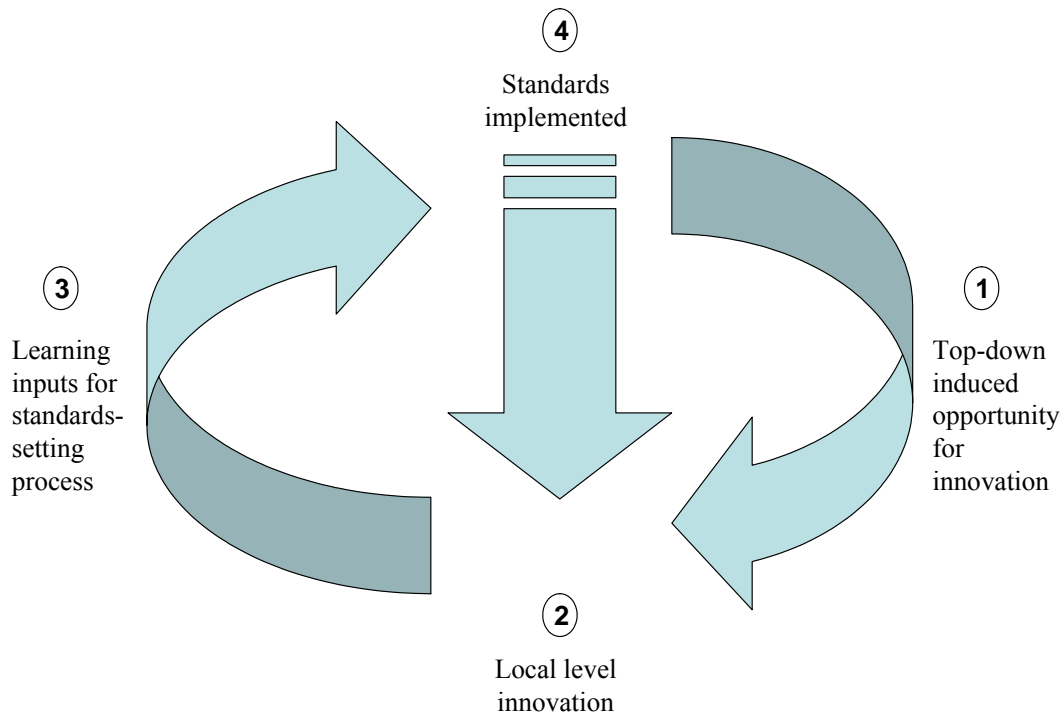


Figure 4.

4.2 Design and Development

Statement 4: The innovation is developed through imitation of private sector practice.

The statement is incorrect for this case study. The new service has been developed through the interaction of expertise and knowledge developed within health and education. Health and education are perhaps the clearest examples of public sector institutions in which innovation and the development of new knowledge occurs with minimal or no influence from the private sector. Alternative education programmes, such as those devised in Blackburn and Liverpool were also born out of academic-health institutional interactions (although these took the form of PhDs conducted by students working in the area rather than a funded project).

To date there are no private sector providers of diabetes education. This is not to say that none will exist in the future. Rather, it probably reflects the current commercial situation. Private sector firms do not typically engage themselves in high risk, basic science because there are no clear opportunities for making returns or establishing market niches. The same is true of basic research in education. The people engaged in the diabetes project therefore did not have an opportunity to take cues or ideas from the private sector but from within their respective public sector fields.

Statement 5: The choices and features of this innovation are influenced by underlying organisational politics, dominant values and beliefs systems.

Again, there is not a clear answer to this statement. It is true to say that the choice and features of the innovation are influenced by two general principles. First, the fundamental trade-off that exists between maximising the quality of service and the need to work within a set of cost and resource constraints. Second, there is the concept of patient-orientated education and the belief that this is beneficial to patients. But scratch the surface, and one finds that different individuals hold very different perspectives on each.

Take the different attitudes to the fundamental trade-off. In general, medical practitioners tend to focus far more on medical efficacy. The criteria of selection which they highlight tend to be those that consider medical benefits and potential risks. Cost is taken as a given factor within which one must operate. By contrast, political stakeholders typically focus on the cost side. They see innovation as addressing ways in which significant savings can be made in the organisation and running of the NHS. As a consequence, determining the merits of an innovation requires going beyond the clinical benefits. One must also consider indicators on the economic and efficiency gains of an innovation. So there is not a single 'dominant' value or belief system within the NHS. Different stakeholders hold differing values and belief sets. A successful innovation – i.e. one that is able to diffuse – is one that mediates between, and appeals to, these different value and belief sets.

The core issue studied by the service innovation studied is 'what *is* patient-orientated education?' Again, though the term is widely used, the definitions and attached meanings can differ enormously. Consequently, the types of programmes that are being developed on the ground differ enormously. The widespread adoption of a term, or concept may to some extent be related to its plasticity, i.e. it can sustain multiple different nuanced meanings and it is this plasticity which holds different stakeholders around it. Yet, on the other hand, there must be a commonality of shared meaning(s) that enable stable stakeholder relationships to form.

The MMU-Salford team engaged in the innovation as a means of exploring what a patient-orientated education programme could look like, how it could be organised and run, and what the advantages and disadvantages of such a programme is compared to a didactic education programme. In other words, it was very much an experiment in basic research. Drawing on their pedagogical knowledge and experience, the MMU team took the lead in devising a facilitation-focused approach. Group facilitation is one possible means of making education patient-orientated. It is the patients themselves who put forward issues, raise queries and seek to develop answers within a collective group. The process requires inputs of information, and so the facilitation process is supported by a specially designed education pack. In this environment, the role of the educator is not primarily that of an information disseminator (as it is in a didactic learning environment). Instead, it is that of a facilitator. A facilitator mediates the discussion, supporting a collective learning process in which the different strengths of individuals within a group are used to address the issues, queries and problems of members within the group. It is through this interaction process that individuals learn to become more self-confident, to realise that it is okay to state one's problems in understanding something because this is a first step to learning. Collective interaction is a key means of learning. Learning how to frame appropriate questions and how to

communicate these effectively are the other key skills that are learnt. Further, the supporting education pack provides information that supports this process *after* the education sessions have ended. As well as providing written material on different topics, at different levels of technical detail, it provides weblinks and other key information sources that encourage patients to continue the process of self-learning, and to enable this to take place as and when patients feel they need it.

To conclude, the detailed choice and features of service level innovation were made against a general background in which there exists a fundamental trade-off between efficacy and cost, and a widely held belief that patient-orientated education is a potentially beneficial path to follow. But there is not a single commonly shared perspective on either of these. Further, in terms of the actual detail of the choices made and the features of education programme that was developed, these were really determined by the MMU-Salford team. The features were very much driven by this team and its beliefs about education.

Statement 6: The end user was involved in the innovation process.

The evidence of this case study supports the basic statement. The MMU team conducted an intensive scoping exercise that involved detailed interviews with patients before the innovation was developed. This was done in order to establish effective design features and mode of delivery. The MMU and Salford teams also drew upon their practical knowledge and experiences in education.

Having said this, patients were not direct participants in the *design* of the innovation. The aim of the MMU-Salford team was, rather, to increase the likelihood of the innovation succeeding and having an impact. It was for this reason, for example, that it did not go down the path of an ICT-supported programme. This was found to be inappropriate for the target group of patients within Salford. Also, the scoping process highlighted the benefits of using images in order to convey messages. So there is something missing from this statement. In health the focus is always about impact. This is as true for local practitioners as it is policy makers who will evaluate the different education programmes.

4.3 Selection, Diffusion and Utilisation

Statement 7: The diffusion of the innovation required effective 1) networking 2) competence building 3) alternative thinking.

The case study supports the statement. Radical innovation requires ‘thinking outside the box’. At the same time, any innovation in this area will not diffuse if its developers do not engage key stakeholder groups. There are many of these in the area of diabetes in the UK. They include Diabetes UK, the NICE and NSF bodies, and PCTs across the country.

Statement 8: The diffusion of this innovation required co-ordination between different governmental institutions and/or departments.

No. In this case, the innovation does not depend on coordination different governmental institutions and/or departments.

4.4 Evaluation and Learning

Statement 10A: Evaluation played a critical role in the innovation process.

Statement 10B: Research institutions played a critical role in the innovation process.

Statement 10C: Interaction with other institutions/firms played a critical role in the innovation process.

The case study strongly supports the different aspects of statement 10 (i.e. parts A, B and C).

Evaluation will play a critical role in determining which, of the alternative education programmes that have been developed, will become the basis for a national standard. Yet, it is not clear what evaluation criteria will be used in the selection process – hence the great diversity across the programmes and the high degree of uncertainty faced by the local education entrepreneurs that have developed them.

Researchers within public sector, non-NHS institutions (notably universities) have played an important role in a number of the education programmes that have been developed. These researchers have worked closely with local NHS and other non-private sector institutions (e.g. the charity organisation Diabetes UK) when initially developing their programmes, and subsequently.

4.5 Other Issues

Statement 11. Public sector ‘entrepreneurs’ played a central role in the innovation process

Public sector entrepreneurs have been essential to the development and testing innovative diabetes education programmes across the UK. For example, the Salford Diabetes Education Team owes its existence in large part to the vision and actions taken by Dr Robert Young, a leading UK expert on diabetes. He pushed for the pooling together the GP resources in order to set up a dedicated education unit. If this unit had not been created, then it is very unlikely that the MMU-Salford collaboration would have later occurred.

The Manager of the Community Diabetes Team, Jackie Steadman, is a second example of a public sector entrepreneur in Salford PCT. She leads has built a team of highly competent specialists that look to take on new ideas from elsewhere, and to apply them

in new ways in their area. This team is continually seeking to improve the quality of diabetes education they deliver, and continually experiment with new educational practices.

Statement 12. There was no interaction between policy and service level (feed back).

This statement is incorrect for this innovation. The story here is one of a complex set of interactions across the different bureaucratic levels of the NHS, of the playing out of inherent demographic problems for the NHS, and of power struggles between different levels in the NHS and between politicians and NHS practitioners.

An important part of the interest in this case study is the way in which a pseudo-market for innovation has been established in this area (see statement 3). There is real interaction between policy level innovations and the stimulus of service level innovations. At the policy level this involves a new way of organising a stimulus for new innovation, encouraging experimentation and competition between different researchers, followed by the establishment of national standards following a critical evaluation of the various service level innovations. We have characterised this as a top-down induced opportunity for radical innovation, created at the NSF and NICE policy level.

5 Conclusions and Policy Prospects

The word ‘innovation’ is not commonly used in the public sector. Instead, terms such as ‘policy change’ and ‘reform’ are used. But, as this report has shown, innovation most certainly exists in the public sector. Indeed, the report has not simply discussed one innovation but rather a number of interconnected innovations. Some are found at the policy level, some at service level, while others cut across the policy and service levels. 6 different categories of innovation have been discussed in the report: conceptual innovation, systemic innovation, policy innovation, administrative/organisational innovation, service product innovation, and service delivery innovation.

Conceptual innovations cut across the policy and service levels. These have played a prominent role in our discussion. Conceptual innovations are often associated with new ‘world views’ that challenge established view about the world. Consequently, conceptual innovations challenge the logic and legitimacy of established services, processes, organisational structures, and even institutions. Patient-orientated education is underpinned by two novel concepts that are closely tied together: consumerisation and patient empowerment. These novel concepts engender a fundamental reassessment of what services should be produced in the NHS, by whom, in what way, at what time, under what type of relationship structures, employing which particular management practices, under what contractual obligations, and so on.

At the policy level, there has been discussion of policy innovation and systemic innovation. Through privatisation, and the contracting-out of public services, the NHS has undergone significant systemic innovation over the last twenty years. New relations

between the NHS and private sector firms, and non-governmental organisations, have been forged and these have fundamentally changed the NHS, and the public welfare system in the UK at large. Policy innovation at the ministerial level has been an essential feature of change within the NHS over this period. This typically takes one of two forms. First, incremental policy innovations can occur, based on policy learning by government ministers. Second, there is radical policy innovation; a sea change in policy that is often sparked by conceptual innovations.

Administrative/organisational innovation alters the institutional structures in which managers and staff interact. This may involve significant changes in interaction between front-line health practitioners and patients, and the range and quality of supporting services provided to front-line practitioners. Type 2 diabetes care has been shifted to primary care trusts - new institutional structures within the NHS that themselves represent a large-scale organisational innovation.

At the service level, the discussion has focused around new product innovation, in the form of a new education programme in Salford PCT, and service delivery innovations that improve the timing and impact of services.

Significant overlap exists between these 6 categories of innovation and recent research on private sector services innovation. True, the services that are produced and delivered differ, as do the number of stakeholders that directly impact upon the innovation process (in the NHS the number of stakeholders is greater than in the private sector). But our case study suggests that the same *generic types* of innovation activities are found in public sector and the private sector.

By studying the innovation activities that occur in the public sector, we find that a number of themes emerge that are well-known in studies of private sector innovation and diffusion. Importantly, our service level case study highlights the significance of management, creativity, and entrepreneurship in the public sector. This does not sit easily with the traditional Weberian image of static bureaucracies in which new ideas are stifled. Instead, we find innovation 'champions' and 'policy entrepreneurs'. These fit better with Schumpeter's definition of entrepreneurship: they are willing to experiment and take risks in applying, for the first time, radically new ideas. The Salford Diabetes Education Team is unique in the UK. In large part, it owes its existence to the vision and actions taken by Dr Robert Young, a leading UK expert on diabetes, based at Salford Hope Hospital who pushed for the pooling together the GP resources in order to set up a dedicated education unit. The diabetes education programme developed by the MMU-Salford team is another instance of entrepreneurship. The team was willing to engage in a highly experimental, previously untested form of diabetes education. The programme has its roots in mediated learning sets, previously developed in higher education, but it is a highly novel and new adaptation of mediated learning which has been developed in order to address a very different set of needs.

Of course, the environment within which innovation champions and policy entrepreneurs operate can be very different to private sector markets. Social responsibility and accountability, plus the alternative networks found in the public sector, give rise to a very different set of barriers and enablers for the diffusion of innovations. Examining the activities of these key agents, indicates a need to study the range of social, technical, and political 'management skills and knowledges' that are

employed by public sector entrepreneurs on a daily basis. This is certainly a novel idea in public policy circles!

Particular features of the NHS environment have been highlighted by the study. Prominent amongst these is the fundamental trade-off within the NHS between maximising service quality and minimising costs and resources. We have seen that this fundamental trade-off pervades all discussions within the NHS. The success or failure of a patient-orientated diabetes education programme will fundamentally depend on how it addresses this trade-off. Another key feature is the range of different stakeholders that exist. These stakeholders may have very different interests and belief systems. Four key stakeholders in diabetes in the UK are political actors (e.g. NSF and NICE), NGOs such as Diabetes UK, medical practitioners at the PCT level, and end-users. For an innovation in diabetes education to succeed, it must mediate the different interests of these different stakeholders.

Innovations that occurred at the service level were closely connected with critical incidents that occurred at the policy level. A radical policy innovation has occurred within NICE and the NSF. Traditionally, standards that are set in the public sector or by government have been *de jure* standards; i.e. they are arrived at through consultation amongst a formal panel of experts. This contrasts with *de facto* market standards which emerge through a process of competition between rival technology variants (e.g. Microsoft explorer versus Netscape navigator).

As yet, it is unclear what a suitable set of standards for diabetes education actually are. Hence, NICE and the NSF have, in effect, established a pseudo market for standards innovation. They have encouraged (in the short-term at least) a window of opportunity for locally-led research into patient-orientated education. After a prescribed period of time (in this case 3 years), the window is closed and a set of standards are defined. This is a highly interesting and new way forward in policy learning. It is a hybrid that seeks to replicate some aspects of standards competition and selection in markets within a *de jure* process. Local innovation experiments provide the learning inputs for effective standards setting. Once the evaluation process has taken place, the nature of the policy process reverts to a more traditional legislative model in which standards are implemented through directives which must be adhered to the local level by all PCTs.

This policy innovation provides a challenging new way of developing effective standards. The long-term success of the education standards that emerge at the end will depend on how two issues are dealt with. The first issue is the extent to the standards address a sense of audience, i.e. will they be able to deal with different local needs? If they are too prescriptive then they will leave no room for local variation. On the other hand, if they are too vague and general then they will not raise the quality of care. For example, it is no use promoting eating 5 fruit and vegetables each day, or regular exercise, because these generic messages are already being promoted elsewhere within the NHS. It could well be that the reforms to the structure of the NHS in recent years may assist in dealing with this. Since responsibility for implementation in the NHS has been devolved to the local PCT level, flexibility may be ensured by enabling PCTs to deal with local variation in implementation. If a balance is struck in the standards then local practitioners may be able to implement them with sufficient scope to deal with local variation. This avoids the problem of trying to cater for the different local needs within the standards themselves.

The second issue concerns the opportunities for continuing innovation over the long-term. The current process presumes that an optimal set of standards can be identified within a very short period. Hence, the pseudo market for radical innovation is only encouraged for a short period. Yet the success private sector markets lies in their openness to continued innovations over time. Technologies, products and ideas are constantly being overturned by new ones. This is not allowed for under the current arrangements of NICE and the NSF. Consequently, there is a danger that the NHS could become locked-in to a set of suboptimal standards. Subsequent innovations, if they are allowed to occur, may reveal that a better set of standards are possible. If this is a real possibility - and the history of technological innovation and scientific discovery suggests it is - then a pseudo market of innovation in diabetes education should be an ongoing, not a short lived, component of a long-term process of standards setting.

If new standards are to succeed then they must have an impact. In this case, they must affect a change in the lifestyle of diabetics. For this to happen, patients need to buy into the ethos of consumer empowerment. Do enough diabetes sufferers really wish to become independent, empowered, and independent consumers who are responsible for their own diabetes health? This brings us to a core topic issue in the report: the concepts of consumerisation and empowerment that underpin the idea of patient-focused education.

We need to recognise the differences that exist between customers of different types of services. Analogies between customers of health services and consumers of domestic household goods, for example, can quickly break down. Decisions between which brand of the cornflakes to purchase, and the long-term impact of such decisions, are very different to the lifestyle changes that are required in order for patients to improve their diabetes health.

The scale of commitment required by the user is also vastly different. It is far harder to become an empowered, independent learner and to fundamentally change one's lifestyle than it is to go out and purchase a packet of cornflakes, or a new car, or a package summer holiday. Herein lies a major conundrum for those pushing patient-orientated diabetes education. Diabetes sufferers are one of the hardest audiences to change. They tend to be older people, and their condition is linked to a history of poor diet and exercise. It is these bad habits which need to be broken. Yet they are of an age where it is very difficult to learn new tricks. Are they now suddenly going to change? Like smokers, they diabetes 2 sufferers know their behaviour is bad for their health. But they may be extremely loathe to change their existing lifestyle, and the difficulties faced in doing so (even if committed) are enormous.

The attempt to use consumer rhetoric, while simultaneously seeking to shift the onus of responsibility from the provider to the client, is fraught with its own dangers. Diabetes patients could turn around and, using the consumer analogy, suggest that the responsibility is on the NHS to 'make them well'. After all, enormous sums of money, raised through their taxes, are paid into the NHS. In return, they could argue, they expect a high quality service from someone else. In other words, the consumer analogy can be used to shift responsibility back to the provider.

Looking ahead, other issues will need to be addressed. For instance, who will actually deliver diabetes education at the local level? As noted, in an attempt to minimise costs

and maximise quality, responsibility for type 2 diabetes patients has been shifted from secondary care to primary care. Unfortunately, not all local GP practices have sufficient competences in this area. If they are to develop the necessary skills then resources will be needed for training in GP practices. Yet GPs and practice nurses are not professional educators. It may prove difficult to turn them into accomplished education practitioners. If this is the case, then two alternatives are likely. One is the outsourcing of diabetes education to the private sector. A different model is provided by the Salford Diabetes Education Team. This is a novel structural and organisational innovation that provides a viable alternative which should be considered by other PCTs in the future.

The service level innovation studied by this report represents one experiment in patient-orientated education. The report has detailed the ways in which this experimental programme dealt with the concepts of consumerisation and empowerment, and with the fundamental NHS trade-off between costs and quality of provision. Other experimental programmes will differ in their content and modes of delivery if they define these concepts in a different way, or treat the fundamental trade-off in a different manner.

The report also examined how the programme tried to address variety in need. This highlights that variety in need is not only contextual (e.g. the white working-class population that predominates in Salford compared to other ethnic and socio-economic groups in other parts of the country). Variety in need is significant within a community. Patient-orientated health needs to grapple with differences between individuals. It also needs to grapple with the changing needs of an individual over time. Hence, the information pack that supports the MMU-Salford programme provides information at different levels of detail and sophistication, and provides links to further key sources of information for those who wish to pursue this, at the time which they wish to pursue it. Great effort was made to distribute learning over time, so that individuals can access information when they feel they are ready. This is in marked contrast to the didactic approach in which all material is delivered up-front to passive recipients. A key advantage of the patient-orientated approach is that it deals effectively with the problem of information overload.

In order for such a programme to work, patients must be given the skills and the confidence necessary to actually become empowered. Too often, at the policy level, it is assumed that the requisite skills, competences and self-confidence are already in place. The findings suggest that they are invariably not in place. A major policy lesson emerges: patient-orientated programmes that are successful will *not* be a cheap option because teaching people how to become more empowered is difficult and time consuming.

The report discussed how different programmes have treated the process of empowerment in different ways. The education programme developed in Liverpool spent a large amount of time in formally delivering mechanisms for empowerment. By contrast, the MMU-Salford programme tried to develop these within a practical context of mediated learning groups. This was due to necessity. The constraints on resources for the Salford Education Team are currently such that it is simply not practicable to take another course of action. Thus, different constraints lead to different innovative solutions being developed.

To conclude, this report has found innovation certainly exists in the public sector. What is more it exists across the policy and service levels and many different forms of innovation exist: conceptual innovation, systemic innovation, policy innovation, administrative/organisational innovation, innovation in service products, and in service delivery. The report finds that the public sector neither not passively imitates nor adopts innovations developed in the private sector. Instead, the public sector is its own engine of innovation. Innovation is a problem-focused activity. People working within the public sector innovate in order to address the issues and problems that they face. There is, of course, influence from private to public sectors (as there is the other way around). Of particular importance within diabetes education in the UK are innovative modes of policy learning that experiment with pseudo markets for innovation. This is not simply an imitation or adoption a private sector phenomena. It is a radical innovation in its own right. At the service level, concepts of consumers, empowerment, and the relationship between providers and clients are all being experimented with, and the outcomes being generated are novel and different to those found in the private sector.

Bibliography

BBC (2000), Blair unveils NHS Blueprint, *BBC News*, 27th July 2000, available at http://news.bbc.co.uk/1/hi/in_depth/health/2000/nhs_reform/852416.stm, December 2004.

Bosanquet, N. (1999) *A Successful National Health: From Aspiration to Delivery*, Adam Smith Institute, Adam Smith Research Trust, ISBN: 1-902737-04-0, pp.15

Cumbo, J. (2001), Better-informed patients question bedside manners, *Financial Times*, Feb. 21st 2001

ONS (2004), *Population Ageing*, National Statistics Online, 9th September 2004, available at <http://www.statistics.gov.uk/cci/nugget.asp?id=949>, December 2004

The Prime Minister (2000) NHS Modernisation, *House of Commons Hansard Debates*, 22 March 2000

APPENDIX 1

Diabetes Patient Interviews

Having diabetes

How long have you had diabetes? _____

How do you keep it under control? Diet only Medication Insulin

Prior knowledge

Did you know anything about diabetes before being diagnosed? Yes
No

If "Yes", what did you know?

What are the sources of your information?

Information given at diagnosis

On the day you were told you had diabetes, can you remember what your GP told you about your diabetes? Yes No

If "Yes", what were did you told?

- 1) _____
- 2) _____
- 3) _____
- 4) _____

Was this useful, and why? Yes No

- 1) _____
- 2) _____
- 3) _____

4) _____

On the day you were told you had diabetes, can you remember what the nurse at your GP's surgery told you about diabetes? Yes No

If "Yes", what were you told?

1) _____

2) _____

3) _____

4) _____

Was this useful, and why? Yes No

1) _____

2) _____

3) _____

4) _____

On the day you were told you had diabetes, were you given anything to read? Yes
No

If "yes" what were you given?

1) _____

2) _____

3) _____

4) _____

Was this useful, and why? Yes No

1) _____

2) _____

3) _____

4) _____

In the following few weeks after that, can you remember what the nurse at your GP's surgery told you about diabetes? Yes No

If "Yes", what were you told?

- 1) _____
- 2) _____
- 3) _____
- 4) _____

Was this useful, and why? Yes No

- 1) _____
- 2) _____
- 3) _____
- 4) _____

Post- diagnosis Information search

After being told you had diabetes, did you look for information about diabetes? Yes
No

If "no", why not? _____

if "yes", what information did you look for?

- 1) _____
- 2) _____
- 3) _____
- 4) _____

How useful was it, and why.

- 1) _____
- 2) _____
- 3) _____
- 4) _____

Where did you look and why?

- 1) _____
- 2) _____
- 3) _____
- 4) _____

Did you use any of the following services?

	Services	Used?
1	Community Diabetes Team telephone contact	
2	Salford Diabetes Integrated Foot Care	
3	Walking for all - Salford Education & Leisure	
4	Diabetes UK local meetings	
5	Diabetes centre help line (out patient centre Hope Hospital)	
6	Exercise on prescription (through GP)	
7	Diabetes UK Charity (telephone service)	
8	Diabetes ward at Hope hospital	
9	British Diabetic Association local meetings	
10	NHS direct	
11	Diabetes UK web site	
12	Balance magazine (diabetes UK)	

Are there any other Salford-based sources of information and/or services that you have used? Yes No

If “yes”, what are they and how did you find it/them?

- 1) _____
- 2) _____
- 3) _____
- 4) _____

Support

After being told you had diabetes, did anyone help you cope with the news?

Yes No

If “yes” who helped you and in what way?

1) _____

2) _____

3) _____

4) _____

Education sessions – decision and expectations

When the nurse at your GPs told you about going to a session to learn about diabetes, why did you decide to go?

What was it that made you decide to go?

What did you expect from this session?

The Education Sessions

Can you describe the session as you remember it?

Breaking down each part of the Education Session

Part 1: 'What is diabetes?'

Can you describe how this part was presented to you?

What did you learn about 'what is diabetes'?

Section 2: Diet

Can you describe how this part was presented to you?

What did you learn about "Diet"?

Section 3: Complications

Can you describe how this part was presented to you?

What did you learn about 'Complications'?

Section 4: Feet

Can you describe how this part was presented to you?

What did you learn about 'Feet complications'?

Section 5: Medication

Can you describe how this part was presented to you?

What did you learn about 'Medication'?

Section 6: Monitoring

Can you describe how this part was presented to you?

What did you learn about 'Monitoring'?

General Assessment of the Education Session

Was there anything that you particularly liked about the education session?

Was there anything that you didn't like or that you think could have been done differently (reassure her/him that the interview is 1: confidential and 2: done with the full consent of Salford's nurses 3: it is all about improving etc.)?

Was there anything that you wanted to know or talk about that was not mentioned in the session?

Yes No

If yes, what was that?

Did you ask questions during the session? Yes No

If "no", why not?

Printed Material

Here is the printed material you were given at the end of your education session.

Which of these did you find most useful (showing the whole pack to see of anything caught their attention in particular)?

Let us go look at each item so that we can get you views on it.

Looking for:

- Presentation
- Use of picture and their usefulness
- Colours
- Comprehensibility
- Level of information given
- Readability
- Usability

○ Comments:

(state pack item number for comments)

Session impacts

Did the session motivate you to change anything in your day to day life? (may need to prompt: eating, shoes, taking the medication, food shopping)? Yes No

If “no”, why not:

If “yes”, can you tell me about the changes?

Did the session help you in any way? Yes No

If “no”, why not?

If “yes” in what did it help you?

Information technology knowledge and usage

Do you know how to use a computer? Yes No

Do you use a computer? Yes No

If yes, what do you use it for (list)?

1) _____

2) _____

3) _____

4) _____

Do you like using computers? Yes No

Do you have a computer at home? Yes No

If “no”, do you have easy access to a computer? Yes No

Have you used the web to look for information about diabetes or aspects of diabetes?
 Yes No

If “No”, why not? _____

If “Yes”, what do you like about it and why?

If “Yes”, what aspects did you dislike and why?

Are there any sources of information on diabetes that you would recommend?

Personal information

Your age:

Sex: F / M

Status: Employed Unemployed Self employed Other

Education:

NVQ	Y N	HND	Y N
O'level/GCSE	Y N	BSc	Y N
A'Level	Y N	Post graduate	Y N

Other (please state): _____

Housing: Flat or House - Council/housing association or Privately Owned

Post code (1st part of your post code e.g. M21):

Income: receiving income support
 less than £10,000
 less than £15,000
 less than £ 20,000
 less than £ 30,000
 less than £ 40,000
 £40,000 or more

Thank you

APPENDIX 2

My Action Plan

Action plan for _____ for the next 6 months

I have identified the following areas for action in relation to managing my diabetes.

1) _____

- _____
- _____
- _____

2) _____

- _____
- _____
- _____

3) _____

- _____
- _____
- _____

Signed (patient) _____ Signed (nurse) _____

Date _____

On the PUBLIN case studies

The following general presentation is based on the PUBLIN guideline report for case study researchers. See also the introduction to the case study summary report.

The overall aim of this PUBLIN study has been to gain insights into the processes of innovation and the associated policy learning in the public sector. These should contribute to the development of a theory (or theories) of innovation in the public sector, and contribute usefully to policy analysis. Within this study framework, the aims of Work Packages 4 and 5 (the case studies) have been *to understand the interplay between policy learning and innovation at the policy level, and innovation at the service level within the public sectors under study.*

More specifically, the objectives of each Work Package are:

1. To understand the innovation processes present within national public health systems/social service systems.
2. To understand the learning processes underlying policy development in publicly regulated health/social service sectors.

Innovation

Green, Howells and Miles (2001), in their investigation of service innovation in the European Union, provide a suitable definition of the term innovation which denotes a process where organisations are

“doing something new i.e. introducing a new practice or process, creating a new product (good or service), or adopting a new pattern of intra – or inter-organisational relationships (including the delivery of goods and services)”.

What is clear from Green, Howells and Miles’ definition of innovation is that the emphasis is on novelty. As they go on to say,

“innovation is not merely synonymous with change. Ongoing change is a feature of most... organisations. For example the recruitment of new workers constitutes change but is an innovative step only where such workers are introduced in order to import new knowledge or carry out novel tasks”.

Change then, is endemic: organisations grow or decline in size, the communities served, the incumbents of specific positions, and so on. Innovation is also a common phenomenon, and is even more prominent as we enter the “knowledge-based economy”.

An innovation can contain a combination of some or all of the following elements:

- New characteristics or design of service products and production processes (*Technological element*)
- New or altered ways of delivering services or interacting with clients or solving tasks (*Delivery element*)
- New or altered ways in organising or administering activities within supplier organisations (*Organisational element*)
- New or improved ways of interacting with other organisations and knowledge bases (*System interaction element*)
- *New world views, rationalities and missions and strategies.* (Conceptual element)

Case study statements

In an effort to define a common methodological framework within which to study innovation in the public sector, several research orientation statements were put forward and related policy questions suggested.

These give a '*problem driven view*' of the issue under study. It should be strongly emphasised that this list was only intended to be indicative of what propositions might be tested and it was revised during the course of the PUBLIN study.

For instance, the following statements were added to the ones listed in the table below:

Entrepreneurs played a central role in the innovation process

- Was there a single identifiable entrepreneur or champion?
- Was the entrepreneurs assigned to the task?
- Had the entrepreneurs control of the project?
- What was the key quality of the entrepreneurs? (management, an establish figure, position, technical competence, access to policy makers, media etc)
- Incentives

There was no interaction between policy and service level (feedback)

- To what extent was the policy learning a result of local innovation?
- Are local variations accepted, promoted or suppressed?
- To what extent does the innovation reflect power struggles at the local and central level?

- Was there dissemination of the lessons learned, and was this facilitated by specific policy instruments?
- Where there evaluation criteria? (When?)
- Who were the stakeholders that defined the selection criteria? Did problems arise due to the composition of this group of stakeholders?
- How did the interaction and/or the interests of the stakeholders influence the selection of the indicators used?

Policy recommendations

Based on your experience from case studies, give concrete policy recommendations.

1. Present also policy recommendations given by the respondents
2. Are there any examples of “good practice”?

The case study reports all try to comment upon these statements.

Moreover, all participants were also asked to use a comparable design for the case study itself and for the case study report.

Service Innovation		Policy Learning	
Statements	Questions	Statements	Questions
Initiation		Initiation	
Public sector innovation at the service level is problem driven	What was the primary rationale for the innovation under study? Were there supporting rationales? Was the innovation developed proactively or reactively? Where did (recognition of) the need for the innovation originate?	Public policy learning innovation is problem driven.	How can specific problem-orientated policy innovations be transformed into more general forms of policy learning? Is policy learning largely a reactive or proactive process?
Performance targets are a driver for innovation. Performance targets are a facilitator for innovation.	What are the most appropriate incentives and drivers for innovation in the public sector system under study? Be aware that it may be a driver and not a facilitator	Policies directed at performance measurement are a driver for policy innovation Policies directed at performance measurement are a facilitator of policy innovation	What are the most appropriate incentives and drivers for innovation in the public sector system under study? Be aware that it may be a driver and not a facilitator
This innovation is “top-down” (i.e. policy-led) as opposed to “bottom-up” (i.e. practice-led).	Does the location of the pressure for the introduction of an innovation impact its diffusion and development? Each country case should describe to what extent it is a top-down or a bottom-up innovation	This innovation is “top-down” (i.e. policy-led) as opposed to “bottom-up” (i.e. practice-led).	Does the location of the pressure for the introduction of an innovation impact its diffusion and development? Each country case should describe to what extent it is a top-down or a bottom-up innovation
Design and Development		Design and Development	
This innovation is developed through imitation of private sector practice.	Where did the innovation arise? Does it have models outside or inside the public sector?	This innovation is developed through imitation of private sector practice.	Where did the innovation arise? Does it have models outside or inside the public sector?
The choices and features of this innovation is influenced by underlying organisational politics, dominant values and belief systems	To what extent have the choices and features been driven by conflicts (specify: power, funding, belief systems ... etc) between different stakeholders? How did the introduction of the innovation overcome the resistance to change at the service level?	The choices and features of this innovation is ° influenced by underlying politics, dominant values and belief systems	To what extent have the choices and features been driven by conflicts (specify: power, funding, belief systems ... etc) between different stakeholders? How did the introduction of innovations overcome the resistance to change at the policy level?
The end user was involved in the innovation process	What was the role of the end user? Were they involved in order to improve the design features or to increase	The end user organization was involved in the innovation process	What was the role of the end user organisation? Were they involved in order to improve

	acceptance of the innovation and/or for other reasons? If they were not involved, explain why.		the design features or to increase acceptance of the innovation and/or for other reasons? If they were not involved, explain why.
Selection, Diffusion and Utilisation		Selection and Deployment	
The diffusion of the innovation required effective <ul style="list-style-type: none"> 1. networking, 2. competence building and 3. alternative thinking 		The selection and deployment of the innovation required an environment that encouraged effective <ul style="list-style-type: none"> 1. networking, 2. competence building and 3. alternative thinking 	
The diffusion of this innovation required co-ordination between different governmental institutions and/or departments	How can inter-governmental roadblocks be by-passed? To what extent does intra-governmental co-ordination depend on direct political interaction? To what extent does intra-governmental co-ordination depend on stimulus from a crisis situation? Does fragmentation of government create a barrier?	The most challenging public policy innovation takes place at the intra-governmental (inter-functional) level.	How can inter-governmental roadblocks be by-passed? To what extent does intra-governmental co-ordination depend on direct political interaction? To what extent does intra-governmental co-ordination depend on stimulus from a crisis situation? Does fragmentation of government create a barrier?
Evaluation and Learning		Evaluation and Learning	
Evaluation played a critical role in the innovation process Research institutions played a critical role in the innovation process Interaction with other institutions/firms played a critical role in the innovation process	Did the innovation meet the expectation of the stakeholders at various stages of the innovation process? Did the innovation have unintended consequences (e.g shifting bottlenecks)? Did the innovation induce other innovations? Is there evidence of policy learning and any associated structure? Had lessons been drawn from earlier innovation processes?	Evaluation played a critical role in the innovation process Research institutions played a critical role in the innovation process Interaction with other institutions/firms played a critical role in the innovation process	Did the innovation meet the expectation of the stakeholders at various stages of the innovation process? Did the innovation have unintended consequences (e.g shifting bottlenecks)? Did the innovation induce other innovations? Is there evidence of policy learning and any associated structure? Had lessons been drawn from earlier innovation processes?

