User Involvement in Change Management: A Review of the Literature

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The customer is always right

((Attributed to) Gordon Selfridge, 1909)

We are here to consult the interests and not to obey the will of the people, if we honestly believe that that will conflicts with those interests

(Robert Peel, 1831)

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Executive Summary

Background

Plans for modernising the NHS aim to improve the quality of care that is provided by ensuring that services are focused on the needs of patients. Involving service users in the process of change is seen as central to achieving this aim. While the potential value of user involvement (UI) in the NHS has long been recognised, previous initiatives have proved difficult to implement. The involvement of service users in the private and voluntary sector has a longer history. In the private sector the survival and growth of a company may depend on its ability to identify and meet the preferences of service users; some voluntary sector services have been created by users to meet needs not addressed by other providers. At a time when health service managers have been given a statutory duty to consult users when planning changes to services, information about how successful UI can be achieved is urgently required.

Aims and methods

We set out to review literature on user involvement in change management across a range of sectors in order to identify factors that promote successful UI. We sought to critically review the literature in order to consider the relevance of these factors for current efforts to involve users in change management in the NHS. Our focus was on change at a local level in order to inform practice within hospital and primary care trusts.

We sought to identify relevant literature through an electronic search of databases and web sites, a hand search of relevant journals and libraries, and contact with experts in the field. Papers that addressed study aims and were published in English between 1980 and 2002 were included in the review. Data extracted from these papers formed the basis of a thematic analysis.

Results

Our electronic search of databases generated over 3000 reports for possible inclusion in the review. Examination of the title and abstract of these reports resulted in 806 papers that were examined in detail and considered for inclusion in the review. We identified a further 168 papers through hand searching journals and libraries, 80 from references cited in other papers, 29 from contact with experts, 10 from user and patient groups and 15 from web sites. Information drawn from these 1108 papers, of which 344 are cited in this report, forms the basis of this review,.

We found little evidence of independent research in any of the sectors that we examined. Most of the reports were discussion papers that illustrated points raised with reference to brief case studies. What research we did find was mainly from health, social and welfare sectors. This was generally in the form of qualitative process evaluation of user involvement initiatives or surveys of service users and providers involved in this process. Methods of involvement that focused on obtaining the views of users (such as surveys and focus groups) were seen throughout the sectors we examined. In the public sector forms of involvement that required a greater degree of commitment from users (such as deliberative approaches, meetings with user groups and co-opting users into management meetings) were also found.

User involvement in health care

The drive to involve users in changes to health care services in Britain and elsewhere has generally been seen as emanating from central government. User involvement has been promoted as a means of improving the effectiveness of services, improving public perceptions of service quality, enhancing accountability, and empowering disadvantaged/excluded service users. We identified evidence of a large number of different methods for involving users across a range of different settings. These included time-limited methods, which aim to obtain user perceptions and preferences, and longer-term strategies that depend on building relationships with groups of service users who are asked to participate in ongoing service review and/or change initiatives. A large number of factors have been presented as facilitating and hindering successful user involvement. Pre-eminent among these are the need for service providers to be clear about the aims of involvement and ensure that service users know what these are. Organisational and professional resistance to UI, and concerns about the ability of service users who take part to represent the views of service users in general, have also been discussed. We found a relatively small number of reports that attributed changes in services to

the involvement of service users. The impact of these changes on service quality has not been evaluated.

User involvement in other public sector services

Data extracted from reports of UI in other public sector services have much in common with data in the health care context. However, local government services have placed greater emphasis on involving local residents who may not be service users. Greater emphasis has been placed on complaints procedures within social services, and there has been discussion about the role that co-production can play in increasing the effectiveness of other public sector services. Organisational and professional resistance are frequently cited obstacles to user involvement. Problems encountered when trying to manage expectations and (often conflicting) demands of users have also complicated the involvement process. While further consideration may need to be given to the most effective methods for engaging carers, older people and children, a range of studies have suggested that these groups are at least as able and willing to contribute to this process as other groups of service users.

User involvement in the voluntary sector

We found very few reports detailing user involvement in the voluntary sector. Methods for involving users are those encountered in the public sector, though there is greater evidence of user-led services. Findings from surveys of providers of voluntary sector services challenge the view that user involvement is more widespread or more successful than in other sectors. Voluntary sector services that succeed in achieving their initial aims may struggle to expand and professionalise the services they provide while maintaining meaningful contact with their service users.

User involvement in the private sector

Involving users and potential users in change management within the private sector is considered an essential part of maximising customer loyalty and growth. In contrast to the health care sector, less emphasis has been placed on how to involve users, with greater discussion of how their views can be translated into changes to goods and services. Methods for obtaining information from users have generally been based on surveys, monitoring complaints and direct observation of customer behaviour. While there is increasing interest in the development of methods that enable users to contribute to the design of products and services, we found no evidence of user involvement in structural or policy changes within companies. Reports describing efforts that companies have made to develop user-focused services emphasise the importance of clarity of organisational aims, the influence of leadership, and organisational responsiveness to change.

Methods for gathering user feedback, systems for making front-line staff aware of the results of feedback, and financial and other rewards are judged necessary to make user-focused organisational goals relevant to employees. As front-line staff have most direct contact with users, they are seen as an important source of information about user experiences of services. Staff empowerment is also judged necessary in order to ensure that the concerns of service users can be directly addressed at the point of service delivery. A variety of reports have attributed increased demand for services, higher levels of user satisfaction and increased customer retention to changes that were based on the experiences and demands of service users. However, the quality of evidence presented in these reports is generally poor.

Discussion

Throughout the sectors, we examined a common factor motivating user involvement in the process of change: identifying and responding to what users want can lead to improvements in the quality of service provision. We found widespread agreement that clarity about the aims and limits of involvement was an essential prerequisite to achieving successful UI. A range of aims for involving users in changes to public sector health care currently exist. These include the belief that UI can enhance local democracy, improve accountability, empower service users, improve public health, and raise public perceptions of the quality of care that is provided.

A wide range of methods for involving users in public sector health care in Britain have been used. We found very few examples of ways to involve users in other sectors that have not already been used in the NHS. User involvement in the private sector concentrates on enabling service users to express their individual preferences rather than on efforts to engage them in ongoing changes to services. While users of NHS services register their concerns about the services through responding to surveys and sometimes making complaints, the willingness of large numbers of NHS service users to contribute to ongoing change through methods such as membership of formal bodies is still uncertain.

Frequently cited barriers to successful UI in the NHS include professional and organisational resistance. Evidence from other sectors suggests that these problems are not unique to health care settings. While the attitude of front-line staff has been seen as an obstacle to UI in the NHS, reports from those seeking to develop user-focused services emphasise the importance of utilising the knowledge that staff have about the needs and expectations of service users and ensuring that staff are empowered to respond to problems encountered when delivering services.

There is general agreement that in order to achieve sustained involvement of users it is important to provide adequate time and resources to enable users to make their contribution, and to ensure that those taking part receive feedback on how their contribution affected service delivery. Emphasis in the literature on the process, rather than outcomes, of UI suggests that users often do not have the information to judge whether their participation made a difference.

Attempts to identify and where possible meet the expectations and preferences of service users are generally seen as being in the interests of private sector companies and their employees. Providers of public sector health care services are required to balance the views of users with other pressures including targets set by central government, the need for clinical governance, and the views of medical, nursing and other health care professionals. Implementing changes suggested by service users that are cost-neutral and make services more efficient is a relatively simple task. Implementing changes that require reallocation of resources becomes more difficult, especially if these conflict with nationally defined service priorities. In such instances the validity of user views or the representativeness of service users who participate may be questioned. The relative absence of evidence about the impact of implementing changes suggested by service users means that service providers are also unclear about the consequences of responding to users' views.

Conclusions

Clarity about the aims of UI in the NHS is required at national and local level. We did not identify methods for involving users in other sectors that have not already been used in the NHS. Factors that promote and hinder successful UI in the NHS have been explored through case studies, surveys and the application of qualitative research methods. Barriers to UI identified in the NHS literature are remarkably consistent with those reported in other public sector services. While available evidence suggests that UI has led to changes in service provision, the impact of these changes on service quality has not been examined. Findings from our review of UI in the private sector emphasise the importance of factors other than obtaining the views of service users that are necessary for the development of user-focused services. Enhancing the capacity of NHS trusts to successfully manage change, and greater involvement of front-line staff, will also be required if the aim of developing a patient-centred NHS is to be achieved.

Recommendations for future research

- Independent evaluation should be undertaken of the impact of changes based on implementing the views of service users, including quantitative comparative research and economic evaluation of the costs and benefits of different methods of involving users.

- Research is required to identify when and how service users in different treatment settings are most willing and likely to contribute to the process of change within the NHS.

- Action research should be conducted in order to maximise organisational learning with regard to the implementation of new methods for involving service users (such as user involvement in electing boards of governors of Foundation Trusts and systems for supporting sustained user involvement in Patient and Public Forums).

- Research is also required to evaluate innovative methods for developing patient-focused services: these include research aimed at improving change management in the NHS and an examination of the impact of involving front-line staff in initiatives aimed at improving patient perceptions of the quality of care they receive.

The Report

Chapter 1 Background and methods

1.1 Introduction

Current plans for modernising the NHS aim to improve the quality of care that is provided by ensuring that services are centred on the needs of patients (Department of Health, 2002b; NHS Executive, 2000; NHS Executive, 1999). The active involvement of service users is seen as central to achieving this aim (Department of Health, 2001b). Recent legislative changes and the development of new bodies representing the views of service users are aimed at strengthening the role of service users. Section 11 of the Health and Social Care Act 2001 requires NHS trusts to consult local communities prior to introducing changes to the services they provide. Service users will be represented at board level with hospital and primary care trusts and each NHS trust will have a Patients' Forum which will aim to represent the views of local service users and will be supported by Overview and Scrutiny Committees in local authorities which will have the power to review service provision and refer contested service changes to the Secretary of State for Health. New services that aim to provide people with information about local services and facilitate the resolution of complaints are also being introduced (Department of Health, 2001a).

While the potential value of user involvement (UI) has long been recognised (Griffiths, 1983), it is acknowledged that previous initiatives aimed at involving service users have proved difficult to implement (Department of Health, 1999). Problems associated with implementing changes in the NHS are not restricted to difficulties encountered with plans for involving service users (Plamping, 1998). Recognition that, despite continuous reform initiatives, organisational and cultural aspects of the NHS remain resistant to change has led to increased interest in the process through which change is managed within health care settings (Iles and Sutherland, 2001). A range of different approaches have been taken to try to understand how and why change takes place and there is general agreement that consideration needs to be given to the context, content and process of change (Pettigrew *et al.*, 1992). While the aims of UI in the NHS have become clearer (NHS Executive, 2000) the process and organisational context of UI remain poorly understood (White, 2000; Crawford *et al.*, 2002).

Promotion of user involvement in the NHS was matched by efforts to involve users in the delivery and development of other public sector services (Barnes, 1999; Audit Commission, 1999; Office of Deputy Prime Minister, 1998). The involvement of service users (more frequently referred to as consumers or customers) of private sector services has an even longer history. In the latter part of the 20th century, liberalisation of markets and attendant competitive pressures, combined with increasing expectations of consumers, meant that companies had no option but to embrace a more customer-focused vision if their enterprises were to have a sustainable future (Vandermerwe, 1999). These pressures led to the development and implementation of a range of efforts designed to make services more responsive to the needs of customers. Available evidence suggests that firms that are able to understand and manage the customer's experience over time are more likely to succeed in the future (Vandermerwe, 1993; Vandermerwe, 2000). User involvement has also been central to the development of many organisations in the voluntary sector, many of which were initiated by users to meet needs not addressed by other providers (Robson *et al.*, 1997; Scott *et al.*, 2000).

If the NHS is to fulfil the aim of developing a service in which 'care is shaped around the convenience and concerns of patients' (NHS Executive, 2000), further consideration needs to be given to the context, content and process of efforts to understand and meet the needs of its service users. In order to assist with the development of this process we therefore undertook a literature review with the aim of identifying the aims, methods, process and outcomes of user involvement in change management across a range of different settings. We sought information about user involvement in health and social care settings in order to identify components of good practice, and compared these with UI in other sectors in order to identify areas for possible research and development.

1.2 Aims and objectives

To review literature on user involvement in change management within health and other public services, and organisations in the voluntary and private sectors, in order to:

1   identify published material that has explored the aims, process and outcomes of initiatives aimed at involving service users in change management

2   identify factors that promote successful user involvement across a range of different settings

3   critically consider the relevance of these factors for current efforts to involve users in change management in NHS hospital and primary care trusts and support the development of a patient-centred National Health Service.

1.3 Methods

The literature in the area of user involvement is large and diverse, and in varying forms. This type of literature poses particular challenges, which we chose to deal with by adapting the methods of meta-study proposed by Paterson and colleagues (Paterson *et al.*, 2001). This approach, originally developed for enabling the synthesis of qualitative research, aims for systematically developed, integrated bodies of knowledge about specific phenomena. This approach draws on the principles of systematic review, requiring the formulation of clear research questions and the use of rigorous searching strategies. It also allows the use of a range of techniques for the synthesis of research findings. In our case, we used the thematic analysis approach described by Mays *et al.* (2001).

1.3.1 Search strategy

We identified papers for possible inclusion in the study by combining an electronic search of databases and web sites, hand searches of journals and libraries, and contact with experts in the field.

1.3.1.1 Electronic databases

Databases were searched from their inception until June 2002:

• *Business and management* – European Case Clearing House (1960 – June 2002), Harvard Business School and associated libraries (1960 – June 2002) and McKinsey and Company (1960 – June 2002)

• *General academic* – EBSCO Information Services (a collection of over 100 databases with inception dates ranging from 1887 to 1990)

- *Grey literature* – European Association for Grey Literature (1980 – June 2002)

- *Social sciences* – Social Science Citation Index (1982 – June 2002)

- *Health care* – Medline (1966 – June 2002), Embase (1988 – June 2002), PsychINFO (1967 – June 2002) and CINAHL (1982 – June 2002)

- *Health care management* – HMIC and HELMIS (1984 – June 2002).

Because of diverse indexing strategies on the databases we examined, the search terms we used varied. Our general approach was to combine terms related to *user involvement* and those related to *change management*. When we piloted our search terms we found that very few reports describing user involvement in change within organisations included terms related to change management. We therefore expanded the set of terms we used to include a broad range of others related to the development and delivery of services. Where databases included subject headings we selected all those related to user involvement, change within organisations and development of services. Where subject headings were not available we used free text searches. The exceptions to this approach were the Social Science Citation Index and the European Association for Grey Literature, where the numbers of references obtained by searching terms related to user involvement were sufficiently small to enable us to examine titles and abstracts of all the references generated without the need to combine them with terms related to change and development of services. Details of search terms are provided in Appendix 1.

1.3.1.2 Search of web sites

We searched web sites of a range of governmental and non-governmental agencies using search terms related to user involvement, including:

- The Audit Commission – http://www.audit-commission.gov.uk/

- Carers on Line, a national carers organisation – http://www.carersonline.org.uk

- Consumers in NHS Research – http://www.conres.co.uk

- Charity Commission – http://www.charity-commission.gov.uk/

- Department of Health - http://www.doh.gov.uk/

- Department of Trade and Industry - http://www.dti.gov.uk/

- HAZnet – a web site presenting the work of Health Action Zones – http://www.haznet.org.uk

- HM Treasury – http://www.hm.treasury.gov.uk

- Institute of Education – http://www.ioe.ac.uk

- National Children's Bureau – http://www.ncb.org.uk

- National Consumer Council – http://www.ncc.org.uk
- National Council for Voluntary Organisations – http://www.ncvo-vol.org.uk/
- National Institute for Clinical Excellence – http://www.nice.org.uk
- Office of the Deputy Prime Minister – http://www.odpm.gov.uk/about/index.htm
- Office of Public Services Reform – http://www.pm.gov.uk/output/page465.asp
- Office of Fair Trading – http://www.oft.gov.uk/default.htm
- The Picker Institute – http://www.pickereurope.org/index.htm
- Terrence Higgins Trust – http://www.tht.org.uk

1.3.1.3 Library research

We made a series of personal visits to libraries known to be a good source of references on user involvement. In addition to facilitating collection of references that had been identified during the search of electronic databases, we used these visits and discussions with local librarians in order to search for reports that were not catalogued on electronic databases, searching catalogues, and browsing selected shelves. We visited the following libraries:

- Commission for Racial Equality
- Joseph Rowntree Foundation
- Imperial College Management School
- Institute of Education, London
- Kings Fund
- London Business School
- Templeton College, University of Oxford.

1.3.1.4 Hand search of journals

We hand searched the following 12 journals:

- *British Journal of Social Work* 1980–2002
- *California Management Review* 1995–2000
- *Harvard Business Review* 1990–2000
- *Health Affairs* 2000–2002
- *Journal of Management Studies* 2000–2002
- *Long Range Planning* 1995–2002
- *Management Learning* 1998–2001
- *Millbank Quarterly* 1990–2002
- *Public Administration* 1996–2002
- *Public Administration Review* 1996–2002
- *Sociology of Health and Illness* 1990–2002

- *Strategic Management Journal* 1994–2002
- *Urban Studies* 1998–2000.

1.3.1.5 Contact with experts in the field

We supplemented our search of electronic databases with contact with experts in the field of user involvement in health and social care. We contacted the following people:

- Dr Marian Barnes, University of Birmingham
- Professor Peter Beresford, Director of Centre for Citizen Participation, Brunel University
- Jacqui Barker, Office for Public Management
- Angela Coulter, Picker Institute
- Professor Stephen Harrison, Manchester University
- Marcia Kelson and Helen Sheldon, College of Health
- Peter Marcus, Joseph Rowntree Foundation
- Dr Pamela Raine, Department of Applied Social Science, Lancaster University.

1.3.1.6 Contact with user groups

We contacted a range of patient and carer groups via two national agencies, the Patient's Forum and Consumers in NHS Research. We posted a request for literature on the e-mail network of the Patient's Forum – an umbrella organisation of patients' information and support groups covering a diversity of health related problems – and included a request for information in the newsletter of Consumers in NHS Research, an organisation that encourages and supports the development of user involvement in health care research.

1.3.2 Selection criteria

We restricted the papers we selected to those written in English and published after 1980. Initial examination of papers demonstrated that information judged relevant to the review was not restricted to academic reports. We therefore decided not to place any restrictions on the type of material that we selected. We therefore included case studies, editorials, reviews and reports from professional, voluntary and other bodies, in addition to papers that reported findings from empirical research. Papers were selected if they addressed the aims, process and outcomes of the involvement of service users in change management.

While the phrase 'patient and public involvement' is increasingly used to describe 'user involvement' in the NHS, we decided to use the latter term in order to take account of the different contexts (local government, private sector, etc.) that we wanted to examine in this

review. We chose broad definitions of 'user' and 'user involvement' based on the definition developed by the College of Health:

> *… current, ex, and potential users and their representatives … taking an active part in [change management].*
>
> (Kelson, 1997)

The term 'user' included a variety of groups who use or may use the services that we examined (i.e. patients, carers, customers, consumers and members of the public).

We included papers that described the process of *change in the development, planning and delivery of services at an organisational level* (i.e. within individual companies, businesses or service providers such as hospital trusts and primary care trusts).

We placed special emphasis on initiatives that aimed to develop services that better meet the needs of current users of services, and on innovative approaches for involving users who have commonly been identified by service providers as difficult to engage with this process – including older people, young people, people from black and minorities ethnic groups (BME) and carers.

User involvement in activities not directly related to change management (such as campaigning for changes in policy at national level) were excluded.

1.3.2.1 Screening of papers

Titles of papers from electronic databases and hand searches of journals were examined. If the title suggested that that paper could include information that addressed study aims, abstracts were then examined. If examination of abstracts suggested that the paper might include information that addressed study aims, full texts were then examined. A final decision on whether or not to include a paper in the review was made following examination of the full-text articles, and was made solely on the basis of relevance.

We chose not to undertake formal appraisal of the papers to be included in the review. The reasons for this are several. Firstly, the papers and reports we were including were of very diverse forms, and of variable quality of methodological reporting, with problems arising particularly in the private sector reports. For example, the most common format for exploring user involvement claimed to use case study design, but many studies reported so little of the motivation and methodology that it would be impossible to assess critically the validity of the approach and findings (Yin, 1989). Secondly, there are no agreed standards of quality for many of the study types we were including; for example, in the area of qualitative research, there are no fewer than 100 different sets of proposals on the criteria defining-high quality work. Finally, there is considerable debate about whether it is appropriate to exclude papers that fail to meet quality standards.

Though there are calls for all research to be formally critically appraised before inclusion in a review, Sandelowski *et al.* (1997) argue that it is wrong to discount studies on the basis of scientific merit, suggesting data 'germane to the purpose of the investigation' are likely to be excluded.

For the purposes of this review, we did not undertake formal critical appraisal of each paper. However, we did, when synthesising data on outcomes of UI, collect data on the nature of evidence used to support claims made for these outcomes. During subsequent analyses, we further attempted to consider the rigour and independence of these reports.

In conducting this review, we therefore prioritised papers that appeared to be relevant, rather than prioritising studies of a particular study type or that met particular methodological standards. We might therefore be said to be prioritising 'signal' (likely relevance) over 'noise' (the inverse of methodological quality), as is suggested by Edwards *et al.* (2000) when approaching a review of a diffuse topic area such as ours.

1.3.3 Data extraction

A pro forma (Appendix 2) was developed to ensure that data were extracted systematically from each full-text paper. Data extracted included the following:

- the type of paper (research, description of a project or initiative that involved service users, discussion of theory concepts, editorial/opinion)

- the organisational context that was reported (health and social care, other public sector, voluntary sector and commercial sector)

- characteristics of users (e.g. age/status) and/or service (e.g. primary care, mental health) if applicable

- the aim(s) of the review that the paper addressed (context and aims, methods, factors that promote and hinder UI and outcomes of UI)

- the relevance of the report for the aims of the study, recorded on a four-point scale in order to indicate those papers that needed to be highlighted in the review.

Detailed notes were made in order to assist with the subsequent qualitative analysis of data. Key words were assigned to each paper and entered onto a bibliographic database (ISI Research Software, 2003) in order to assist sorting and cross-referencing.

1.3.4 Qualitative analysis

The meta-study approach (Paterson *et al.*, 2001) allows a flexible approach to the choice of the methods for synthesis. Given that the body of literature we were reviewing was unlikely to be suitable for meta-analysis, we decided to undertake a thematic analysis. In particular we drew on the tabular approach to synthesising data on outcomes reported in different contexts proposed by Mays *et al.* (2001).

The thematic analysis initially involved familiarisation with the retrieved papers. We then identified concepts and themes to inform the development of a thematic framework. This comprised a series of emergent topic headings, under which the concepts of each paper could then be summarised as appropriate. Within these themes, it was possible to assess the extent to which consensus across the various contributing papers was evident, and it was also possible to identify links between the themes. As far as possible we have tried to represent the themes as a logical and coherent structure.

We grouped themes from the literature in UI into five different settings: health care, social care, voluntary sector, public sector (excluding health and social care) and the private/commercial sector. We then compared literature from these sectors in order to identify similarities and differences in the context, aims, process and outcomes of UI.

1.3.4.1 Determining the sufficiency of the sample of papers

In undertaking this type of review, researchers are often confronted with the problem that there are many more papers and reports than it would be feasible to include. Schreiber *et al.* (1997) and Booth (2001) both suggest drawing on the sampling techniques of primary qualitative research in order to deal with this problem. In primary research, theoretical sampling is conducted with a view towards the evolving theoretical development of the themes of the analysis. A researcher continues sampling until the point of theoretical saturation is reached. This is the point where, after each new interview or observation, no new relevant data seem to emerge regarding a category, either to extend or contradict it (Strauss and Corbin, 1990). This approach has already been used in a review of accident and emergency care for older people (Bridges *et al.*, 1999). We have therefore opted not to include all possible papers that might address the question of the review, but instead to purposely select papers that would help in the development, extending, or testing of themes, and that were particularly useful in illustrating the themes.

1.3.4.2 Terminology in classifying user involvement

While various attempts have been made to classify types of UI according to the role that users play and the control that users have

over the process and outcomes of their involvement (Arnstein, 1971; Calnan *et al.*, 1998; Magidson and Brandyberry, 2001), we found that descriptions of UI initiatives used terms such as 'consultation', 'collaboration' and 'partnership' inconsistently and that the terms were used differently in the different sectors that we examined. Rather than trying to classify examples of UI according to a single scheme we therefore decided to try to obtain detailed information about the tasks users performed in the different examples we studied.

1.3.4.3 Formative evaluation of the synthesis

Having collected data and synthesised data on study aims we undertook a second phase of analysis in which we presented initial findings of the review to members of the project steering group (including study applicants, academics, service providers and service users and carers involved in UI in the NHS) and local service users and providers. We used comments from steering group members in order to refine the presentation of study findings and decide which elements of UI across different settings may have relevance to UI in public sector health and social services in the UK.

1.4 Results of the search strategy

The electronic search of databases generated over 3000 reports for possible inclusion in the review. Examination of the title and abstract of these reports resulted in 806 papers that were examined in detail and considered for inclusion in the review. We identified a further 168 papers through hand searching journals and libraries, 80 from references cited in other papers, 29 from contact with experts, 10 from user and patient groups and 15 from web sites. Data extracted from these 1108 papers forms the basis of this review, of which 344 are cited in the report. Additional papers provide supporting material for issues raised in the review.

1.4.1 Structure of the remainder of this report

We have structured the subsequent sections of this report around user involvement in specific sectors. In Chapter 2 we present findings from reports of UI in public sector health care services. This is followed by chapters on user involvement in social care services, other public sector services, voluntary sector services and in the private sector. At times categorising reports in this way proved a difficult task. Several cut across these divisions, such as community care for people with chronic health problems and user involvement in public sector services that were undergoing privatisation. However, we were keen to separate the results of the review in this way in order to facilitate the interpretation of the findings and the discussion of the differences in the context and outcomes of UI in the different sectors that we discuss in the final two chapters of this report.

In Chapter 2 we detail different methods that have been utilised for involving service users in change within public health care services. As many of these methods have been used in the other sectors we decided to avoid repeating these descriptions and restricted ourselves to outlining the principal methods that had been used in each sector and any innovative methods of involvement that we had not encountered in UI in change within public health sector services.

In addition to describing outcomes of UI in each sector we have included a table which presents a summary of the findings of those reports that identified outcomes of UI in each of these sectors (Appendix 3).

Following discussion with representatives of the National Coordinating Centre for NHS Service Delivery and Organisation, we were asked to highlight examples of user involvement that had focused on the needs of people who may be socially excluded or difficult to reach for other reasons. We have therefore included a separate chapter (Chapter 7) in which we describe the involvement of children and young people, older people and people from black and ethnic minority communities. We included a discussion of user involvement initiatives that have focused on the needs of carers in this section.

Chapter 2 Public sector health care

2.1 Context and aims of UI in public sector health services

Comprehensive accounts of legislation and policies aimed at promoting user involvement in health care in Britain can be found elsewhere (Kelson, 1997; Barnes, 1999; McIver and Brocklehurst, 1999). The drive for UI in Britain is generally seen as emanating from central government but other groups including patients and the public have also played an important part in the development of UI within health care (Barnes, 1999; Simpson and House, 2002). Motivations for UI in health care and other contextual factors relating to different stakeholders are summarised in Table 1.

Table 1 Motives for/expectations of user involvement in NHS in Britain: some stakeholder perspectives

Stakeholder	Motives for/expectations of user involvement
Central government	History of policies and directives for involving users: • introduction of Community Health Councils (CHCs) in 1974 • consumerism policies (Griffiths Report, 1983; Working for Patients, 1988; NHS and Community Care Act, 1990; Local Voices, 1992) • partnership policies (NHSE Patient Partnership Strategy, 1996; NHS Plan, 2000) • recognition of carers' input into health and social care (Carers' Act 1995; Caring for Carers, 2000) • strengthening local accountability of NHS service providers: Section 11 of the Health and Social Care Act 2001; plans for Foundation Trusts (Department of Health, 2002a) • improving the patient experience (Department of Health, 2002b).
General public/ service users	• users demand better services • campaign for citizens' rights (at national and local level) • growth of public knowledge on technical aspects of medicine • growth of publicity on medical malpractice, leading to a 'general shift away from blind trust in experts' (Barnes, 1999) • more influence demanded by involuntary users (to reduce stigma and oppression) with users identifying with new social movements resisting institutionalised oppression (Croft and Beresford, 1992; Calnan *et al.*, 1998) • articulation of alternative models of disability, illness, etc.
Managers, clinicians, purchasers	• in order to facilitate public health initiatives such as mass vaccination (Rifkin, 1981) • emphasis on better management and quality control within the NHS: patients can identify poor practice (Coulter, 2002a) • recognition that patients can be 'co-producers' of their health (Calnan *et al.*, 1998), so health outcomes can be improved • user involvement diffuses responsibility for difficult decisions, may be used to legitimise preferred options of other stakeholders (Cooper *et al.*, 1995; White, 2000; Lomas, 1997b) • user involvement provides a new way of legitimating decisions about funding in an era of resource constraints (Burns-Tisdale *et al.*, 1994; Hildebrandt, 1994; Honigsbaum, 1992) • legislative requirement to implement central government directives on UI.

Within these pressures for UI a variety of different aims can be found, including the following.

2.1.1 Improving the effectiveness of services and the health of the public

Most commentators agree that a central aim of user involvement in public sector health care services is to make them more effective and, through improving service quality, to improve the health of the public (Metsch and Veney, 1976; Beresford and Croft, 1993; Barker *et al.*, 1997). Service users and carers are seen as experts who are 'often in the best position to know what they need in managing their own condition' (Hogg, 2002), and user involvement is seen as a means both to utilise this expertise, and to simultaneously make services more sensitive to the needs of patients; to 'show up gaps in thinking' (Bates, 1983). It is hoped then that changing services in response to the views of services users will make services better at meeting health needs and result in improvements in health and quality of life of current and future patients (NHS Executive, 1999).

2.1.2 Improving public perceptions of the quality of NHS care

In common with previous governments, the Labour government elected in 1997, having decided to adopt health service investment and improvement as a central aspect of its manifesto, wants the public to experience services as improved and improving. In this context improving service users' *perceptions* of quality of services is of primary importance (Ham and Alberti, 2002). The aim of 'improving the patient experience' is one of five key priorities for funding the NHS over the next three years (Department of Health, 2002b).

2.1.3 Enhancing democracy and accountability

User involvement in health care has also been seen as a way of increasing democratic accountability (Pritchard, 1993; Barnes, 1999). Moves to involve the public in local health service care provision reflect a growing interest in participatory democracy (Harrison and Mort, 1998) and are seen as a means of ensuring that services are provided fairly and equitably (Barker *et al.*, 1997). As current and potential service users pay (through taxation) for the services they receive, they have a right to contribute to how they are managed, a view summarised by White (2000):

> *Where 'exit' is not a viable alternative, due to the public monopoly on health services, 'voice' is typically seen as an equivalent, democratic expression of preferences and expectations that can help ensure accountability to the users or consumers of health-care services.*

2.1.4 Therapeutic value

It is argued that user involvement has the potential to empower those service users who take part in the process (Barnes and Walker, 1996; Barnes, 1997; Rose, 2001). Therapeutic aspects of user involvement include being an expert, running your own life, and sitting on boards with social and professional elites. The role that involvement may play in improving the self-esteem of service users has been highlighted among people such as those in contact with mental health services, who may be socially excluded (Barnes and Wistow, 1994a).

2.1.5 Obtaining public support for provider-led changes

An alternative view is that UI is not designed to devolve power to users but rather to legitimise the decisions of policymakers and administrators (White, 2000). It is argued that through consulting with service users support for decisions that would otherwise be unpopular can be obtained (Donovan and Coast, 1996; Cooper *et al.*, 1995; Burns-Tisdale *et al.*, 1994; Hildebrandt, 1994; Coulter, 2000; Honigsbaum, 1992). The Oregon 'experiment' has been presented as an attempt to minimise opposition to plans to reduce expenditure on Medicaid services for those dependent on public health care services in the USA (Warner, 1991; Bowling, 1992b), in which:

> *The public dialogue and debate it engendered … gave the appearance of accountability to a government undertaking a politically delicate task … The process served mainly to gauge the public acceptability of certain … decisions, and to ensure that [those decisions] would be politically unassailable.*

(White, 2000)

Harrison and Mort have summarised user involvement as:

> *… technologies of legitimation which can be seen as a means by which managerial legitimacy is maintained in the context of an increasingly pluralistic policy arena.*

(Harrison and Mort, 1998)

2.2 Methods for involving service users

We found evidence of a considerable range of methods being employed to involve users in change within public sector health services. These included time-limited and ongoing initiatives that are initiated by service providers and the individual and collective action of service users. Methods for involving users are illustrated in Figure 1, and the following discussion gives a brief account of the literature concerning some of these.

Figure 1 Methods of UI in public sector health care

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                    ┌─────────────────────────────────────────┐
                    │   METHODS THROUGH WHICH USERS             │
                    │        ARE INVOLVED                       │
                    └─────────────────────────────────────────┘
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INITIATED BY SERVICES PROVIDERS			**INITIATED BY SERVICE USERS**

INITIATED BY SERVICES PROVIDERS

| **Time-limited** | | **Ongoing relationships** | | **Other methods** |

INITIATED BY SERVICE USERS

- Complaints
- User groups*
- User-led research
- User-led services*
- Choice
- Political action

Time-limited

Research methods	**Deliberative approaches**
• Surveys • Interviews • Focus groups • Rapid appraisal	• Citizens' Juries • Public conferences • Deliberative polling

Ongoing relationships

With user/ community groups	**With formal bodies**
• User groups* • Local health panels • Other groups	• CHCs • Patients' groups • Advocates and link workers • Committee reps

Other methods

- Employing users and ex-users
- Media
- Audit
- User-focused monitoring
- Staff appointments
- Staff training

*   User groups and user-led services have been initiated by both service providers and service users

2.2.1 Service-led models for involving users and the public

If user and public involvement is to bring about change in health services, both lay people and providers must co-operate. However, in separating service-led from user-led models of involvement, we reflect the fact that some types of involvement are in the gift of service providers or require service providers to 'outreach' service users, while others, such as autonomous user groups, establish themselves for a range of purposes which may not even include service development.

2.2.1.1 Time-limited models

Time-limited models of user involvement include a variety of qualitative and quantitative research methods as well as 'deliberative methods' in which information is provided to people prior to obtaining their views. We describe them as time-limited because they do not create bodies (such as user groups or health panels) that can feed into future consultation exercises; and in most cases, issues raised and views given have limited relevance to future development. It may be difficult for consulted parties to monitor the outcomes of time-limited consultation.

(a) *Research methods* A well-conducted survey provides an opportunity to obtain the views of large numbers of service users in a relatively short period of time (McIver, 1991). While use of random samples allows information to be sought from a representative sample of patients of service users, such surveys often have low response rates (Hamilton-Gurney, 1994). Response rates can be improved by targeting groups of people in particular venues: surveys conducted among people in waiting areas of maternity and GP clinics often report high response rates (McCourt and Page, 1996; Bradford Health Authority, 2000). It has been argued that the quality of survey data can be improved if they are combined with those collected using qualitative methods (McIver and Brocklehurst, 1999), and the findings are fed into quality assurance programmes and repeated to measure impact of change (Kelson, 1996).

Qualitative research methods have also been used in order to obtain the views of service users. Focus groups have been recommended as a way of giving confidence to those who may not feel able to express their views in other settings (Barker *et al.*, 1997; Mullen and Spurgeon, 2000). Data collected from initial meetings should be used to refine prompts used in subsequent groups (Sutton, 1989) and care should be taken to ensure that members of groups are relatively homogeneous (Burns-Tisdale *et al.*, 1994). Rapid appraisal techniques, unlike focus groups, are

able to accommodate the views of different groups of stakeholders (Barnes, 1997).

Recent guidance from the NHS Modernisation Agency (2003) available at: www.modern.nhs.uk/improvementguides/patients, describes the application of research techniques to health service contexts, introducing terms such as 'discovery interviewing' and 'patient shadowing'. Patient shadowing involves a member of staff or volunteer accompanying a patient on their journey through the health system. While it has been recommended as a means of measuring service performance and helping to identify staff training needs (Thomas, 1996), it is important that the patient being 'shadowed' is fully aware of the role of the 'shadower', provides informed consent for them to be a party to their interactions with clinical staff and that care is taken to ensure that sensitive clinical information remains confidential.

(b) *Deliberative approaches* involve providing service users with information about aspects of health care in order to obtain the *considered* views of patients or members of the public. Citizen's Juries have been championed as offering a unique combination of 'scrutiny, deliberation and independence' (Coote and Lenaghan, 1997). While this model was developed in Germany and the USA, a series of pilot studies conducted in the UK by the Kings Fund (McIver, 1998) provides a valuable source of practical information about the process of conducting a Citizens' Jury. Groups of between 12 and 16 randomly selected 'jurors' were provided with information and opportunities for discussion and asked to address a specific question regarding the development of health care services. The evaluation stressed the importance of having a simple, answerable question, the need to allow sufficient time for evidence and dialogue, and the desirability of holding the Jury in public in order to maximise accountability. Coote and Lenaghan (1997) argued that the process has greater credibility when independent bodies recruit the jurors, and that offering payment at the end of the process can enhance sustained participation by jurors. Claims that the process provides a representative view have been challenged (Elizabeth, 1998): although random sampling enables equality of opportunity for potential jurors, juries are too small to capture the views of the community from which they are drawn. Some have argued that this model of UI is too costly to consider unless other options are considered to have failed (Elizabeth, 1998), and deliberative polling has been suggested as a way of obtaining informed views of service users without the expense associated with Citizens' Juries (Coote, 1993).

Public meetings or conferences can be also be used to access informed opinions from service users. A common strategy, the stakeholder conference, organises public participation around particular services and/or client groups, although Rose and colleagues (2002) challenge the implied equality between patients

as stakeholders and staff as stakeholders. Attendance at public meetings can be improved by using the media and by door-to-door canvassing (Bowling, 1992a). Research conducted among people who have attended public meetings suggests that they often lack the confidence to voice opinions in large meetings (Wilson and Goodwin, 1997) and would value an independent facilitator (Shepherd, 1995). Meetings are considered more successful when a clear question is asked (Kirk *et al.*, 1997) and when the aims of the meeting are explicit (Barnes and Wistow, 1994a). Observational evidence suggests that members of the public are as likely as other participants to accumulate knowledge during presentations (Wilson and Goodwin, 1997). However, concerns have been expressed that attenders at meetings are given insufficient time to consider the issues that are raised (Hendessi, 1994) and are often unrepresentative of the communities from which they are derived (Bowling, 1992a). Stratified sampling of those invited to attend meetings may help to ensure that the views of a broad range of service users are properly represented. In setting up a conference on HIV and AIDS, organisers consulted the Public Health Laboratory Service to find out the characteristics (age, gender, rural/urban residence, ethnicity, route of infection, etc.) of patients (Robinson, 1999) so as to seek representative attenders.

2.2.1.2 Models that require ongoing relationships

Two main approaches to involving users through ongoing relationships have been utilised: relationships with formal and statutory bodies which have been set up in order to provide a forum for user involvement, and relationships with community and other groups that may or may not include health service users.

(a)   *Relationships with formal bodies* Community Health Councils (CHCs) were established in 1974 and were the first nationwide structure for involving the public in health service decision making. CHCs have a vast range of different tasks including assisting and advising patients and the public, consulting them, and representing their views to health authorities and other bodies (Buckland, 1994). CHCs have helped patients wanting to set up user groups (Barker and Peck, 1987), and supported service users who advise hospital trusts (Winkler, 1987). While some CHCs have relationships with GP practices and primary care trusts, these relationships are not as well established as those with health authorities and secondary care services (NHS Executive, 1999; Chen, 1999). CHCs have been praised for providing quick responses to pressing issues, and as a useful starting point for broader initiatives aimed at involving patients and the public (Lupton *et al.*, 1995; Department of Health, 1994a), and are particularly valued as intermediaries because of their independence from service providers (Welsh Office, 1998). However, health authorities determine the level of

contact they have with CHCs, and CHCs that are most willing to criticise health authorities may also be those that are least likely to be consulted (Buckland, 1994; Lupton *et al.*, 1995). Many CHC members come from backgrounds that are not typical of the population they serve, which may reduce their ability to represent local service users (Cooper *et al.*, 1995; Mullen, 1977). Linking CHC members to other local community organisations may provide a way of strengthening links between CHCs and the communities they serve (Levenson and Joule, 1992). The importance of adequate funding, and the value obtained from providing opportunities for different CHCs together to share experiences (National Consumer Council, 1992), have also been highlighted.

(b) *Patient groups* Service providers have supported the development of a number of different types of groups that have contributed to changes in services. The term 'Patients' Council' is usually used to describe informal groups of psychiatric inpatients who meet together with an independent facilitator to discuss the services available to them (Haafkens *et al.*, 1986). Although provider staff attend only by invitation, Patients' Councils require a route for taking concerns to management (Wright, 1999; Hudson, 1999). Similarly, though usually under the direction of service providers, 'Patient Participation Groups' meet in primary care settings (Richardson and Bray, 1987; Pietroni and Chase, 1993) and 'Maternity Services Liaison Committees' meet to provide input into maternity and primary care services. We found reports of other groups that have been organised around patients with physical and learning disabilities, HIV and AIDS. These reports highlight difficulties in setting up and sustaining groups, tensions between service users and providers about what the aims of such groups should be, and concerns about the representativeness of service users who engage with groups. Some groups of patients (for example, older people who need help to move, and those with sensory impairments) require additional support and resources to participate in service development through user groups (O'Keefe and Hogg, 1999; Hawcroft *et al.*, 1996). Payment of service users (Berger *et al.*, 1996) and training (Hawcroft *et al.*, 1996) have been advocated as ways to increase the motivation of service users. Motivated service users can sometimes be recruited from other community groups (Meredith *et al.*, 1998), but this approach may fuel concerns about the breadth of opinion that those involved in UI are able to represent.

There is general agreement that patient groups need a working relationship with service providers if they are to influence services, but the way this is organised differs markedly among different groups (Hawcroft *et al.*, 1996; Gell, 1987). Service providers are seen by some as enabling groups to focus on issues that can be successfully acted on, but others see them as placing unnecessary constraints on patients' wishes. Failure to see changes resulting

from suggestions made by the group is often cited as a reason for loss of motivation to participate among group members (Ovretveit and Davies, 1988). Service providers may be unable to respond to issues over which they have no control and there is a need for personnel supporting such initiatives to be explicit about what groups may or may not be able to achieve from the outset (Pilgrim and Waldron, 1998). A commitment by senior managers to act, where possible, on the recommendations of a group is seen as central to a group having a sustained effect (Lord *et al.*, 1998). One commentator states that service providers are more likely to act on a point raised by a group if it is in the form of a written report (Gell, 1987).

Those working with patient groups are advised to have realistic expectations regarding the ability of service users to represent those who do not attend meetings (Ovretveit and Davies, 1988). Rather than aiming to present the collective concerns of users in general, such groups should aim to enable as many different opinions as possible to be voiced (Gummer and Furney, 1998). Data from patient groups can be supplemented by surveys of service users in order to obtain the opinions of those who do not attend meetings (Maxwell and Weaver, 1984).

Health panels meet several times annually in the manner of a focus group of relatively fixed membership to address questions set by health professionals (usually commissioners). Members are usually invited to join because their circumstances reflect characteristics of the local population of potential, rather than actual, service users (Bowie *et al.*, 1995). Bowie *et al.* suggest (contradicting Mullen and Spurgeon, 2000) that they are amenable to considering hypothetical questions, such as priorities for spending.

(c) *Link workers and advocates* Another strategy for developing UI is to employ link workers who attempt to enhance communication between service users and providers. Link workers may be of particular value in accessing the views of patients who speak minority languages (Bence, 1996) or those with hearing or other communication impairment (Hawcroft *et al.*, 1996). Concerns have been expressed about link workers becoming the 'sole representative of the users' voice' (Philpot, 1994; Levenson and Joule, 1992), and some safeguard against misrepresentation is introduced if service users accompany link workers to meetings with service providers (Poole, 2000). A lack of independence from service providers may make service users reluctant to engage with link workers (Survivors Speak Out, 1989), and it is advised that such workers should be managed by someone who is not directly involved in providing clinical services (Barnes and Wistow, 1994a). Patients' advocates can enhance UI by reporting the concerns of service users anonymously (Atkinson, 1999). Careful consideration needs to be given to the mechanism through which advocates provide feedback information to service providers (Higgins, 1993).

It has been argued that, in order to be effective, time and resources should be made available to advocates to allow them to follow up the outcome of the suggestions they pass on (Winkler, 1987).

(d) *User representatives at management meetings* Lay representation has been called for on committees that oversee a wide range of tasks within primary and secondary care trusts, including clinical audit (College of Health, 1994), staff selection (Bowl, 1996b) and, more recently, clinical governance (NHS Executive, 1999). While members of the public support the notion that service users should be represented at planning meetings, only a small minority express willingness to take part themselves (Leonard *et al.*, 1997). The effectiveness of lay representatives can be varied (Summers and McKeown, 1996) and is affected by the attitude of other committee members (Young, 1975). Lay representatives have been reported as feeling isolated and overwhelmed (Paap, 1978): appointing more than one lay representative to each committee (Barnes and Wistow, 1994a), enabling members to access clerical support and limiting the amount of written material users are sent may help to reduce these tendencies (Smith, 1984). Users can make a greater contribution to meetings if they are treated equally and the use of unnecessary jargon is avoided (Poole, 2000). Training for service users should be responsive to problems of immediate relevance to members (Greer, 1976). Ensuring that lay representatives have ongoing relationships with other service users either via formal bodies (Winkler, 1987) or user groups (Greer, 1976) can help to address concerns about their ability to represent users (Lomas, 1997a), (Cooper *et al.*, 1995).

(e) *Employment of service users within health care service* Within mental health services, current and former service users have been employed to support the delivery of services. A recent review of published literature on user involvement in the planning and delivery of mental health services identified reports of over 30 such projects (Simpson, 2002; Simpson *et al.*, 2002). These projects have included roles specifically designed for service users, which aim to utilise former service users' ability to establish rapport with current users, and projects that have supported users to take up generic mental health posts. Experimental research suggests that such projects can work well (for example, Solomon and Draine, 1995), with clients managed by user-employees doing as well as control/comparison groups, and in some cases requiring less time in hospital (Klein *et al.*, 1998; Clarke, 2000), and expressing greater satisfaction with living situations (Felton *et al.*, 1995; Klein *et al.*, 1998). However, concerns have been expressed that, outside of these projects, users who have gone on to seek employment in mental health services feel that their experience is disparaged rather than valued, both at recruitment and in

employment (Lindow and Rooke-Matthews, 1998). A survey of mental health trusts in London in 2000 found that mental health service users have some involvement in training and appointing staff in around two-thirds of these trusts (Crawford *et al.*, 2003), but there was no evidence of policy directed toward the formal employment of service users.

2.2.2 User-led models of involving users and the public

Not all models in which service users effect changes to health care services are initiated by service providers. The actions of individual service users can affect service delivery through pursuit of a complaint or, where available, exercising a (limited) right to choose: complaints from many users about similar failings may well effect change, if providers have a commitment to monitor and address complaints. Collectively, groups of service users have also brought about changes to service provision through providing user-led services and campaigning and political action, possibly through establishing voluntary sector organisations (see Chapter 5).

(a) *Complaints* Service users may signal the need to review or change services through making a complaint and monitoring complaints can provide a simple means of raising issues of concern to service users (Department of Health, 1994b). The number of comments and complaints can be increased by simplifying complaint procedures (Milewa *et al.*, 1999). Retrospective studies of complaints suggest that at least half concern interpersonal aspects of care (Pitarka-Carcani *et al.*, 2000; Scwartz and Overton, 1987). It is argued that complaints are more likely to lead to changes in service provision when they are open to scrutiny by an independent body such as a CHC (Winkler, 1987).

A recent national evaluation of the NHS complaints procedure reported considerable variation in the resolution of complaints at local level (internal to trusts), and poor integration of complaints procedures and outcomes into Board performance measures, and into clinical governance/quality frameworks (Department of Health, 2001b).

(b) *Choice as a method of involving service users* While choice is a method by which service users may influence service provision, opportunities to choose from a range of different options within public sector health care are very limited. In Britain the 1990 NHS and Community Care Act aimed to strengthen the role that patient choice could play in a quasi-market for health care (Saltman, 1994; Craig and Manthorpe, 1999). More recently the NHS Plan also emphasised the importance of making choices available to patients (NHS Executive, 2000). Attempts to introduce greater choice within public sector health care services in Britain and elsewhere have been discussed at length in the literature. The

literature has tended to focus on discussing theoretical advantages and disadvantages of consumerism as a system for providing public sector heath care. Attempts have been made to enhance patient choice within public health care services in Australasia and North America (Bates, 1983; Fougère, 2001). Barnes and Prior (1995) and Winkler (1987) provide further discussion of this important topic.

(c) *Groups and services initiated by users* Increasing numbers of service users are becoming involved in self-help groups or directly involved in providing health care (Wilson, 1999). Literature accessed through the Patient and Public Forum network alerted us to comprehensive internet and magazine information and campaigning support supplied to users of diverse services by voluntary sector organisations, including those for diabetes, multiple sclerosis, cystic fibrosis and Alzheimer's disease. The composition and structure of user committees can vary considerably: studying mental health forums, Bowl (1996b) found that the majority of members reported being elected to their positions, although some nominated themselves and gained membership as the only interested party (an impediment to their accountability). Membership of user-led organisations can range from including all stakeholders (users, carers, workers, managers) through to being 'separatist' (only including those self-defined as users or ex-users). An intermediary model permits professionals to be involved in some limited capacity – for example, to provide support to user members (Harris, 1989).

Services not managed by users may employ users in various capacities. Groups aiming to provide treatment and support for people with alcohol and substance misuse problems have a long history of employing service users as therapists (Trice and Staudenmeier, 1989) and experimental evidence demonstrates that user-led training for people with chronic medical conditions can bring about improvements in health (Barlow *et al.*, 1998). Users have also been involved in training mental health professionals and student nurses: in rare cases where this has been evaluated, it has been shown to influence professional practice and attitudes (Cook *et al.*, 1995; Wood and Wilson-Barnett, 1999), though how long such effects persist is uncertain. Mental health service users have also been proactive in both critiquing and offering alternatives for services (Chamberlin, 1988; Lindow, 1999; Brandon, 1991). Self-help groups for users of mental health services are rated favourably (Kopolow, 1981) and service users employed by community mental health services may prove an effective means of engaging clients in services (Lyons *et al.*, 1996). User-led organisations have also been commissioned by providers to conduct research among users, most notably in the field of mental health, where it is felt that users can speak more freely to peer researchers (Rose, 1998, 2001), particularly if their views of services are negative (Clark and Scott, 1999). Service users have also influenced the development of health

and social services through campaigning and direct political action, most notably in relation to services for people with physical disabilities (Beresford and Campbell, 1994) and people in contact with mental health services (Campbell, 1999).

2.3 Areas of involvement

In addition to the methods discussed in the previous section through which users have been involved in changes in the organisation and delivery of local services, users have been included in a variety of other forms of change. These additional areas of involvement are summarised below.

2.3.1 The involvement of patients in their own treatment and care

Over recent decades a consensus has emerged that traditional 'paternalistic' approaches to the provision of medical care need to be replaced by a 'partnership' approach (British Medical Association Secretariat, 1994; Mead and Bower, 2000). A review of the methods and implications of partnership in the treatment of individual patients is beyond the remit of this review, but is touched upon here because the willingness of providers to ascertain and address users' individual preferences may lead to more widespread change in policy and practice, as well as increased confidence in implementing involvement. While external pressures may hinder partnership (Charles *et al.*, 1999) and patients' desire to be involved in their care may vary (McKinstry, 2000), it has been argued that increasing the involvement of patients in their own care, combined with the application of information technology, has the potential to facilitate self-management and improve the effectiveness and cost-effectiveness of treatment (Adomeit *et al.*, 2001; Christensen *et al.*, 2000; Ferlie, 2001; Coulter, 2002a).

2.3.2 Development of clinical guidelines and treatment protocols

Service users are increasingly involved in drawing up guidelines on the treatment of conditions at both a national level, through NICE (www.nice.org.uk; Bastian, 1996) and at local level (van Wersch and Eccles, 1999; Carlson and Rosenqvist, 1990). In Britain, service users have contributed to the development of National Service Frameworks (NSFs) for mental health (as well as NSFs for older people, coronary heart disease patients and diabetes patients) (Hogg, 2002) which lay down national standards for service provision.

The appropriate role of the public and service users is disputed because of the current emphasis on evidence-based medicine and technology: there is dissent among professionals in relation to the competence of lay people to understand the complexities of present-day practice (Coulter and Fitzpatrick, 2000). Nevertheless, service users are increasingly represented on clinical governance committees of trusts (Crawford *et al.*, 2003). Part of the incentive for such

involvement may be a more holistic approach to evaluating treatment: if patients cannot tolerate an effective treatment, there is little value in attempting to introduce it.

2.3.3 User involvement in quality control measures

In Britain, recommendations for the use of patient satisfaction surveys as a measure of quality of service provision were made some years ago (HMSO, 1989). Since that time satisfaction surveys have been widely used as measures of the views of service users. Coulter and Fitzpatrick (2000) have suggested that the complexities of modern health care cannot be reliably evaluated using global ratings (such as 'how satisfied were you with your care in hospital X?'). The Picker Institute uses qualitative work (interviews and focus groups) to establish relevant indicators of good and bad care within the 'patient's journey' through the health service: on the basis of these, large numbers of patients receiving the same or similar clinical interventions can be surveyed to discover 'whether or not certain processes and events occurred during the course of a specific episode of care'. The Picker approach has been successfully used in national programmes, such as the planning, implementation and monitoring of the NSF for Coronary Heart Disease (Airey *et al.*, 2001).

Larsson and colleagues (1989) criticise satisfaction surveys because high ratings may derive from the low expectations of patients; one validation study (Boniface and Burchell, 2000) found the results of such surveys to be particularly inconsistent when used with South Asian patients. Draper and colleagues (2001) report on a series of surveys of new mothers between 1989 and 1999. Following radical change to midwifery models, commissioners were surprised to see no improvement in satisfaction: further work to identify and address problems in implementation was reflected in later satisfaction surveys. By contrast, development of a large-scale state-wide tool to consider inpatient care across all 92 hospitals in Victoria (Australia) was not a good guide to development, since by the time it was analysed and returned to source, some thought it out of date, and the survey format was too generalised to identify exactly where problems arose (for example, specific wards or services) and so to change them (Draper *et al.*, 2001).

2.3.4 Involving the public in health care planning

Public involvement in health care planning has been most notable in North America and Canada. In the USA, public – but not necessarily patient – involvement in regional health planning has been a legislative requirement for community mental health centres since 1963, and more generally in regional health planning since 1975 (Nutt, 1976). Sullivan and Scattolon (1995) conclude that the 1986 demise of health systems agencies (HSAs), required by law to have at least 50 per cent

consumer membership, 'essentially put an end to consumer involvement in health policy planning' in the USA (although within areas such as mental health, national strategy may encourage patient involvement (see Salzer, 1997)). Legislation also requires public involvement in health care planning in Canada. In their case study of community planning for health care by Calgary Regional Health Authority, Maloff and colleagues (Maloff *et al.*, 2000) describe how the Authority devised a comprehensive framework for the process and outcomes of public involvement, including which decisions should be taken by or with the public, and what level of influence over outcomes their views might have.

In the UK, Community Health Councils (CHCs), have played a leading role in facilitating public involvement in health care planning since 1974. It is argued that their ability to influence changes has been limited by allowing service commissioners and providers to decide if, when and how to involve CHCs, and it has been argued that those CHCs that are believed to be most likely to challenge plans of service providers may be least likely to be involved (Lupton *et al.*, 1995). Following the publication of *Local Voices* (NHS Executive, 1992) it was intended that Local Health Authorities should take a lead in ensuring that users were involved in decisions about health planning:

> *If health authorities are to establish a 'champion of the people' role, their decisions should reflect, so far as is practicable, what people want, their preferences, concerns and values.*

> (NHS Executive, 1992)

Reviews of the literature suggest that health authorities attempting to gauge public opinion seem to have found it easier to access established user and carer groups than the general public (Hamilton-Gurney, 1994; Rose *et al.*, 2002).

The US Oregon experiment (Honigsbaum, 1992) is the best-known attempt at involving the public in decisions concerning rationing. In deciding which treatments should be available to Medicaid (poor) beneficiaries, and which denied, the State authorities attempted to combine two measures: evidence-based measures of efficacy and effectiveness, and public ranking of what the minimum cover should provide. Initial work combining available measures of cost, medical outcomes, quality of life measures and politicians' preferences for preventive rather than curative medicine was laid before the Oregon public in the form of public meetings and telephone surveys. It has been argued that the project was undermined by the large number of people who refused to participate in the phone surveys, the poor attendance at public meetings, and major discrepancies between public and politicians' views, which sometimes resulted in political climb-down (for example, the permitting of transplants after a child died for want of a bone marrow transplant), but more often involved the Commission ignoring public views (Warner, 1991). It remained unclear to the public quite how the final ranking was arrived at, but it is clear that health

professionals and people using private health care services were over-represented and that few of those actually using Medicaid services contributed to the exercise (Bowling, 1992a; Bowling, 1992b; Honigsbaum, 1992). A priority-setting exercise conducted in East London proved more successful at obtaining the responses of users of local services, but difficulties encountered in balancing the priorities of local users and providers of health care services made implementing changes on the basis of the results of the consultation difficult to achieve (Bowling, 1993; Bowling and Jacobson, 1993).

2.3.5 Public involvement in attempts to improve public health

Methods employed in efforts to promote public health are outside the scope of this review as they have traditionally consisted of actions taken by health care providers to encourage people to take steps to become or remain healthy (Rifkin, 1981). More recently, developments such as Health Action Zones (HAZs) have sought to encourage local people to play a more active role in contributing to the development of services aimed at improving public health. HAZs implement strategic approaches in areas identified as having significant health problems alongside indicators of disadvantage and social exclusion (poor housing stock, high unemployment, etc.). They are specifically designed to create capacity, and promote joint working, by bringing together 'synergistic' partnerships between statutory, voluntary and community agencies responsible for both health and non-health resources, with joint local governance structures accountable for funding. This model is essentially similar to that of Single Regeneration Budget, New Deal for Communities, and other regeneration programmes, with initial 'kickstart' funding assuming the generation of additional resources from a variety of sources. HAZs have a complex and ambitious remit which seeks to improve capacity for joint and cross-agency/sector working, as well as improving public accountability, building new governance systems and improving health (Barnes *et al.*, 2001). Improving access to, and amalgamating, existing services, rather than the development of new services, may be a key feature, with 'virtual' healthy living centres to promote information transfer and self-help strategies. Our specific interest is in emerging evidence about the engagement of local people in HAZs: Westland and Unwin (2000) have written a preliminary report on this aspect (downloadable from www.haznet.org.uk).

Stakeholder interviews (conducted during 1998–2000) in the Luton and Sandwell HAZs (Barnes *et al.*, 2001) demonstrated growing awareness among statutory providers that voluntary sector organisations did not have strong links with community and public opinion and personnel; that they themselves were more 'advanced' in their use of consultation methods (public meetings, surveys and citizens' panels); and that voluntary sector organisations should not necessarily have rights to be consulted by or included in decision-making bodies on a par with actual

providers of local services. The authors suggest that voluntary sector organisations need considerable resources and incentives if they are to become 'agents for encouraging community and public engagement'. Meanwhile, there is as yet no evidence that partnership working between sectors necessarily promotes access to communities beyond that already established by individual agencies. The interim report of the National Evaluation (Barnes *et al.*, 2001) demonstrates wide variations between and within agencies (according to interview data) in terms of the stated purposes of community involvement, and partners have found it difficult, within limited resources, to build capacity for community involvement at strategic (rather than at 'project or sub-local') level.

A separate discussion of eight different HAZ zones (Lawson *et al.*, 2002, available at www.admin.haznet.org.uk/hazs/evidence/nat) comments on the training of local residents in three HAZ areas to conduct evaluation interviews. There was little evidence of the capacity of HAZ consortia to engage local people in planning and implementation, and authors commented upon the absence of 'community infrastructure' in some areas, while others, such as the South Yorkshire Coalfields, retained some of the grassroots community and welfare organisations from their recent industrial past. It is our impression that local people have been involved in discrete capacities (for example, focus groups, public meetings, on particular themes) in HAZ projects, but that involvement at the higher planning level has been less likely, owing to lack of representational structures, and unexpectedly poor liaison between voluntary sector organisations and the general public.

2.4 Factors that promote and hinder UI in public sector health care

Several factors that promote and hinder user involvement in public sector health care are specific to the method of involvement that is used. For instance, much has been written about optimal methods for collecting qualitative data (Murphy *et al.*, 1998), conducting questionnaire based surveys (McColl, 2001) and methods used to elicit public preferences for health care (Ryan *et al.*, 2001). However, a variety of process issues discussed below are less specific to the method of involvement that is used.

Feedback from service providers involved in implementing new structures for involving users is available at the Department of Health web site (www.doh.gov.uk/involvingpatients/tabprojects.htm). Issues raised appear to reflect process factors that were important in previous initiatives aimed at involving service users and are discussed below.

2.4.1 Clarity about the aims of UI initiatives and the extent to which users can influence the process and outcomes of involvement

Few accounts of involvement report that the participants were told beforehand how much weight would be attached to their views, suggesting that the convenors had not decided, or that this was dependent on the extent to which views coincided with those of other key decision makers. This is a difficulty, because participants may be demoralised by the insignificant outcomes of their efforts, and may conclude that the 'costs' of participation outweighed any benefit (McGrath and Grant, 1992; Hogg, 2002).

> *Members of the public … bring goodwill and commitment (to involvement activities). However, in very many cases, they do not fully understand the purpose of the project, perceive any real impact or outcome from it, or receive feedback after their involvement ended … [generating] disappointment [and] distrust.*

(Stewart *et al.*, 1999)

A rare example where the influence of users' views was pre-determined is the maternity coalition convened by the Chief Executive of a Welsh provider trust (Chadderton, 1995). The coalition comprised equal numbers of service users, members of the public, and health care professionals. The group had access to technical expertise, and was therefore able to follow an informed and deliberative path toward consensus (Harrison and Mort, 1998). The Chief Executive committed herself 'not to unilaterally change proposals made by the group': that is, prior to the start of deliberations, she agreed that the group's proposals would be followed. The ambiguity included in this statement reminds us that it is very difficult for health service managers to promise to honour commitments to public or user pressure when other

factors such as changes in national policy or funding arrangements may prevent the implementation of users' recommendations.

2.4.2 Representation and representativeness

Concerns of service providers about the representativeness of service users who contribute to UI are a frequently cited impediment to successful involvement. In a survey of mental health trusts and user groups in London in 2000, trust concerns about the representativeness of users who took part were the most frequently stated obstacle to successful UI by both service providers and service users (Crawford *et al.*, 2003). Barnes and Wistow (1994a) argue that this is due to two reasons: the practical difficulties of making contact with people who have hitherto been excluded from decision-making processes, and the potential for concerns about 'representativeness' to be used to undermine the legitimacy of views expressed. Lindow (1995) agrees that:

> *… one phenomenon of user involvement in the UK is that survivors [of mental health services] who say something unpopular are likely to be disempowered by being told they are not representative.*

Professionals are not expected to represent the views of their profession when they take part in a decision-making process, so it is difficult to escape the conclusion that the aim of such challenges is to undermine users of services (Bowl, 1996b).

Statements about representativeness are very common in the literature but the meaning of the term is rarely considered. (Barnes, 1997) argues that there are at least three types of representativeness, which are clearly related to accountability, and the purpose and method of participation.

1 *Democratic representativeness* – involves an individual (or group) elected by a democratic process to represent the views/interests of those who elected him or her. This model of representation implies that those elected are accountable and have a duty to explore issues on which they are canvassed with those they represent, but also requires that the model of user involvement in which they are involved permits sufficient notice for them to do so. Representatives do not necessarily share the same characteristics of the electorate.

2 *Statistical representativeness* – a representative sample selected following statistical methods to represent the characteristics of the total population. The sample do not act as 'representatives', and are not accountable to the population. The selection of the sample, which is likely to involve a fair number of people, is under the control of the researcher, so it is not possible to 'opt into' the group.

3 *Typical representativeness* – an individual who is typical of others or who has shared similar experiences. In this model the aim is not

to quantify views or experiences but to explore the nature of them. Participants are not accountable to others and take their own decision to be involved.

Levenson and Joule (1992) argue that although it may be difficult to access a proportionate cross-section of community views in the absence of formal democratic channels, this should not be used as reason for not involving lay people. 'User involvement does not depend on finding the holy grail of perfect representation' – perfection implies a finished product whereas involving users is a dynamic process. They use a jigsaw analogy to explain why representation is not essential:

> *... the more pieces there are, the better and clearer the picture will be although it is possible to get a reasonable overview if some of the pieces are missing, especially if there is some awareness of what kind of pieces are missing.*

(Levenson and Joule, 1992)

Historically, CHCs and health authorities have not been filled by lay members or consumer representatives per se, but by those in power inviting or nominating people who are thought to have an additional professional expertise to offer, though that may not originate in the health care field (Bates, 1983; Ferlie *et al.*, 1996). White's (2000) review of the Canadian health system suggests that 'randomly selected citizens were overall the least preferred of decision makers' not because of apathy, but because of poor accountability and administrative competence. Health care professionals, citing the difficulties of involving users and the public, complain somewhat inconsistently about both the inability of lay participants to represent the patient view, and about the inability of those same participants to understand the dilemmas of technical and managerial practice: 'There is a clear tension between lay participation as a democratic versus an efficiency-enhancing process' (White, 2000), and it may be that some compromise in efficiency should be accepted as the price of more user-friendly services. The danger is that a preoccupation with representation may paralyse involvement initiatives and their influence.

2.4.3 Collaboration and independence

Users of mental health services have made a major contribution to the literature on user participation in changing health services (Barker and Peck, 1987; Campbell and Lindow, 1997; Lindow, 1995; Beresford, 1988). However, because the 'survivor' movement has its own agenda for reform, authors have recognised the limitations of collaboration with health professionals. Professional workers may tend to control the agenda, or give too much help, which was experienced as 'intrusive and disempowering' by the subjects of one study (Bowl, 1996b). Users with ongoing or episodic mental health problems may have difficulty in voicing concerns in front of those responsible for treatment (Harris, 1989). A further hazard is the tendency for patients to become 'professionalised' or 'co-opted' to professional ways of thinking, thus losing their ability to represent patients and convey the patient view.

> *Co-optation means that the dedication, independence and zeal of an individual or group becomes diminished or altered as a result of compromises necessary to maintain collaboration and dialogue.*

> (Kopolow, 1981)

The unique contribution of NHS patients ought to be their capacity to think about need and solution to need in ways not tied to existing services. The more familiar with jargon and the discourse of professionals they become, and the more knowledgeable about existing services, the more 'they may want what they know rather than know what they want' (Biehal, 1993).

On the other hand, some authors (for example, Smith (1988)) argue that collaboration with mental health service providers is essential for change, because patients and service providers are mutually dependent. Benefits of collaboration identified by a survey of mental health forums included: being able to identify appropriate officers with whom to make contact on particular issues; access to professional networks, contacts and knowledge about the system; and continuity and support (Bowl, 1996b); while an evaluation of three mental health user-led services concluded that those who collaborated with community mental health centre programmes had the additional benefits of public recognition of their competence as users, and of easier access to funding (Kopolow, 1981).

Peck and Barker (1997) conclude that:

> *The statutory partners in the partnership will involve users in the process … but will carefully control, and, if necessary, dilute the outcomes of that dialogue.*

Operating from outside of health system structures may create more effective pathways into decision making (White, 2000; Berry, 1981) as it enables individuals or groups to retain the capacity for independent, oppositional action based on self-defined goals.

2.4.4 Opposition from health care professionals

Several reports highlighted ambivalence or opposition to UI from clinicians (Kopolow, 1981; Brown, 1999; Pritchard, 1993). In their literature review of the involvement of mental health service users in change management, Rose and colleagues found that opposition from health care professionals was the most frequently stated factor that hindered successful UI (Rose *et al.*, 2002). Literature on Canadian public involvement consistently identifies doctors as opposing the influence of the public on health care planning, or competing directly to dominate service planning (Young, 1975; Sullivan and Scattolon, 1995; Lord *et al.*, 1998). In the UK, Ham and Alberti (2002) note similar tendencies, and suggest the need for a renegotiation of the relative roles of the medical profession, the public and the government within the 'contractual system' which is the NHS.

Reports of professional resistance to UI are not restricted to the medical profession. Read and Wallcraft (1992) demonstrate (with funding from COHSE, the then major health service union) common cause between users of mental health services and health service front-line workers such as nurses, who:

> *… have felt over-burdened by management expectations that they should develop new ways of working (such as setting up patients' councils) without adequate training or back-up … Mental health workers often have little control over their working lives.*

Workers may feel that patients' and carers' complaints are taken more seriously than their own, while their own attempts to address failures of patient care will be penalised as whistle-blowing (Read and Wallcraft, 1992). Barnes (1997) reminds us that the introduction of user authority inevitably introduces challenge to professional authority, and to the institutions, training, qualifications, peer regulation and supervisory hierarchies on which professional authority is based. It is therefore difficult for workers at the bottom of organisational hierarchy not to feel that the move to patient power is a redistribution of some of their own power (Croft and Beresford, 1992; Brandon and Brandon, 1987).

2.4.5 Organisational response to criticism

Barnes and Walker have described the characteristics of organisations that may be more open to user involvement (Barnes and Walker, 1996): see Chapter 3, on social services. These include openness and responsiveness to review and change. Barriers to change within the NHS (Plamping, 1998) may be significant obstacles to successful user involvement. Studies that examined responses to complaints and criticisms of services suggest that practice within the NHS is often defensive. Jain and Ogden (1999) conducted a qualitative investigation of 30 GPs' responses to patient complaints, reporting widespread negative outcomes (shock, depression, feeling out of control, self-doubt), some 'immunity' to complaints, and only a small minority experiencing complaints as 'a learning experience'. Barnes and Walker (1996) comment that 'staff hurt' is an impediment to successful UI:

> *One informant within one of the statutory agencies … commented on the lack of responsibility shown by the panels [of elderly people with various functional impairments] … for reporting on negative experiences of services, rather than identifying what producers were doing well.*

Promoting user involvement in decision making within health care services inevitably introduces the potential for conflict, as different stakeholders disagree about the best course of action.

> *Periodic conflict should be expected - it is natural - but it should not prevent managers and users from listening to each other.*

> (Hogg, 1992)

2.4.6 Other factors

Other factors that affect the process of UI that we encountered in the literature include the following.

- *The timing of UI initiatives*: the importance of deciding at what stage UI is introduced, and concerns about involving users once decisions have already been made (Paap, 1978; Barnes, 1999).

- *Training requirements of service users and providers* in order to ensure that both parties are prepared and able to engage in productive involvement (MIND, 1991; Lindow and Morris, 1995; Dewan and Read, 1998; Bowl, 1996b).

- *Payment to service users* The need to reimburse costs incurred by service users who participate in initiatives is generally accepted. More recently there have been calls to acknowledge the contribution of service users by paying people for the time they spend in meetings with service providers and other UI initiatives (MIND, 1991; Gummer and Furney, 1998; Hastings and Crepaz-Keay, 1995; Campbell and Lindow, 1997; Barker and Peck, 1987; Connor, 1999). Care needs to be taken to consider the impact of payments on the benefits of unwaged service users. Guidelines on

payment of service users involved in research in the NHS (Consumers in NHS Research, 2002) are helpful for those planning UI initiatives and can be downloaded at http://www.conres.co.uk/pub.htm.

- *Involving service users in data collection* Patients may be more willing to discuss problems or deficiencies in the treatment they were offered when interviewed by other service users (Polowczyk *et al.*, 1993). 'User-focused monitoring', which consists of training people who have used services to help them learn how to conduct interviews with current patients and inspect sites where services are provided, has been used to evaluate service quality in mental health units and in services for people with chronic neurological disorders (Rose, 1998; Poole, 2000).

- *Providing feedback to service users* Reports based on case studies of UI in the development of services have concluded that service users need to see change resulting from their work if user involvement is to be sustained (Ovretveit and Davies, 1988; Todd *et al.*, 2000).

2.5 Outcomes of UI in public sector health care

We have highlighted reports stating outcomes arising from UI in public sector health care in table format in Appendix 3. From the table it can be seen that the most frequent outcomes are:

- changing attitudes of service providers to UI

- increased self-confidence among users and lay people involved

- production of new or improved sources of information for patients

- moves to make services more accessible through simplifying appointment procedures, extending opening times, improving transport to treatment units and improving access for people with disabilities

- commissioning of new services as a result of the requests of service users.

Attempts to gauge the overall impact of UI have been made by conducting surveys of participants and retrospectively examining records of meetings. A survey of those leading public involvement initiatives of Health Systems Agencies in USA in 1980 asked respondents to judge the effects of UI (Checkoway, 1982; Checkoway *et al.*, 1984). Of the 154 (76 per cent) that replied, 75 per cent said that UI had improved the quality of health services and 46 per cent said that it had led to improvements in people's health. In a survey of 63 primary care-based patient participation groups in Britain in the mid-1980s, 32 (52 per cent) were able to provide details of at least one change that groups had initiated (Richardson and Bray, 1987).

Facilitated meetings between primary care workers and patients with diabetes in 17 primary health care centres in Stockholm in the mid-1980s generated 196 plans for improving patient care. Eighteen months later the extent to which plans had been implemented was evaluated (Carlson and Rosenqvist, 1990). The authors report that 70 per cent of plans had been implemented.

A retrospective examination of records from meetings of five mental health forums in Kent identified 57 concerns raised by groups over a two-year period (Milewa, 1997). Of these, 22 (39 per cent) resulted in a response from service providers that was judged acceptable. A survey of 17 (94 per cent of 18) mental health trusts in Greater London enquired about changes resulting from the involvement of service users (Crawford *et al.*, 2003). All trusts were able to identify at least some change that had resulted. Most specific changes resulting from user involvement were attributed to responses to complaints made by users, with 11 trusts (65 per cent) listing a range of changes including improvements to ward environments, organisation of outpatient services and systems for supporting patients in crisis. A further 8 trusts (47 per cent) gave details of how service users attending planning meetings had influenced service development and policies.

Harrison and colleagues (2002) carried out a national survey of UI in 167 primary care groups/trusts, in which around 30 per cent reported changes to services and policies because of user input. Almost one-third of changes were said to involve the development of new services, and 25 per cent involved relocating or refiguring services. 35 per cent of informants in a subsequent qualitative study in three health authority districts identified changes in services and procedures that they attributed to user involvement (primarily consultation) initiatives. However, informants working for the primary care organisations were more likely than other local stakeholders interviewed to attribute changes to user input: and the authors question whether these changes would not have taken place anyway without involvement, thus throwing into doubt its real impact.

Finally, we identified three systematic reviews that have sought to gauge outcomes of UI within the health care context. Simpson and colleagues (Simpson *et al.*, 2002) identified 13 comparative studies that examined the effects of involving users of mental health services in the delivery and evaluation of services. They were unable to identify any studies that compared methods for involving users in the planning and development of services, but concluded that service users can be involved as employees, trainers or researchers without detrimental effect.

Rose and colleagues have recently reported findings from a systematic review of reports on user and carer involvement in change management in a mental health context (Rose *et al.*, 2002). Their comprehensive search strategy enabled them to identify over 850 abstracts or papers,

of which 112 papers were included in their final review. While considerable information about the process of involvement was obtained from these reports, the majority of reports stated that outcomes of UI were unclear or unknown. The authors commented that outcomes in the remaining papers were '… hardly ever measurable ones. They are the writer's opinion of what has worked and what has not'. In our previous review of patient involvement in the planning and development of health care (Crawford *et al.*, 2002), we identified 42 papers that detailed the outcomes of user involvement and concluded that, while the balance of evidence supports the view that changes to services have been made following consultation with service users, the impact of these changes has not been evaluated.

Chapter 3 Social services and community care

This chapter outlines the background to user and public involvement in personal social services (for children and families, elderly people, people with learning difficulties and mental health problems, and disabled people). Chapter 4 discusses involvement in local government services other than personal social services. However, much of the context, background and motivation for involvement applies to all local government services.

3.1 Context and aims of UI in personal social services and community care

Local authorities are responsible for the provision of personal social services, including community care, to local people. In many respects, the motives for involving service users and the public in planning and developing local government services are the same as those identified for the health care sector (Section 2.1). Based on case studies of local authorities in Britain, the Audit Commission proposed a range of reasons why service users should be involved in the planning and development of services. These are listed in Table 2.

Table 2 Reasons for local authorities to consult service users and the public

1	Statutory duty, or government direction, to involve (e.g. community care planning; Best Value)
2	Services should be tailored to what users want
3	Take-up can be increased, lowering unit costs (and increasing income from charges)
4	Service quality can be monitored by comparing consultation results over time
5	Problems in service design can be anticipated and avoided (i.e. plans amended before implementation)
6	Local democracy strengthened (as are rights and dignity of users as citizens)
7	Authority's role in community leadership strengthened (needed for community regeneration funding)

Source: adapted from Audit Commission, 1999

Local authorities are already subject to democratic processes, which they may regard as adequate or seek to extend. At the same time, they remain (despite the NHS and Community Care Act of 1990, which changed their status from providers to purchasers of some social services) providers of a range of services, for which they are accountable to service users. They are also key participants in, and may co-ordinate, local regeneration projects, which are commonly thought to depend on community participation for their success and sustainability (Stewart and Taylor, 1995). Public sector bodies are expected to be agents of inclusion, and user involvement in the

development of local authority services is seen as providing an opportunity to tackle social exclusion (Miller, 1999).

Biehal (1993) discusses consultation with users as an aid to greater managerial efficiency, but warns that 'this will not necessarily be accompanied by any real increase in power of service users to determine the range and quality of the services available to them'. Discrepancy between what managers want of UI, and what users want, may be a major source of dissatisfaction for service users, since the managers' definitions tend to prevail (Biehal, 1993).

3.2 Methods for involving service users

Social and community care services tend to prioritise the views of users and carers, rather than potential users or citizens, although holding 'stakeholder' conferences around particular service areas can be a way of drawing in past users, local carers, local professionals and other parties with a material or academic interest in particular services. All of the methods presented in Figure 1 (Section 2.2) are found in identical or similar format in the field of social services and community care, although the terminology of 'patient' is replaced by service user or client, and user groups and forums are more likely to be attached to community resources than to hospitals. Although local authorities are senior partners in commissioning community care, they work closely with health authorities or primary care trusts and providers from all sectors to develop community care, and share individual clients/patients, methods of involvement and joint planning structures. There are also strong similarities in 'levels' of involvement: both patient (Coulter, 2002a) and client (Stevenson and Parsloe, 1993) should be involved in their own individualised treatment and care arrangements (a field outside the remit of this review), but should also be able to contribute, in combination with others, to the wider planning of services.

Users of community services in all client groups can be involved in managing or overseeing the services they use, whether these are day services or residential services. Innovative examples of involving client groups with dementia (Small and Rhodes, 2000), with severe communication problems (Youll and McCourt-Perring, 1993), with mental health problems (Bowl, 1996b) and with learning difficulties (Ross, 1995; Ovretveit and Davies, 1988; Cambridge and McCarthy, 2002) suggest that involving people of different capacities in some aspect of services is rarely if ever impossible: but the will to do so may require a fundamental shift in ideology and culture rather than the simple introduction of mechanisms of participation. Comprehensive examples of public and user involvement in community care planning include Wistow and Barnes (1993), Barnes and Wistow (1994a and 1994b), Thornton and Tozer (1994), Office for Public Management

(1993a), Lindow and Morris (1995), and Bewley and Glendenning (1994).

We describe below two additional methods of user involvement where literature is specific to practice in personal social services. Local authorities also have direct access to borough residents/taxpayers, and may utilise some of the additional approaches discussed in Chapter 4 (in relation to non-social/community care services).

3.2.1 Complaints and complaints procedures

Complaints procedures are an important method through which users of social services departments can express dissatisfaction (Simons, 1995). In theory, such systems increase transparency and accountability, act as conciliation mechanisms, act as a device for improving 'customer relations' and quality assurance, and pre-empt more serious conflict (such as litigation, recourse to the press in cases felt to be scandalous). Such mechanisms may also seek (not necessarily successfully) to 'depersonalise conflict', so that the process of making and investigating complaints is easier for vulnerable users (who fear repercussion) and demoralised staff, by instigating a step-by-step procedure which encourages local, and rapid, restitution. Simons acknowledges the disparity in status between complainants and the professionals they complain of, which may be exacerbated in contexts where users are coerced into 'using' services (for example, the families of abused children). In reality, departments may not publicise their procedures adequately, given the range of vulnerable, sensorily impaired and non-English speakers they provide services to. In her survey of 86 social services department (68 per cent of the total sample responded), Simons found that recorded complaints were highest in 'Children and Families' services (37 per cent of total), followed by older people (29 per cent): people with sensory impairments were least likely to complain, averaging 5 per cent of the total (Simons, 1995).

Service users may not know what local authorities are required to provide, making it hard for users to know when current provision is unsatisfactory.

> *I was told once that social services have got a legal obligation to provide some play provision for children with special needs … I think I have found it in section 18 of the Children Act … I really could do with a professional sitting down and advising …*

(Mother, quoted in Kumar, 1997).

Advocacy services have been recommended as a means of facilitating user involvement (Atkinson, 1999). In 1993, only two of 86 social services departments were found to be providing advocacy services (Simons, 1995).

3.2.2 Direct payment schemes: users manage domiciliary services

Although not universally available or adopted, direct payment schemes in personal home-based support have enabled some service users to exercise control over services they receive. Keigher (1999) discusses schemes in Europe and North America, where care may be paid for either by Managing Care Organisations or by private individuals. The degree of support that users receive in recruiting and employing personal carers can impact heavily on the 'success' of these schemes from the perspective of users, as well as on the conditions of employment experienced by employed workers.

> *Homecare is provided in imperfect local markets currently characterized by lack of information for both users and workers.*

(Keigher, 1999)

These imperfect markets severely impede the exercise of choice for both parties. However, the continued expansion of direct payment schemes strongly suggests that savings (for example, in postponing entry to residential care, and in saving of organisational running costs) must be apparent, despite the payment of previously unpaid informal carers. Increasing take-up rates by service users suggest some satisfaction over alternative provision. Older people are the largest group of people receiving domiciliary care, and Age Concern (1998) recommends that direct payments are made available to them to give them greater flexibility in who they hire to do which tasks.

3.3 Areas of involvement

3.3.1 User involvement in quality control and purchasing services

Contract specification is an area of service management in which users can be brought together for limited purposes on a limited number of occasions, with no necessary ongoing arrangements for further input (Raynes, 1998). The engagement of service users in contract specification therefore seems relatively straightforward. Johnson and

colleagues (1998), describing regulation and the enforcement of contracts in social care, argued in a case study of adult social services that, given the problems of defining, observing and measuring quality, 'feedback from users is of paramount importance in the monitoring and evaluation of services'. In the field of personal social services, particularly where total care is purchased for vulnerable users, the purchaser/provider split has made monitoring all the more important: however, 'the commitment to facilitate user involvement is not matched by effective strategies for its achievement'.

An example of total care contracts are those 'purchased' by social services on behalf of older people who are unable to live independently. Much of the data on UK social care services assume public sector orientation, but most of the care homes in the UK today are private, with private beds rising from 28,000 in England in 1983 to 196,000 in 1999 (Kerrison and Pollock, 2001). Furthermore, around one-third of residents are self-funding (with a further 50 per cent being funded by local authorities). How contracts for total care provision are monitored could not be more important to the typically vulnerable individuals whose lives are determined by them. Standards in care homes are enforced by the National Care Standards Commission: neither the Commission nor the legislation it enforces requires the consultation or involvement of users of care homes (Kerrison and Pollock, 2001). Raynes (1998) describes a project in Greater Manchester that invited care home residents to become involved in service contract specification by involvement in centralised focus groups, to which the research team provided transport and other support. (39 of the 52 residents had special needs, such as sensory disabilities.) Residents' participation depended on the consent of the 50 homes contacted: two homes refused, but seemingly this had no impact on their contracts with health/social service purchasers.

3.3.2 Best Value

Promoting service user participation is one of the themes of Best Value. Best Value is: 'a system of purchasing designed to replace cost- and market-led systems of purchasing with arrangements that take account of quality considerations' (Cambridge and McCarthy, 2002) established by performance reviews and consultation with the community. Users of social services are in a good position to define the relative value of different services and the outcomes they want from their use of services (although the data derived from participation may require some translation for use in planning).

Bovaird and Halachmi (2001) reviewed similar initiatives in US, European and Australian services, and concluded that Best Value strategy could benefit from (among other recommendations) greater transparency in contract letting, more stakeholder involvement in budget setting and community audits of 'who gains, who loses'. While some of the local government strategies cited appeared to inform (rather than consult)

the community, it was unclear to what extent, if any, users wished to participate in the financial management of social services.

3.3.3 Social work practice and training

Social work training and practice has tended to emphasise the empowerment in individual work with clients (Lee and Charm, 2002; Biehal, 1993), with the worker/client dyad working together (ideally) to identify need and produce a care plan. Commitment to the participation of service users in planning their own care has long been a principle of practice, but social services departments have found it increasingly difficult to fulfil this aim, within the current stresses of high caseloads and increased administration as purchasers. Workers' approaches tend to become 'routinised', with servic e-led referrals, and workers can be deflected from a more open discussion by their own anxiety not to overload 'vulnerable' clients with information, choices and responsibilities which they had not expected (Barnes and Walker, 1996). Research on user involvement in social work practice found social workers:

> *… most likely to allow (sic) participation in decision making in cases where they did not object to the users' goals, where they considered that the users' goals would not increase the level of risk … and where … conflicts were not an issue.*

> (Biehal, 1993)

This comment could well be true of managers as well as front-line workers.

Service users have been involved in providing training for social workers, notably within mental health and social services. The NHS Executive (NHS Executive, 1994) combined with a panel of users and survivors of mental health services to produce a development pack for users and survivors (involved in the work of the Mental Health Task Force) wanting to improve skills as trainers, speakers and workshop facilitators, and this is recommended, as is the slightly more specialised *Survivors' Guide to Training ASWs* (Hastings and Crepaz-Keay, 1995). This is a guide for users, which offers many practical tips and guidelines including ensuring that you are involved from the very beginning in the planning of the training course. It warns of the need to ensure that the user input comes as early as possible in the course because 'the more training they get from professionals, the narrower the trainees become in their outlook' (Hastings and Crepaz-Keay, 1995).

3.3.4 Community care planning

In the field of community care planning and provision, local authorities were driven to involve users and carers more fully with the imposition of a statutory duty to consult with 'independent' (private and voluntary sector) providers, and with 'voluntary organisations who appear to the authority to represent the interests of users of community care services and their carers' (Section 46, NHS and Community Care Act, 1990; Barnes, 1993b). The stated motive for consultation is that 'services will only be properly developed in the interests of users and carers if there is a sound partnership between the authority and users and carers'. Authorities must also 'state in the community care plan how they intend to consult in the next round of planning'. Specifically, views should be invited on 'proposals, not the final document'; reasonable time must be allowed for consultees to formulate a view, and 'views must be taken into consideration'.

An early analysis of social services' involvement of disabled people in community care planning (Bewley and Glendenning, 1994) suggested that most 'involvement' focused upon publicising draft plans and inviting commentary, both through written submission and public stakeholder meetings. Formal voluntary sector organisations (often organisations *for*, rather than *of*, disabled people) were more likely to be consulted than service users themselves (with only 16 per cent of authorities involving user-led organisations), and planning bodies were based upon 'traditional' service divisions, emphasising the separate incapacities of client groups (older people, people with learning difficulties, mentally ill people) rather than the common experience of social restrictions. (We do not know how recent community care plans would compare: an updated comparative account would be useful.) Based on a sample of 42 local authorities, the Office of Public Management attempted to consolidate an impression of the level of involvement in the process of community care planning and delivery which was current at that time (Office for Public Management, 1993b). Of the sample of local authorities, 52 per cent involved users in community care plans, in accordance with statutory requirements (which were only just being implemented in 1993). Users and carers were least likely to be involved in the allocation of budgets; and local authorities rated commitment to user-run services as second to last (in present practice and future plans) in a list of possible priorities.

Professionals may sometimes comment on unreasonable expectations of users who choose not to consider financial restraints and imperatives, while it may be that users are not permitted to consider them. In all areas of involvement:

> *… information giving and consultation were most common, and only very rarely are users and carers given full decision making power.*

(Office for Public Management, 1993b)

3.4 Factors that promote and hinder UI in social services and community care

3.4.1 Good practice on consultation with users of local authority services

Following their review of previous reports and a series of case studies, the Audit Commission published the following factors considered to be good practice for consulting service users about the delivery and development of services by local government (Audit Commission, 1999).

1   Consultation should relate clearly to a decision that the authority plans to make, and be open to influence. It should be made clear 'what consultees can change by responding to the consultation' (and, by implication, what cannot be changed); feedback should be given to consultees about what did and did not change, and why.

2   Consultation must be done competently so that it is effective, with valid results. Authorities that do not have expertise (in research methods, for instance) should seek partnership with, for example, academic or technical bodies, or better-equipped authorities.

3   Consultation should be inclusive. The Audit Commission survey found that local authorities found it hardest to consult with: homeless people (85 per cent of responding authorities); young people, travellers and ethnic minority groups (each specified by 65–75 per cent of responding authorities); and older people (around 15 per cent). Using non-statutory organisations and events and venues attended by such persons is suggested (but see below).

Consultation should be linked to changes in decisions and practice. Failure to do so is common, and may arise from using inappropriate consultation methods and questions, so that the results are useless, from inability of policymakers to take account of conflicting views, or from lack of transparency in explaining how consultation informed practice. The report summarises this view:

> *All public consultation should relate to a decision that you are intending to make, and that can be influenced by the result of that consultation.*

(Audit Commission, 1999)

3.4.2 Limited financial and other resources

Research describing the integration of user and carer involvement highlights the need to resolve 'tensions between approaches designed to encourage user participation on the one hand, and meeting the requirements of planning systems on the other' (McGrath and Grant, 1992). Mismatches in timing, participation and meeting methods and expectations, financial constraints and coordination difficulties all arose, with planning groups unable to meet tight timetables effectively marginalised despite the effort expended by participants. Control and power remains with practitioner/managers, whose guiding principles may be financial (Tanner, 1998). Tanner concludes that 'political rhetoric somehow implies that individual responsibility is somehow synonymous with empowerment, or giving more control to the individual, yet the effect of responsibility without … resources to assume control will be to disempower'. Local authority social service departments are financially accountable to local ratepayers: although service users are certainly included within this population, there must inevitably be instances where the needs or demands of service users are judged to be unacceptable to local taxpayers.

3.4.3 Democracy and accountability

> *While the emphasis of the NHS white paper on alternatives to the electoral process represents an attempt to make good a perceived 'democratic deficit', in the case of social services the problem is … the perceived failure of the local democratic machinery to ensure adequate accountability and safeguard the interest of users. The white paper notes, for instance, that it will no longer be 'acceptable for elected members to claim that they are shocked when evidence emerges of serious service failures'.*

(Small and Rhodes, 2000)

Kumar's (1997) qualitative investigation of local authorities explored accountability in the provision of social services. Asked to describe how they both ascertained, and then acted upon, the views of local social service clients, government managers cited service level agreements and provider contracts, user information about services, various opportunities for consultation and dialogue, public meetings, complaints procedures (of authority, of provider partners), and officers acting as 'surrogate' clients, by asking client-centred questions of organisations they contracted with. It is not clear that these methods, in themselves helpful and laudable, go much beyond 'consultation' and 'listening': clients do not have rights to information about why policies and practices are adopted or rejected, and do not directly participate in decisions about services.

Emphasis was on the extent to which officers 'facilitated people to comment, and informed and educated them about "what to ask for" and "how to ask for it", thereby forcing the policymakers and service deliverers to account to them' (Kumar, 1997). This does not amount to

changing what is available to be requested, and the same officers thought that lack of choice among services (little competition, no alternative service providers) in any case constrained user ability to 'exit'. With no alternative but to stay with the service, users found it difficult to criticise service providers, as they feared jeopardising relationships with them. It did not appear from Kumar's research that local authorities were involving users in compulsory competitive tendering and the shortlisting and selection of contractors who compete to be local service providers.

3.4.4 Organisational barriers to involvement

Local authorities seeking to fulfil their statutory duty to consult identified obstacles such as professional and staff attitudes, lack of time and money to invest in consultation, and concerns about the representativeness of consulted users and carers – 'User/carer interests were often described as personal rather than strategic' (National Consumer Council *et al.*, 1999a), illustrating the mismatch between the client's experiential perspective and language, and the managerial provider perspective and language. Users of health and social care services frequently complain of the unreasonable expectation that they present their views in managerial language: failing to do so may mean that those views are never considered seriously (Barnes and Wistow, 1994a).

Following their exploration of user involvement in community care, Barnes and Walker (1996) summarised factors which may make organisations more open to empowerment (and, by implication, achieve more successful involvement of lay people). These factors are summarised in Table 3.

Table 3 Service organisation models

Bureaucratic model	Empowerment model
service/provider-oriented	user-oriented
inflexible	responsive
provider-led	needs-led
power concentrated	power sharing
defensive	open to review
conservative	open to change
input-oriented	outcome-oriented

Source: Barnes and Walker, 1996

While the bureaucratic model (inadvertently) encourages client dependency, the empowerment model 'emphasises the interdependent status of service users as citizens requiring assistance but with the right of autonomous decision making' (Barnes and Walker, 1996). Organisational openness to criticism was also highlighted as a key requirement for successful user involvement within social care in a study that examined whether features of user-controlled services could make social services more responsive to the needs of its users (Joseph Rowntree Foundation, 1994).

Employee respondents to a survey of local authorities (National Consumer Council, 2001b) suggested that 'administrative systems are designed to support institutions rather than people'. For example, it can be difficult to find £10 in cash to pay for a user's taxi to a meeting. These logistical details, although minor, clearly influence the will to involve. Other difficulties, shared by other sectors, include lack of clarity about how far managers 'were really prepared to go along the consultation – participation – power sharing continuum'. Others pointed out the dangers of 'grafting "token" users or carers onto existing planning and operational structures … either the user and carer become institutionalised, or both sides continue to have very different agendas'.

3.4.5 Professional resistance to UI

Wilson (1999) has argued that 'the position of service users has been weakened because the involvement of users has been confused with public participation and health professionals have been given the authority to define users' needs for them'. Within social services, advocacy is emphasised in the training of front-line social workers: 'used to acting as advocates, they could feel they were being de-skilled if users were directly consulted or involved' (Ferguson, 1998). Banks (1998) agrees that user involvement in social services may be 'seen as a challenge to professional expertise and the traditional distance between client and professional'.

3.5 Outcomes of UI

Reports that we found that described outcomes of UI in public sector social services (and community care) are presented in Appendix 3. While there was a general paucity of outcomes reported, we focused on material outcomes which could be traced to user/carer influence, thereby emphasising 'the importance of viewing consultation as a precursor to action' (Barnes and Bennett, 2002). Barnes and Bennett (2002) have argued that participation can be worthwhile even when it has no material outcomes: 'the success of [UI] projects cannot be measured solely by reference to objective changes within service agencies'. They identify intrinsic benefits to elderly participants, including learning, social contact, and increased confidence to criticise services; some felt they had gained 'enhanced capacity to exercise control over key aspects of their lives'.

Measuring the impact of user and carer involvement has sometimes been enabled by compiling numbered action points from the consultation process. A retrospective examination of records from meetings of five mental health forums in Kent identified 57 concerns raised by groups over a two-year period (Milewa, 1997). Of these, 22 (39 per cent) resulted in a response from service providers that was judged acceptable. Barnes and Wistow (1994b) evaluated a carers' forum set up (as part of a special UI initiative in Birmingham) to consider standards and measures to be used in evaluating community care development: 11 action points were adopted by providers, having been ratified by a broader questionnaire exercise (to which 318 of 531 respondents contributed). The authors comment that an additional 5 issues (financial problems; need for specialist help to deal with particular illnesses/disability; staff attitudes; stress of caring; need for carers to be cared about) identified by carers were not designated for action by the Birmingham project's partnership agencies. Although two panels (meeting during daytime and evening to facilitate caring) were established to monitor the 11 points, no concrete action had been taken some twelve months later. This is disappointing, since in this case professionals were permitted to select from the carers' action plan, but still failed to deliver. Other psychological and social benefits of participation were identified by carers, but expectations were surely not fulfilled.

Chapter 4 Public sector services (other than health and social care)

4.1 Context and aims of UI in other public sector services

Public services exist within complex frameworks that include elected politicians representing bodies at a local and national level. The conflicting multi-party dimension to public sector user involvement is a common factor in the examples of UI that we identified. Large-scale external factors such as privatisation, changes in world markets and international regulation or de-regulation of markets have all played a part in the need for change within this sector (Paliwoda and Osing, 1992).

In North America and in Europe public consultation is a legislative requirement of public sector services. In the UK, many local services are provided by elected local authorities: see Chapter 3 for local government motives for involvement of, and accountability to, local people. However, we found examples of UI in local government that were undertaken for a variety of additional reasons including:

- the need to meet or manage public expectations in order to maintain electoral support or defuse public opposition to change to services (Johnson, 1993; Walters *et al.*, 2000)

- the perception that involving service users would lead to more effective services (Seybold and Marshak, 1998) and higher levels of satisfaction (Tunstall, 2001; Office of Deputy Prime Minister, 2002)

- the belief that involving service users would contain or reduce the cost of services (Brudney and England, 1983)

- recognition that the knowledge (and sometimes skills and labour) of local people is an important resource for community regeneration work (Burns and Taylor, 2000)

- the belief that user involvement can play an important role in reducing social exclusion (Furbey *et al.*, 1996; National Consumer Council *et al.*, 1999c).

Walters and colleagues (2000) identified three interrelated aims of UI in the development of state public policy in Utah (USA), none of which implies direct input into decision making: to discover public views; to influence them through information and debate; and to obtain public support for difficult decisions through developing consensus.

Local government and other local agencies engaged in social, economic and environmental regeneration projects seeking to combat

disadvantage are thought to be unlikely to generate positive and sustainable outcomes without substantial community involvement at all stages of planning, implementation and review (Stewart and Taylor, 1995), and evidence of such is required for Social Regeneration Budget funding (Office of Deputy Prime Minister, 1998).

While these factors concern the motives of service providers for enabling user involvement, there is little material which addresses the reasons why local people, including service users, want to be involved. A survey in the early 1990s found that only 3 per cent of the population claimed to be very interested in local politics, with some three-quarters of people saying they had either not much or no interest at all in local politics. However, about two-thirds of those questioned did say they would take action if the council did something of which they strongly disapproved (Lynn, 1992, quoted in Office of Deputy Prime Minister, 1998). The public, then, distinguish 'local politics' from 'local services', demanding greater involvement in the latter, where issues may be relatively concrete and transparent.

It is envisaged that the recent decision to include 'customer-focused targets' in the service delivery agreements of public services in the UK will provide a powerful incentive for those providing public services to consult with local people (www.hm-treasury.gov.uk).

4.2 Methods for involving service users and the public

Methods for involving service users described in health and social care are also seen in other areas of public sector services (see Figure 1). These include surveys (Broussine and Wakefield, 1997; Scharitzer and Korunka, 2000; Johnson, 1993c), focus groups (Broussine and Wakefield, 1997), public meetings (Buchy and Race, 2000; Steelman, 2001), meetings with community and special interest groups (Snary, 2002), analysis of complaints (National Consumer Council *et al.*, 1999c), and devolution of services to local service users (Tunstall, 2001). Contacts with local media have been recommended as a method for publicising and managing UI initiatives (Johnson, 1993; Walters *et al.*, 2000). Data collected by central government suggest that interactive web sites accessed through the internet or on a local authority-specific intranet, inviting e-mail messages from users on particular local issues or service matters, are increasingly being used by local councils as a way of facilitating feedback on services from local people (Audit Commission, 1999).

Methods for consulting with users of local government services in Britain were investigated in a survey in 1997 (Department of the Environment, Transport and the Regions, 1998), and reported by the Audit Commission (1999). The different methods used by local authorities are summarised in Figure 2.

Figure 2 Methods used for consulting users of local government services

Consultation methods used by local authorities
Authorities are increasingly making use of new methods.
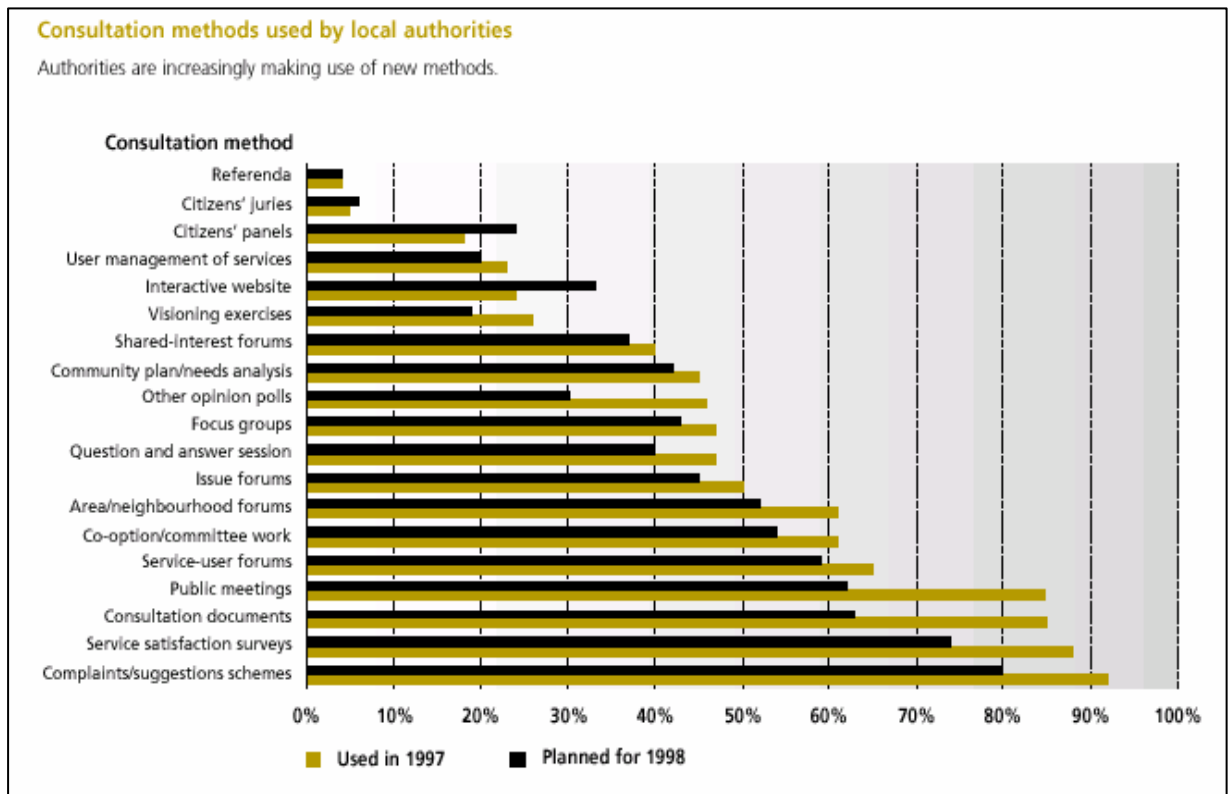
Source: Audit Commission, 1999
(Reproduced with kind permission from the Audit Commission)

An acknowledged difficulty in the involvement of local people in decision making is the potential for uncovering and publicising conflicting views which cannot be reconciled (Office of Deputy Prime Minister, 1998). A range of techniques for consensus-building/conflict resolution forms of meeting or exchange – round tables, consensus-conferencing, workshops – are described in LGA/LGMB Democracy Network (1998).

4.3 Areas of involvement

4.3.1 Setting and monitoring standards of service delivery

There are opportunities for members of the public to be involved as voluntary contributors to the management of national and local public sector bodies. Lay people can put themselves forward to serve on Research Ethics Committees (www.corec.org.uk); join the Board of Prison Visitors (www.homeoffice.gov.uk/bov), and become school governors (www.dfes.gov.uk/governor; www.schoolgovernors-oss.co.uk). All of these roles combine advocacy (for research subjects, prisoners and schoolchildren) with representation of one's own views on issues and standards of public provision, social justice, and patient and prisoner protection. Some of these bodies consist entirely of appointed members: school governor boards include some parent members elected by other parents. Although it may be assumed that elected parents represent the interests of themselves and other parents as service users, it is less likely that appointed members are recruited to represent (share characteristics and perspectives with) the views of schoolchildren or even of 'the community'. School councils (to be discussed in Section 7.2.2.5), which are set up to promote the views of students, rarely have any links with governing bodies (ACE, 1995). The School Governors One-Stop Shop is dedicated to 'Recruiting Governors with Management Skills for Inner City Schools' (see www.schoolgovernors-oss.co.uk). The emphasis in such recruitment is on technical skills, and willingness to contribute time and expertise, rather than capacity to represent. Thody and Punter, (2000) suggest that such governors have offered fresh and objective strategic perspective, and so improved the quality of management by school governors. Even elected school governors have no obvious capacity to consult other parents, unless parents approach them with specific concerns. Although we found no literature evaluating such initiatives, the National Consumer Council (2001a) observes that volunteers for prison visiting and school governing have been difficult to recruit and retain across the UK and 'particularly in geographical areas of disadvantage and greatest need'.

Another example of UI in setting and monitoring standards of service delivery comes from Hateley Heath estate, managed by Sandwell Borough Council (National Consumer Council *et al.*, 1999c). In this example council tenants were selected at random from identified sub-groups of the population to take part in survey interviews, to ensure that all sections of the community were represented. Volunteer tenants helped design, distribute, and analyse the survey, and the results of the survey were used to draft a tenants' charter of quality standards the Council pledged to maintain. Tenants had an ongoing role in

monitoring the charter, and project co-ordinators used a variety of mechanisms for feeding back current plans and drafts to tenants, with consultation breaks built into the implementation timetable. Training volunteer tenants to conduct interviews was found to stimulate more useful, open, qualitative material than the use of professionals, and interviewers targeted 'hard-to-reach' tenants. Many of the tenants' demands were cost-free, and tenants were found to be 'the Council's best allies in identifying waste and inefficiency'.

Executive agencies delivering public services to self-selected persons may use the techniques of customer consultation. The Public Services Productivity Panel (see www.hm-treasury.gov.uk) aims to include 'consumer-focused targets' in Public Service and Service Delivery Agreements. Foster (2000), reporting an evaluation of customer service in three agencies of the Department for Environment, Transport and the Regions (the Driving Standards Agency, Driver and Vehicle Licensing Agency and Highways Agency), describes how agencies identified major deficits through customer surveys, mystery shopping exercises (where bogus customers mimic the customer's experience) and complaints analysis. Many of these concern access. The extension of opening hours, and the development of new technologies of access are being developed, and Foster identifies seven principles of effective customer service that appear equally relevant to public and private sector services. Performance measures based on customer-focused outcomes (such as response times) have been introduced in such services.

4.3.2 Involving the public in policy development

Following a review of previous literature and a study of public involvement in the development of policy in Utah, USA, Walters *et al.* (2000) argued that the method of involvement should be determined by contextual factors such as the degree of conflict surrounding the issue, the number of stakeholders involved, and the quality of the information available on which to make a decision. They argue that clearly structured methods of involvement such as referenda or elections should be used to decide issues where there was little conflict, fewer stakeholders and high-quality information on which to make a decision, but that less-structured methods of involvement, such as focus groups and neighbourhood meetings were required if there were higher levels of conflict, larger numbers of stakeholders or poor-quality information on which to make a decision (see Table 4).

Table 4 Deciding on methods used during public involvement in local policy making

Context	Method of involvement		
	Well structured	*Moderately structured*	*Ill structured*
Degree of conflict	Consensus	Consensus/conflict	Conflict
Number of stakeholders	Few	Few	Many
Information confidence level	Confident	Confident	Not confident
Number of alternatives	Limited	Limited	Unlimited
Knowledge of outcomes	Certain or marginal risk	Uncertain	Unknown
Probability of outcomes	Calculable	Incalculable	Incalculable

(Source: based on Walters et al., 2000

A contrasting approach to the 'whether to consult' question comes from guidance to UK local authorities. A publication from the Office of Deputy Prime Minister (1998) based on the (surveyed) practices of existing authorities suggests that consultation may be counter-productive where a clear policy or manifesto commitment already exists; where public debate could create or exacerbate community tensions (for example, siting of travellers' camps); or where decision making was heavily constrained by cost, time or legal requirements. Authorities surveyed said they might proceed to consult despite these factors in the face of irresistible strength of public feeling – a desire to allow people to have their say, and/or a concern to explain, as far as possible, the basis on which a decision had been taken. The discussion concludes that 'in some circumstances there is no point in denying that the local authority is in a 'no-win' position'. Public involvement practised selectively to avoid conflict may show greater commitment to political advantage than to democracy.

4.3.3 Co-production

Co-production has been defined as 'the involvement of citizens, clients, consumers, volunteers and/or community organisations in producing public services as well as consuming or otherwise benefiting from them' (Brudney and England, 1983, quoted in Alford, 1998). The major theories of co-production were established between 1977 and 1984 but implementation floundered as the theories were largely interpreted as co-production using volunteers – not a sufficiently reliable motivation on which to base public functions (Alford, 1998).

Alford cites a number of examples of client co-production in the public sector, including the case of Australia Post, who were able to hold down the cost of stamps by engaging their clients in co-production. The public were educated and motivated to write the postcode in orange boxes positioned in a precise location on envelopes to enable the Optical Character Recognition technology to sort the mail. Another

example is the co-production of services for unemployed people in the Commonwealth Employment Service in Australia. The Commonwealth Employment Service provides a job referral service to the unemployed, but the service requires the input of the unemployed persons, to improve their skills as suggested, and present themselves positively at interview in the manner suggested by the agency. Co-production with the public housing sector has also been highlighted as a means of improving the quality of service that tenants receive (Alford, 1996, 1998), and was also used by public regulators of the Danish fishing industry in order to improve the quality of data collected to assist fishermen in planning their work and improving their income (Nielsen and Vedsmand, 1999).

More recently, Newcastle upon Tyne City Council have won an Institute for Public Policy Research (IPPR) award for establishing resident Eco Panels to discuss how the city should manage waste and recycling, and to promote the idea that waste is a shared responsibility, a key requirement of co-production (*Guardian*, 11 December 2002). Judges praised the large number of residents involved, and 'good links with decision makers'. Although not all residents became involved through commitment to environmental causes, their continued involvement as volunteers, and increased expertise, as well as widespread public participation in recycling, challenges Alford's pessimism: unpaid people will co-produce if they feel they are achieving worthwhile ends.

4.3.4 Devolution of management

A report to the Office of the Deputy Prime Minister (1998) states that a survey of authorities carried out in 1997 found that 'about a quarter of all authorities engaged in initiatives which gave citizens direct control over the management of services', most commonly through Tenant Management Organisations. Tenants may be active in Associations which advise or pressure council landlords (National Consumer Council *et al.*, 1999c), they may control estate management, holding council officers to account (Tunstall, 2001), and they may (though we discovered no direct studies of these) take over ownership of housing stock as co-operatives (Jackson, 1999). Such organisations deal with diverse matters including the vexed management of arrears, evictions for anti-social behaviour, drug use, vandalism and repairs. Their ability to modify their own behaviour, and to pressurise neighbours into conformity, suggests that housing management by tenants is also an example of co-production.

4.3.5 Local regeneration projects

Community involvement in local projects concerned with regeneration is thought to generate extra resources for the project, seeking to identify and make use of existing skills, labour, finance, communications and support networks (Burns and Taylor, 2000). Stewart and Taylor (1995) discuss regeneration in housing, social enterprise and environmental aspects, but offer (as they point out) relatively little evidence of outcomes. Community co-operative enterprises aimed at income generation are particularly widespread in rural Scotland, although collectively managed enterprises such as community credit unions (there were around 240 such in 1991) and LETs schemes (140 in Britain in 1995) have made steady progress throughout the UK through the 1990s (Stewart and Taylor, 1995). Models of involvement identified are predominantly public meetings and committee formation. Authors emphasise the need for new projects to build on what is already happening; to recognise the heterogeneity of communities, and to refrain from 'dumping' responsibility without resources on residents, particularly in relation to intractable problems such as criminal activity.

The Office of Deputy Prime Minister (1998) identifies four stages of community development in which the community could participate: initiation, bid preparation, implementation and forward strategy (for sustainability). As in the early development of bids for health and social care funding, it is possibly unusual for lay people to be involved in the first two stages, so that, by the time their participation is sought, the change agenda is largely set. Participatory development approaches (Ong, 1996) in which (theoretically) communities help to define their own problems, are more commonly associated with developing than industrialised countries, possibly because consultation among heterogeneous industrialised populations leading very different lifestyles could generate a much broader range of conflicting priorities than is expected among pre-industrial communities.

4.4 Factors that promote and hinder UI in the public sector

A comprehensive account of factors that promote and hinder user involvement in local government services has been produced by the Office of the Deputy Prime Minister (1998) and is available at http://www.local-regions.odpm.gov.uk/epplg/index.htm. This document also provides a 'guide to other guides' that explore different methods for involving service users, and lists over 30 reports that have considered process factors that support and hinder UI initiatives. Process factors that have repeatedly been highlighted are discussed below.

4.4.1 Allowing adequate time and resources at different stages of change process

Several reports of UI in the public sector emphasised the need for flexibility in consultation periods, sometimes alongside the combination of different methods at different stages of the change process. The United States Forest Service in West Virginia undertook a programme of involvement as part of changes in the 1980s (Steelman, 2001). The initial plan took five years to draft and included scoping sessions with the public to review their concerns and detailed discussions with the timber industry to reflect their position. This plan was then published for public review, and copies were sent to two well-organised associations that had not shown interest in the planning procedure thus far, the Sierra Club (an outdoors activity organisation) and the West Virginia Department of Natural Resources (the government department tasked with the management of wildlife such as bears, deer and turkey). Realising that the plans heavily favoured the timber companies, these organisations not only produced detailed comments on the proposals but also held public meetings, which generated further comments from members of special interest groups and members of the public. The second phase of consultation included a large number of public meetings (from which the timber company was excluded) held in the state to explain the plan. The final stage was detailed negotiations for the final draft, which included all interested parties in open forum as well as detailed meetings with the main interest groups. The final plan represented the consensus at these meetings (Steelman, 2001).

Lack of sufficient support and resources is a frequent complaint of service users who have taken part in UI initiatives in the public sector. As part of mandatory consultation over changes to waste incineration in the UK, Snary (2002) reports that users, who included representatives from key local community groups, such as a local school leaders, and local community liaison officers were given inadequate information to fully understand the issues involved. Insufficient time was also stated as a reason why local users were unable to make the contribution to this process. Insufficient time and resources were identified by council officers as the major obstacles to UI in local government in Britain (Lowndes *et al.*, 2001). Service providers and commissioners may have difficulties in a number of areas, including the funding of involvement: should participation be financed by way of an 'integrated' or a 'special' resources approach? (Office of Deputy Prime Minister, 1998). Guidance based on structured research is not available, though there is general disapproval of UI as 'a bolt-on extra'.

4.4.2 Problems of representation

To avoid potential problems of 'small unrepresentative cliques' dominating tenants' associations (TAs), Leeds City Council has tried to regulate the workings of such TAs (Office of Deputy Prime Minister, 1998). An association can become accredited (for example, eligible for grant) only if it can show that it has a paid-up membership of 33 per cent (rising to 51 per cent in year 3) of the eligible estate population; or that committee members have been elected in an election in which a minimum of 500 persons participated. Over one-third of the city's tenants are now members of accredited tenants' associations. Leeds claims that their insistence on evidence of representativeness has avoided 'small clique' problems. Problems of involving a wide range of people surface throughout the literature on public sector services. The combination of different methods of involvement has also been recommended as addressing concerns about the representativeness of users who take part (Buchy and Race, 2000). In an exercise seeking to involve tenants in housing management, the National Consumer Council *et al.* (1999c) reports that quotas were set for interview samples, so that these reflected proportionately the different types of tenant to ensure broad representation. In a similar initiative concerning parental involvement in education, the report (National Consumer Council *et al.*, 1999b) comments that active, assertive parents often had very narrow perspectives, but that improving the confidence of less articulate parents – showing them their contributions were appropriate and valued – was possible (though time-consuming) through one-to-one interviews.

The National Consumer Council has summarised lessons from a two-year action project (reported in more detail elsewhere) in a list of 'top tips' on the planning and implementation of projects to involve service users (National Consumer Council *et al.*, 1999a, 1999b, 1999c). Most of them address the issue of representation, though not always directly:

> *… draw up a profile of users … to ensure you get a spread of views; don't rely on paper-based communication; meet users at a time and place convenient to them; when using surveys, ask a group of users what questions they want to be asked …*

as survey responses are higher when questions are meaningful to respondents. The proposed methods of consultation are important to the ability to consult particular types of people, as the account of the North Cheshire Benefits Agency consultation demonstrates (National Consumer Council *et al.*, 1999a; see Section 4.4.6 below).

4.4.3 Conflicting or excessive expectations and demands upon services

A report of user involvement in changes within the Avon Probation Service illustrates the effects that external pressures can have on the impact of UI initiatives (Broussine and Wakefield, 1997). Managers within the probation services used a number of small focus groups to gather the views of employees (probation officers), and a set of one-to-one interviews to gather views of the sentencers (judges, magistrates and magistrates' clerks) and clients (offenders). Through examining these views they discovered significant differences between the expectations of these service user groups. Mixed programme outputs included a greater emphasis on preparation for the job market for the offender clients through employment training, more evaluation and resourcing of accommodation, and a swifter production of probation reports for the judiciary. However the authors note that this process coincided with implementation of budget cuts imposed from central and regional government, which led some probation officers to see the research and the ensuing changes as a means of cost cutting rather than of stakeholder involvement or quality enhancement.

Several authors described the fear of raising expectations among those consulted: whether the aims of a project are very modest (for example, the production of a home-school agreement (National Consumer Council *et al.*, 1999b)), or completely open (the questioning of housing tenants about causes of dissatisfaction (National Consumer Council *et al.*, 1999c)), 'it can sometimes seem easier simply not to ask [people] what they want'. Having 'asked parents what mattered to them', the report of the education consultation exercise (National Consumer Council *et al.*, 1999b) distinguished between what could and what could not be addressed within the existing framework, and reported accordingly to parents. This study concluded that low – rather than unrealistically heightened – expectations of the purpose and outcomes of involvement were the greatest threat to the project.

4.4.4 Professional resistance

Examining how national policy on the formation of tenant management associations to take over the management of council housing was implemented, Tunstall (2001) noted great disparity in the attitudes of council employees, with some lacking any confidence in the ability of tenant-led organisations to improve services. Although a survey of local councils found widespread support for the policy, some councils were found not to have implemented any elements of either devolution of power or tenant participation: in some cases, rent accounts had not been released to enable the new tenant management officers to manage arrears. Lack of support from council officers and councillors was also found to be an important obstacle to successful UI in local

government service in a survey of British councils by Lowndes and colleagues (Lowndes *et al.*, 2001). The National Consumer Council (National Consumer Council *et al.*, 1999b) also found that highly-skilled teachers tended to be resentful of 'interference' from parents who had little understanding of modern teaching practice; teachers already felt themselves to be under pressure to achieve much with limited resources. Professionals may also find themselves an unwitting impediment to the consultation process when service users 'blame' them for the policies they implement (National Consumer Council *et al.*, 1999a), and may then need to delegate involvement exercises to less stigmatised personnel.

4.4.5 Community distance from funding and implementation agencies

Factors that impede community participation in regeneration (Communities and Organisations – Growth and Support (COGS), 2000) include: bureaucracy of funding procedures; remoteness of strategic decision making; weakness of community networks and involvement capacity; and the assumption that local authorities have the capacity to lead negotiations with fundholders, although often they are relatively inactive in drawing in other stakeholders. One aspect of 'distance' is explored by Atkinson (1999), as he discusses how the political use of terms such as 'empowerment' and 'partnership' in ministerial speeches and Departmental guidance are constructed to reinforce existing power disparities between officials in urban regeneration, reinforcing Arnstein's (1971) conclusion that communities rarely achieve even partial control of material or symbolic resources. Stewart and Taylor (1995) also criticise the 'top-down' pressure on disadvantaged communities in 1990s urban development, with the concept of social and economic inclusion (rather than citizenship) emphasizing responsibilities rather than rights, thereby reducing incentives for public involvement.

4.4.6 Combining different methods for UI

A report by the National Consumer Council *et al.* (1999a) described a consultation with clients at branches of the North Cheshire Benefits Agency which emphasised the value of combining different methods to involve service users. Mixed methods were used to enhance participation: existing groups were visited, customers were surveyed (by oral questionnaire, and later by telephone), customers were invited to interviews, posters, flyers and press articles advertised a dedicated line for anonymous callers. Particular emphasis was placed on involving people dispersed through rural areas with poor access to transport, illiterate people and people who mistrusted officialdom. Some meetings were led by the local Citizens Advice Bureau or the National Consumer Council, rather by Benefits Agency staff, because of perceived hostility. Evaluating responses, the authors found that written publicity

was quite unproductive of responses; survey responses lacked qualitative detail; and holding group meetings, where people found confidence to speak up, gave most insight into clients' views. Project staff relied on local voluntary sector groups to set up (and sometimes to run) these meetings. A new charter for service standards was delivered by the project.

4.4.7 Other factors

A recent survey by Lowndes and colleagues (2001) of citizens' attitudes to various methods of citizen involvement revealed that the favourite methods of involvement were, in order of preference, postal questionnaire, face-to-face interviews and public meetings. Findings from focus groups that the authors conducted suggested that public involvement should be successful if it:

- addresses issues of concern for local residents and involves all relevant agencies

- invites or actively recruits participants, rather than waiting for citizens to come forward

- employs a repertoire of methods to reach different citizen groups and address different issues

- shows results – by linking participation initiatives directly to decision making, and keeping citizens informed of outcomes (and the reasons behind them).

Lowndes and colleagues (2001) also surveyed local councils to discover what types of involvement/participation innovations were actually taking place in local government. Traditional methods such as public meetings, consultation documents, consumer satisfaction surveys and complaints departments were used by between 85 and 95 per cent of councils. Service user meetings were held by 40–63 per cent of councils and focus groups by 45 per cent; 22 per cent of councils reported supporting devolved services that were run by users; Citizens' Juries had been used by less than 5 per cent of councils.

Baxter and colleagues combined a literature review and series of case studies in order to examine factors that promote and hinder user involvement in research across a diverse range of public services including education, public health and overseas development (Baxter *et al.*, 2001). Their report concluded that six factors were central to the success of such public sector projects:

- the attitudes of professionals involved

- a recognition of diversity among service users taking part

- a recognition of the local knowledge that users may have

- an awareness of power differentials between users and providers and a commitment to share power on the part of service providers

- provision of sufficient time and resources to support user involvement and a recognition that projects involving users may require additional time and money

- a need for all those who take part to be honest and open with each other.

They also recommended that payment for service users should always be provided and argued that those facilitating user involvement in research should receive specialist training.

4.5 Outcomes of UI

Recommendations for UI in the public sector have highlighted the need to describe changes that were made to services as a result of involving users (Burns and Taylor, 2000; Audit Commission and IDeA, 2002). Despite this, most of the reports that we identified did not describe the outcome of UI. Evaluating initiatives may not be a priority for managers (Office of Deputy Prime Minister, 1998), and a quote from a local councillor is used to explain why formal evaluation may not take place:

> *If you can put resources into cracking the problem in front of you, or evaluating what happened ... it's difficult to convince people that evaluation is important ... We tend to move on to the next initiative rather than complete the loop.*

(Office of Deputy Prime Minister, 1998)

Reports that have discussed outcomes of UI in public sector services are summarised in Appendix 3. These include:

- *Increased satisfaction with services* Reorganising the customer-facing service organisation in the Austrian Housing Department was evaluated using repeated cross-sectional surveys of staff and customer satisfaction (Scharitzer and Korunka, 2000). This demonstrated greater satisfaction for customers with the processes but not the outcomes of the service.

- *Promotion of further UI initiatives* Following the UI initiatives within Avon Probation Services the organisation agreed to follow up their work with annual surveys of service users (Broussine and Wakefield, 1997).

- *Improved management* Thody and Punter (2000) evaluated the impact of the co-option of business people on to 35 school boards. Through conducting focus groups of teachers and governors and surveying the views of headteachers, they concluded that the co-opted people brought objectivity to boards and a strategic non-operational approach, and clearer understanding of the difference between management and governance.

- *Changes to service priorities* UI in the evaluation of Avon Probation Services led to changes in the priorities of the service including a greater emphasis on preparing clients for work, and a

swifter production of probation reports for the judiciary (Broussine and Wakefield, 1997).

- *Other outcomes* In her examination of the impact of the development of tenant management associations, Tunstall (2001) reports the views of council workers that devolving control to local residents led to improved staff–resident relations, universal improvements in repair services and some localised improvements in management of rent accounts and caretaking. However, they also reported concerns about areas of reduced effectiveness, such as a reduction in auxiliary services including refuse collection, which had a particularly detrimental impact on areas not managed by tenants. Some staff found it difficult to work to tenant supervision; and where councils retained control over problematic areas such as allocations, housing benefit and rent accounting, the impact of tenant management was less. Resident board members commented on their own personal development through participation, but also on a heavy voluntary workload.

- *The impact of school councils* Information about school councils (in which pupils meet to discuss school policy issues) can be found at www.schoolcouncils.org.uk. In addition to improving democratic expression in schools, teachers and pupils report that councils deliver additional benefits in improving policy and compliance with policy, and reducing exclusions, bullying and racism (Davies, 1999: see also Section 7.2.2.5). These outcomes have not been demonstrated through experimental methodology.

In their survey of local councils Lowndes *et al.* (2001) reported that 20 per cent of council participants felt that citizens' participation had a strong influence over their final decision, and a further 16 per cent felt that they had made better-informed decisions. The others felt that citizens confirmed their previous decisions (20 per cent), that citizens' participation was of very little significance (20 per cent), or that citizens' participation was becoming more important (13 per cent).

Chapter 5 Voluntary sector services

We found very few published accounts of voluntary sector initiatives designed to involve service users, but we do not conclude that they do not do so. We would suggest the following reasons for the relative absence of published literature in this field.

1   Much involvement work takes place quietly and continuously, as part of the process of caring for and working with people (Ridley, 2002).

2   Some voluntary sector organisations are run by users, so user involvement is taken for granted.

3   Staff of voluntary sector organisations do not have the same incentives to publish accounts of their work as do NHS and social service providers. The sector is generally less well resourced, and so less time and money are available for writing and publishing reports.

4   Some of the more influential involvement work of the voluntary sector may be carried out on behalf of statutory organisations. Participation of voluntary sector organisations would be at the invitation of statutory services, who may well claim (as some of our sources suggest) ownership of the consultation, and describe the outcomes in published material.

Voluntary sector organisations include very large multinational NGOs, national charities and tiny unincorporated groups of collaborators with local or personal interests. While it is difficult to generalise, there are issues around involvement that seem to relate to the developmental phase of each organisation, and its relationship with statutory providers. This account concentrates (as the literature tends to) upon organisations contributing in some way to health and social outcomes of beneficiaries.

5.1 Context and aims of UI in the voluntary sector

Voluntary sector providers of social and health services are Janus-like organisations, looking toward their service beneficiaries, who may well be founder members, and toward the organisations, predominantly local authorities and commissioning health authorities, who can fund them through the contracting system. When organisations are founded by people with particular need, founder members may strive through continued involvement in management to maintain the original, or evolving, objectives of the organisation (McLean, 1995). The extent to which voluntary sector organisations were founded and are managed by beneficiaries is, however, very variable: those founded for, rather

than by, beneficiaries may have less incentive to involve them. Nevertheless, statutory providers may expect the voluntary sector to 'specialise' in involvement of service beneficiaries, whether or not this is justified.

> *Since the implementation of the National Health and Community Care Act, 1990, and the introduction of 'best value' in Local Government, the social care business has radically changed to one of 'mixed care' … with provision coming not only from the traditional partners in the voluntary sector but now also from the growing and influential 'for-profit' sector.*

> (Crook, 2002)

In the challenge to differentiate themselves and win local authority contracts for social care provision:

> *… charities could and perhaps increasingly need to point out that it is the users of their services that drive the mission and the values.*

The Housing Corporation (governing all registered social landlords (RSLs)) promotes standards such as responsiveness to residents' views and priorities, continuous improvement based on user and community feedback, and high standards of probity so that the RSL's affairs 'are accessible and transparent to residents and other stakeholders' (Housing Corporation, 2001). Some organisations may understand 'transparency' to mean published accounts, while others may hold some parts of management meetings in public.

5.2 Methods for involving service users

The two most common forms of user involvement within the voluntary sector that we identified were consultation with user groups (that were generally supported by organisations) and the appointment of user representatives on governing bodies of organisations. A survey of voluntary organisations in Britain in 1995 by the Centre for Institutional Studies at the University of East London revealed that over half the 42 organisations that responded had one or more service users on their governing body (Robson *et al.*, 1997). Fewer organisations were in contact with or organised local user groups. Some of these were informal support networks while others were set up by voluntary groups specifically to assist the process of consulting with service users. The survey also found that while senior managers in three-quarters of organisations stated that the organisation was trying to increase the extent of user involvement, only one-quarter had agreed a policy or programme that stated how this was to be achieved.

5.3 Areas of involvement

5.3.1 User-led voluntary sector organisations

Mowbray (1998) describes the funding of five user-led service provision demonstration projects through small grants (up to $20K in 1982–3) from Michigan Department of Mental Health. Positive advantages recorded from the evaluation were that deficits in the co-ordination of community services (for example, when patients were discharged from hospital) were overcome very cheaply, but user/providers were paid 'discriminatory' low salaries, and some were stressed by the demands of service provision. Overall, these projects confirmed the conclusion that the more a service moved from the 'support/befriending' function toward more technical or complicated services (production), the less likely they were to succeed in becoming wholly user-run or profit making, because of the demanding range of functions (such as marketing, people management) the organisation had to provide for, many with no apparent relationship to the experience of being a mental health service user. Even small user organisations report skills deficits: users say they need 'training on how to get grants, and things like that … [and] assertiveness training' (Kumar, 1997). The formation of consortia may help smaller organisations to pool expertise without compromising the staffing and focus of the whole organisation (Ferguson, 1998).

User groups that have more limited objectives and ambitions may still require external support. In the field of residential care for elderly people, difficulties in mobility may demand that a user group be set up within the institution to monitor standards. In one such case:

> *User liaison meetings [between residents and commissioners of care] appeared to be an excellent accountability mechanism in theory: in practice, the researcher found that in certain cases, they had not been functional for some time … . When the researcher visited an elderly day care service to interview committee members … the user representatives were all found to have died several months before.*

> (Kumar, 1997)

Public sector managers and commissioners may point to user groups as signifiers of good practice, but do not necessarily investigate or facilitate their survival.

McLean (1995), in an excellent case study of an advocacy organisation staffed by former and current users of psychiatric services, describes how the employment of leading staff who combined provider and user status, and the division of labour (between managerial and 'menial' jobs), created internal hierarchies which disaffected service users. At the same time, the aims of the organisation veered between the 'professional' advocacy service promoted by leading staff, which was most likely to be acknowledged and funded, and the more relaxed, self-helping, non-hierarchical, drop-in organisation that the users wanted.

'Lacking economic power in an organisation that depended on such power, the consumer members of the Quad often found their own needs subordinated to the consumer organisation's struggle to perpetuate itself', with managers caught between their accountability to external funding organisations and to the individual users of the service. In such conflict, managers tended to attribute conflict to the mental illness of users, further alienating them, and reinforcing divisive, hierarchical distinctions within the group. McLean's account is consistent with other accounts of the difficulties faced by voluntary sector organisations in both addressing users' needs and gaining funding and professional status, as well as the anti-democratic influence exercised by managerial postholders in small, voluntary sector organisations (Croft, 2002).

5.3.2 UI in voluntary sector organisations that are not user-led

Robson *et al.* (1997) surveyed 200 voluntary organisations. Assuming interest in increasing user involvement in the control and management of these organisations, the researchers proposed ways to increase involvement, and invited responses. Their response rate of 42 casts doubt upon the first assumption of Robson and colleagues: of those 42, only 24 (57 per cent) had service users on their governing bodies, although users did participate in less influential roles, as advocates, trainers, campaigners and volunteers. Notable exceptions included the RNIB, with visually impaired people comprising 70 per cent of its executive council. Over half the respondents (chief executives) thought that users were disinterested in participating in management of the organisation. Other disincentives suggested were that users were too disabled, would become stressed, or could not travel to meetings, or that they lacked knowledge of committee procedures and language; but only 12 organisations (29 per cent) were actively trying to develop UI. Nearly half the respondents thought involving users would increase conflict and conflicting interests between professionals and users. Handing all or part of organisational control over to users may then be seen as undermining the development of rationality, efficiency and objective governance of the organisation, with a real risk that the impassioned views of users may alter both the aims and operational capacity of the organisation. As one former chief executive commented: 'my nightmare is that a group of highly political users will take over' (quoted in Robson *et al.*, 1997).

Robson *et al.* (1997) describe some incremental programmes of change in pursuit of UI: the Association for Spina Bifida and Hydrocephalus began to develop as a cohort of children and young people survived into adulthood: initial consultation, and the establishment of an internal body for user representation, developed into involvement at executive board level. This is conceptualised as a relatively long-term process, with the need to 'overcome resistance of trustees and paid staff,

demonstrating to them that users can be involved without upsetting the status quo'. The identified 'turning point' (in the secession of some power to users) came when the user body's statement of position on government proposals on disability rights was adopted by the wider organisation. However, it is unclear how organisations might handle differences of opinion between user and executive bodies. There is also confusion within charity law about appointing trustees (who must be unpaid) who themselves benefit from the charity, since traditionally trusteeship has explicitly prohibited benefit: but the Charity Commission (in their 2000 publication, available from the Charity Commission web site http://www.charity-commission.gov.uk/tcc/default.asp) clarifies their current support for user participants as full trustees, provided they are in the minority. The pressures on charities and voluntary sector providers to operate as, and compete with, statutory and private providers (see next section) encourages them to recruit professional expertise (in personnel issues, fundraising, networking, finance, etc.) to their executive boards, possibly reducing the influence of user representatives.

Organisations may justify the decline of user influence in management by the pursuit of more professional standards. However, 'professional' complaints procedures, and UI through research techniques (surveys, focus groups, panels etc.) being piloted in statutory services, may be poorly developed in this sector. Kumar concludes (1997) that:

> *… all voluntary sector respondents reported that although their organisations had complaints procedures, voluntary organisations would not encourage people to use them, as they would be viewed as negative feedback or criticism.*

Housing Corporation survey research (Coulter, 2002b) showed that around 75 per cent of housing associations had tenant members on their boards, but 'while a relatively high proportion of Registered Social Landlords' (89 per cent of 322 respondents, all managing over 250 units) 'indicated that their tenant participation strategy influenced their business planning process, there was little evidence to show how this translated into practical applications'. Lessons from ten case studies (comprehensive summary available at www.housingcorplibrary.org.uk) suggest that tenants are consistently keen to be involved in meetings and groups, but not in formal organisational roles; and some organisations with little formal or financial emphasis on participation showed the greatest staff commitment to involvement in everyday practice, front-line staff attitudes being apparently more influential than organisational policy. The Housing Corporation has also published *Just do it! A directory of examples of service user involvement in supported housing* (2000), which intends to provide practical direction.

5.4 Factors that promote and hinder UI in the voluntary sector

5.4.1 Charitable ethos

Other authors support the conclusion that voluntary organisations that represent, or provide services to, disabled people may be no better than statutory organisations in promoting:

- issues and research agendas raised by disabled people (Flower and Wirz, 2000), and

- disabled people as incumbents of positions of authority within the organisation (Drake, 1996; Ridley, 2002).

Drake suggests that the traditional charity ethos of paternalism, and reference to 'personal tragedy' and the medical model of disability, cast disabled people in roles of powerlessness.

> *Consumers are invited by those managing the organisation to play an active part … but within limits presented/determined by the managing group.*

Non-disabled management saw:

> *… 'consumer participation' as a sort of gift, bestowed upon disabled people by those in charge of agencies.*

> (Drake, 1996)

Asked to identify the intended aims of their charities, respondents identified beneficiaries as 'other' agencies, parents and carers, and the addressing of disembodied 'needs'. On the other hand, many charities sought to improve democracy and, in some, every person with a specified condition had a standing invitation to attend committee meetings.

There are ambiguities about the ownership, purposes and cultures of voluntary sector organisations that resist the involvement of able beneficiaries. Altruistic aims common in voluntary sector charities sit uneasily with user involvement, with organisations 'for' rather than 'of' disabled people (Ridley, 2002). Speaking of elderly people, Thornton and Tozer (1994) reflect on a failure of services to make distinctions between organisations *for* and organisations *of* groups of older users, commenting that *:*

> *… in some areas it seems that voluntary organisations speaking for users must compete with users themselves for places at the joint planning table.*

5.4.2 Organisational development and its impact on user-led objectives and management

Empowerment for the organisation on a wider stage of commissioning, contracting and involvement in local and national policy may be incompatible with empowerment for the individuals that organisation proposes to serve. Organisations that appear successful in managing to gain funding and influence statutory providers may sacrifice some of their user-led, grassroots status, employing professional staff and managers, and systems designed to show accountability to funders, rather than members or users*.* Smaller organisations that are truly grassroots initiatives then find it very difficult to compete for resources. Drake's (1996) survey found that:

> *Of 37 agencies who received grants from central government, only two (5.4 per cent) were governed by disabled people. Of 46 agencies with annual incomes in excess of £50,000, just three (6.5 per cent) were led by disabled people.*

Barnes (1999) gathers similar evidence of the difficulties faced by autonomous organisations:

> *Movement from oppositional action to action to develop new forms of institutions … demands different forms of organisation and thus change in the nature of the movements themselves … once they seek to impact on mainstream welfare services, or seek funding from the statutory sector.*

As organisations develop as players in the mainstream system, they may lose the support of members who looked outside the system to achieve a 'redefinition of self'. It may also be unclear whether groups are held together by common identity (as black people; as disabled people) or by common interest (reforming legislation; reforming services). Barnes goes on to argue that user self-organisation (in the fields of disability and mental health which she discusses):

> *… is significant in its own right as a means of enhancing the citizenship of excluded groups, not simply as a means through which producers can access users to provide consumer feedback.*

User groups stand to dissipate their energies on reacting to official agendas, experiencing 'consultation overload', and failing to determine and promote their own aims. Engagement with services may be a

condition of adequate funding, but with no power to influence the terms and outcomes of engagement, it may not feel empowering.

5.4.3 Privacy, confidentiality and stigma

The prominence of users may be important to the success of some organisations, in order to establish credibility with intended clientele. In Canada, Roy and Cain (2001) report that 'many agencies set up to provide prevention education have needed to re-examine their mandate to provide more support services', because the target recipients saw such support as their priority need, without which they were unwilling to engage. The status of personnel delivering services was also found to be a major issue (although in this organisation, the status of organisational managers and decision makers, being hidden, was not such an issue).

> *By having HIV-positive peer counsellors, many clients believe they will not be judged and can talk freely.*

(Roy and Cain, 2001)

Training volunteer counsellors has then become a key part of an organisation set up for health promotion purposes. Dixon *et al.* (1994) describe the advantages of employing former service users in mental health outreach services in the USA (see also Solomon and Draine (1995)). Although in both cases volunteer users appear to have contributed dramatically to the legitimacy of the organisation (in the eyes of clients and funders), their unpaid status clearly obscured their value, and potentially confuses their accountability to the organisation (in terms of confidentiality, following codes of practice, etc.). The Terrence Higgins Trust (THT) (personal communication) reports on the difficulty of distinguishing employees who are also 'service users' within an organisation that is fundamentally opposed to pressurising people to declare their health status: positive discrimination in employment is not possible in this context, although THT does have an Expert Reference Group willing to declare themselves as service users to advise on all policy.

5.4.4 The penalties of contracting with the statutory sector

Voluntary sector organisations (whether for or of users) have been targeted for consultation by statutory providers in relation to community care planning, and many are reported to have found such activity 'a significant drain on resources' at the expense of their own priorities (Bewley and Glendenning, 1994), and with no compensation. The impact of involvement was (in 1992–93) obscured by confusion about the remit and authority of planning groups (Joint Consultative Committees) and the weight that would be attached to the views of different members.

Craig and Manthorpe (1999) describe how the implementation of the NHS and Community Care Act (1990) both promoted mixed markets and increased the need for contracting out to community-based voluntary sector organisations. Voluntary sector organisations were consequently 'drawn almost exclusively into service-providing roles at the expense of the sector's traditional roles of advocacy, development, representation and campaigning', and became unhealthily dependent on uncertain and uncommitted financial support from local government. Some organisations consequently over-reached themselves and folded. An increasingly dependent relationship with statutory services may lead service users to lose confidence in the organisation's ability to act independently of statutory funders.

'Successful' voluntary sector organisations plug gaps in local services, which may mean a shift from relatively insecure or piecemeal funding toward being entirely funded from social services budgets. Kids-Care, an organisation providing support to families of disabled children, lost its support from a national charity when the implementation of the Children Act (1989) brought its remit into statutory provision (Scott *et al.*, 2000), but it was contracted by the local authority to continue to provide the service. Voluntary sector managers then put in place procedures and mechanisms acceptable to funders, to whom they became accountable, changing the character of the organisation to such an extent that users lost interest in managing the organisation, since service specification was now, for example, part of the contract led by social services, rather than open to debate. Kids-Care lost its role in working directly with families to match them to volunteers, and was confined to the training and management of volunteers. Towards the end of the three-year contract, workers were explicitly gagged from reporting the state of negotiations with social services to its (diminished) user advisory group. Eventually, the organisation lost the social services contract when it was put out to competitive tender (presumably in pursuit of Best Value):

> *We tried to get the local authority to meet users to explain their decision [to withdraw funding] – that did not happen.*

(Manager, Kids-Care, quoted in Scott *et al.*, 2000)

The families (the service users) were handed over to the new provider.

Crook (2002) describes a similar grassroots organisation that invested heavily in an innovative scheme proposed by the local authority:

The contractual arrangements failed to materialise, and the risk resulted in a substantial loss and the need to shed staff.

In a contractual economy, statutory services can 'contract out' public and user consultation and participation: it may also contract out financial risk taking, to the detriment of small voluntary sector organisations.

A catch-all language of partnership increasingly shapes the operations of voluntary organisations.

(Passey *et al.*, 2002)

The use of such a term is a rhetorical disguise for inequitable power relations which tend to dilute the ethical edge and innovative practice for which the voluntary sector is valued. Voluntary sector organisations contracting with statutory authorities move further toward Barnes and Walker's (1996) 'bureaucratic' organisational type (see Table 3).

It is possible then that local authorities can distance themselves from service users and local people by contracting with voluntary sector organisations who act as 'buffers'. In the Kids-Care example above, the organisation managed to arrange for senior social services officers to attend a meeting with users to explain and justify proposed changes in service delivery which would further distance the organisation's workers from the client families. No previous user consultation had taken place: such was the strength of feeling expressed, that the proposals were withdrawn. Whether such strident opposition from users influenced the eventual failure of Kids-Care to win the contract renewal is unknown, as the selection is not transparent to stakeholders, including in this case Kids-Care's management, users and the volunteers who are essential to the service.

5.4.5 Responsibility for UI

Other studies (for example, Kumar, 1997) have raised the possibility that the contracting system allows local authorities to hive off the involvement process to voluntary sector organisations with which they contract.

Nearly all local government respondents assumed that voluntary organisations consulted with users on behalf of purchasers, 'lobbied purchasers' and 'advocated' on behalf of users … By liaising with their partners, they [the local authority] were to a certain extent 'taking users' views into account'.

(Kumar, 1997)

These are huge assumptions, even when they are contractually specified:

> *User accountability is inherent in the contract … we are asking in that specification for a fully responsive service.*

(Local government manager, quoted in Kumar, 1997)

From an early evaluation of multi-agency working in Health Action Zones, Westland and Unwin (2000) suggest that, as experience of multi-agency partnership developed, significant change had taken place in expectations of voluntary sector services:

> *In 1998 there was some expectation on the part of some statutory services that the sector could somehow access local communities directly … This had been seen as one of the functions of the voluntary and community sector … [By 2000] there was no sense that the voluntary and community sector could be assumed to have secured high levels of community participation.*

Within this framework, the authors comment that statutory bodies were beginning to question the expectation that voluntary organisations should be included on decision making bodies as of right.

5.4.6 Other factors

In the survey by Robson and colleagues (Robson *et al.*, 1997), the most frequently stated problem that senior managers in voluntary organisations identified as hindering user involvement was that service users were more interested in service quality than in management issues. Other frequently stated problems were: uncertainty about whether or not charity law prevented someone using a service from being a member of its governing body; conflicts between service users and providers; and the impact that poor health had on the ability of some service users to contribute to change within organisations. Factors such as allowing sufficient time to develop relationships with service users, strong commitment among staff, and the provision of appropriate training for users, were considered to facilitate user involvement in the voluntary sector.

5.5 Outcomes of UI in the voluntary sector

We were not able to identify many outcomes of UI in the voluntary sector in the literature that we examined. Recent coverage in the *Guardian* newspaper (11 December 2002) of the Institute for Public Policy Research (www.ippr.org.uk) public involvement awards (open to entrants in all sectors) cites several voluntary sector winners: Wrekin Housing Trust, for a project to train and support 'tenant auditors'; Wansbeck Council for Voluntary Organisations, for a project to train volunteers as researchers to investigate local concerns and report to service planners; Mencap, for a project to pair learning disabled young people with peer supporters in order to work toward greater involvement in the planning of their care; and Skye and Lachalsh Young Carers' Project for its involvement of young carers in the development and running of the project. These projects, which are predominantly capacity building (rather than illustrative of particular changed outcomes) have not, as far as we know, been written up for publication (and are not included in our table of outcomes because of insufficient information).

Voluntary sector organisations which campaign for recognition of the needs and rights of particular types of people have obvious educational outcomes which may not be measured or recorded. For example, the Terrence Higgins Trust (THT and UK Coalition of People Living with HIV and AIDS, 2001) reports on a national survey and public meetings undertaken during the government consultation on HIV, AIDS and sexual health services. Such exercises, like many THT activities, potentially have significant educational outcomes, influence policy and may affect participants, but we have no evidence of the nature and extent of these outcomes.

Goss and Miller (1995) have described the work of a wide range of voluntary groups who work with provider services. Interesting and productive examples concern the expansion of the groups' roles during the partnership as capacity becomes apparent to funders. In Sheffield, a user-led network of disabled people applied to the local authority to join the community care planning project, and expanded its activities, from the dissemination of a rights charter to the writing of a business plan to employ a full-time worker and deliver services to local people. In Sutton, consultation with service users about a new day centre developed into a user-led learning resource centre under contract to the local authority. This account is a good example of local authorities permitting and supporting voluntary sector organisations to generate outcomes, and we are aware that, in accounts of similar projects, the local authority might take the credit both for outcomes, and for the publication.

Chapter 6 Private sector services

Compared to the extensive literature on customer satisfaction, retention and defection we were able to find relatively few papers that described the process and outcomes of user involvement within the private sector.

6.1 Context and aims of UI in the private sector

User involvement in the private sector is almost exclusively concerned with protecting and/or expanding market share and increasing profitability. It focuses on understanding what services and goods are required by product users, and attempts to ensure that providers enhance users' satisfaction so that customers remain loyal (Reichheld and Sasser, 2000). The measurement and utilisation of satisfaction and customer retention have both been extensively studied, and reviews of these topics can be found elsewhere (Parasuraman and Berry, 1997; Parasuraman *et al.*, 1991; Reichheld and Sasser, 2000; Blattberg *et al.*, 2001).

We found examples of customer involvement in many areas of organisation function. These could be categorised according to organisational function which users are recruited to influence, or by the breadth of change in which customers are involved; but the starkest differentiator is the degree of involvement of the user in the change process. Magidson and Brandyberry (2001) describe different levels of customer involvement in product/service development. They suggest that companies typically engage their customers in one of three ways.

- (Companies) design *for* the users, relying on in-house experts to decide what customers need.

- (Companies) design *with* the users, interviewing customers to get their input and then retreating to do the design themselves.

- Less frequently, they let their customers take over: design *by* the users. End users are asked not only to specify the product requirements but also to sketch out in rough terms what the product would look like and how they would use it. The company then works with a subset of those customers to develop a prototype, which is repeatedly refined based on feedback from the larger group.

6.2 Methods for involving service users

The principal methods for identifying customer views are surveys, focus groups and interviews, all of which have been extensively used throughout the private sector (Holland *et al.*, 1990; Ford *et al.*, 2001; Sculley, 1987; Gilmore and Pine, 1997; Seybold and Marshak, 1998; Dholakia and Morwitz, 2002; Taylor, 2002). Other methods for involving users are described in the sections that follow.

6.2.1 Monitoring and responding to complaints

Koa, a leading Japanese household product manufacturer, has mechanised the feedback process from customer to product development. They have developed a system where their telephone operators enter complaints about their products into a database system: this information is available for the marketing department to identify product refinements required by customers (Helfat and Raubitschek, 2000).

Monitoring and responding to complaints is integral to user involvement in most private sector companies and was a central component of attempts by British Airways to become more sensitive to the needs of its customers. British Airways transformed their customer complaints department to a 'customer champion department': by giving staff the mission to retain customers, they sought to change what was a defensive part of their organisation into a forward-looking one (Kotter and Leahey, 1993). British Airways found that, while less than 10 per cent of their customers ever contacted the airline's customer relations department about a service issue, between 40 and 50 per cent of these customers defected if they did not receive a response to a complaint within five days (Prokesch, 1995).

Research within IBM underlined the importance of successfully managing customer complaints. Examination of their sales records showed that 84 per cent of customers who had purchased a product went on to buy products from IBM on a second occasion. However, among those who had made a complaint which was successfully resolved, the re-purchase rate was 93 per cent (Basch, 2002).

6.2.2 Co-production and product design

Some companies have redrawn the boundaries of customer involvement by inviting customers to take over the development of their products. It should be noted that none of these processes are one-off initiatives, and that constant innovation is crucial to continued success. Additional elements are introduced here, including the building of on-line communities that support the organisation's aim of selling more products. While the information technology sector is particularly well

suited to this process, users have been involved in product design in other areas such as food and retail sectors.

Prahalad and Ramaswamy (2000) note that some organisations have recognised that customers can provide key competences for organisations: for example Microsoft 'employed' more than 650,000 programmers to test their Windows 2000 software within their own environment. The testers (who were mostly unpaid) co-operated in order to explore the value of the new Windows software to their own businesses, and some were motivated by the opportunity cost to their businesses if they did not have Windows 2000 compatible products at launch. It has been estimated by Microsoft that the effort that Microsoft's customers put into co-developing the software was as much as $500 million in terms of time, effort and fees.

Cisco, the data-networking company, used customers to provide user support. By making their support information, resources and systems available to their customers as an on-line service, they found that their customers could engage in a dialogue and could solve each other's problems. When companies such as LSI Logic Corporation provided customers with do-it-yourself semiconductor chip design kits, they removed the costs of hiring costly chip design companies (where the tacit knowledge is held by a small number of individuals). The CAD/CAM libraries in the DIY toolkit helped the value of the custom chip sector grow from a handful of high-volume customers to hundreds of thousands of customers, spending a total of $15 billion on the production of custom integrated circuits (Thomke and von Hippel, 2002).

Dell Computers followed a similar model, and allows customers to define and order their own PC over the internet. The PC is then built for that customer and shipped directly to them, with all interactions happening over the web. Diagnostic and trouble-shooting sessions specific to the customer's own PC are also made available over the web. Dell have therefore given much of the traditional retailer's power (selection of goods for sale and post-sales support) into the hands of the customer, allowing for a slimmed-down company and cheaper computers to the consumer. This consumer power has also been passed into the private corporate intranets, with Dell providing IT procurement services for companies by tailored intranet pages. This blurs the traditional boundaries of customer and retailer, by providing software to achieve what people and shops had previously done, and allows Dell to provide a service to corporations which enables them to save money on IT procurement (Seybold and Marshak, 1998).

iPrint, the US internet-based business stationery printer, has also used a similar model to enable commercial stationery to be procured on line. iPrint provide design software on line which allows customers to 'design' and order their own stationery. By providing pro forma designs, and easy-to-use design tools, people with a range of technical and design

skills can now have professional business cards and other stationery delivered to their door within days. It is argued that by partnering with local printing shops, and with United Parcel Services (UPS) for carriage, iPrint can provide a seamless service to customers, storing designs and orders on line to enable easy re-orders and, like Dell, providing tailored versions of the web pages and design software for larger corporate clients (Seybold and Marshak, 1998).

Examples of co-production also exist outside the field of IT: Bush Boake Allen, a global supplier of specialty flavours, gave responsibility for their product flavour design processes to their customers. These companies developed tools in house that enabled the customer to control the iterative development cycle for the product, for example making a smokey bacon flavour more smokey. The elements required for successful co-development are a complex and multi-iterative design process, a user-friendly toolkit that does not require intensive support, libraries of building blocks from which to build the product and also an understanding of the capabilities and limitations of the production process (Thomke and von Hippel, 2002). What these examples have in common is that they provide the customer with the tools to produce a highly personalised product.

6.2.3 Obtaining information without the direct involvement of service users

We identified several reports where private sector companies had attempted to obtain information about the expectations and needs of service users without their direct involvement. These include systems for monitoring interactions between staff and customers and meetings with front-line and other staff in organisations in which service providers were asked to generate information about the experience they thought service users had (Basch, 2002). The Medical College of Virginia Hospitals, a provider of private sector health care services in the USA, decided that they needed to attract more fee-paying customers to their hospital. Senior managers within the organisation met groups of up to 20 employees from all areas of the hospital in order to discuss the strengths and weaknesses of existing work practices (Holland *et al.*, 1990). The views of staff within the hospital were considered to be a valuable resource that could give managers a better understanding of the problems experienced by service users.

6.3 Factors that promote and hinder UI within the private sector

We identified numerous publications that explored factors that are considered necessary in order to ensure that methods used to generate information about the expectations and needs of service users result in customer-focused services. Many of these factors relate to the process of delivering services that focus on the needs of service users, rather than on factors that promote the involvement of service users per se. However, they are included in this section because they were stated to be important in the examples of user involvement in change within private sector services that we examined.

6.3.1 Clarity of organisational aims

Clarity in the organisational vision and aims is considered an essential precursor to developing user-focused services (Basch, 2002; Kotter, 2001; Sawhney and Prandelli, 2000; Peccei and Rosenthal, 2001). Organisations also need to ensure that these aims are disseminated to all employees, that all employees have the same understanding of the goals (Vandermerwe, 1993), and that they cascade down into the goals of specific sections of the organisation (Reichheld, 2001).

6.3.2 Leadership

Leaders within organisations need to actively support the aim of developing and delivering user-focused services (Gouillart and Sturdivant, 1994). Successful change and movement toward a customer-focused approach is said to depend upon the prior experience of the members of the board (Westphal and Frederickson, 2001). Previous experience of large-scale change and user involvement in change is also considered essential (Ford *et al.*, 2001; Young *et al.*, 2001; Vandermerwe, 1997; Schlesinger and Heskett, 1991; Reichheld, 2001; Paliwoda and Osing, 1992; Young, 2000; Westphal and Frederickson, 2001). Senior management within organisations need to see at first hand, on a regular basis, front-line activities (Reichheld, 1996). At the motor manufacturing company Ford, this took the form of a carefully planned initiative whereby managers at each level in the organisation spent time with the employees they supervised to convey and discuss key organisational principles. This ensured that employees met to discuss change initiatives (Kotter and Leahey, 1993).

The connection between senior management and front-line staff needs to be a dynamic connection and requires continual reinforcement. It cannot be achieved by sporadic visits to front-line activities (Band, 1995). In turn, senior managers need to be seen by employees to be actively pursuing the organisation's aims of developing user-focused services (Schlesinger and Heskett, 1991; Reichheld, 2001; Reichheld,

1996; Young *et al.*, 2001). Senior executives at the American credit card company MBNA spend four hours a month monitoring routine customer service calls, and card cancellation calls (Reichheld and Sasser, 2000). As experiences at the computer manufacturer Honeywell have shown, individual leaders' actions must support all aspects of the change, from demonstrating their participation in customer-focused activities through to chairing meetings of sections of the organisation that may be failing to deliver customer-focused services (Boyle, 1984).

6.3.3 Organisational responsiveness and ability to change

If organisations are to be responsive to the needs of service users they need to be open to change (Abrahamson, 2001). Berthon and colleagues examined the performance of a range of manufacturers and their performance during the 1970s and 1980s and concluded that those organisations that were orientated to their customers but not orientated to change found it difficult to remain competitive (Berthon *et al.*, 1999). There has been much discussion of those factors that determine an organisation's ability to manage change successfully (for example, Kotter, 2001). Different reports highlight: the importance of managing the pace of change (Abrahamson, 2001); transparency about the process through which it is intended that change will occur (Larkin and Larkin, 1996; Schlesinger and Heskett, 1991); and providing regular feedback to all those involved (Bryson and Anderson, 2000).

6.3.4 Knowledge management and information technology

Organisations which seek to change in response to the views and expectations of service users need to have properly functioning systems for knowledge management (Matusik, 2002). Successful knowledge management requires social systems for generating important data as well as technical solutions for managing the data (McDermott, 1999). McNamara argues in favour of simplified structures that help an organisation to focus on their primary aims (McNamara *et al.*, 2002). IT systems that are able to process data and present it in a way that can readily be accessed and acted upon are also required (Helfat and Raubitschek, 2000; Jones and Sasser, 2001; Seybold and Marshak, 1998; Thomke and von Hippel, 2002).

6.3.5 Staff empowerment

Front-line staff play a central role in delivering user-focused services. It is therefore recognised that staff need to be fully involved in developing and delivering user-focused services (Parasuraman *et al.*, 1991; Chase and Dasu, 2001; Reichheld and Sasser, 2000; Peccei and Rosenthal, 2001; Ford *et al.*, 2001). It is recognised that successful change happens *with* employees rather than *to* them (Kotter, 2001; Wheeler and Sillanpaa, 1998).

When problems occur in the relationship between service users and providers it is front-line staff who are asked to deal with them. If they are to improve the quality of services that people receive, employees have to be given the power to respond directly to the needs of service users. When seeking to increase their customer retention rate, MBNA asked employees to gather feedback from each dissatisfied customer and gave them the means to try to resolve their complaint (Reichheld and Sasser, 2000). Ensuring that front-line staff have the ability to respond directly to the needs of service users is considered to be essential if user-focused services are to be delivered (Hart *et al.*, 1999; Hart, 1995; Reichheld and Sasser, 2000; Reichheld, 2001; Ford *et al.*, 2001).

6.3.6 Rewarding staff for achieving user-focused goals

It is argued that if the goal of delivering user-focused services is achieved it needs to be relevant for employees. Relevance can be achieved through recognition and positive feedback from managers as well as financial rewards in the form of bonuses or promotion (Basch, 2002). UPS and other companies have rewarded employees who achieve customer-focused goals with stocks and shares (Basch, 2002). Field managers working for Enterprise Rent-A-Car are not promoted unless they achieve customer satisfaction scores above the company average (Taylor, 2002). Customer defection rates were used by the credit card company MBNA America as the basis for the company's bonus scheme (Reichheld and Sasser, 2000). Employee incentive schemes, both monetary and non-monetary, have been recommended by a number of commentators as a way of ensuring internalisation of the customer orientation (Sawhney and Prandelli, 2000; Kargaard Thomsen and Hoest, 2001; Hart *et al.*, 1999).

6.3.7 Monitoring impact of organisational response to users' views

The relevance of customer-focused goals can only be demonstrated if systems are in place for providing feedback on whether or not goals are being achieved. Most of the examples that we identified of organisations that obtained and fed back the views of customers used measures of consumer expectations and satisfaction with services or complaints (Parasuraman and Berry, 1997; Reichheld and Sasser, 2000). Systems for monitoring customer responses to change may be more effective when they are simple (Sheahan, 1999). For instance, rates of feedback from patients attending medical services were increased by providing people with a 'poker chip' which they placed into a box adjacent to a face that indicated satisfaction (happy face) or dissatisfaction (sad face) with services (Basch, 2002).

6.3.8 Scale

Large organisations may find it particularly hard to be responsive to service users (Basch, 2002). Chick-fil-A, the US fast-food provider, tries to avoid this potential problem by strengthening links between local customers and local service providers. Managers are only allowed to manage a single store, in an attempt to try to ensure that they remain focused on their particular customer group. In the rare instances where managers have two stores, they are judged every month on their customer satisfaction in order to justify management of both stores (Reichheld, 2001).

A US car-rental company has put in place similar arrangements in order to ensure that there is a close association between field managers and local customers through matching levels of satisfaction of customers at individual rental units and those providing local services (Taylor, 2002).

6.3.9 Consideration of users' expectations before and after the point of service contact

Vandermerwe (1993) has emphasised the importance of developing an understanding of service user expectations and needs both before and after the point at which they have direct contact with services. Focusing exclusively on the point of service contact may mean that the main concerns of service users are not identified or addressed. These may include difficulties accessing goods or services and problems encountered when these are put to use. It is argued that the quality of products and services can only be improved when companies fully understand the 'customer activity cycle' in which knowledge of customer experience of purchasing goods and services is combined with information about the pre- and post-purchase period and that all this information is used to inform future service developments.

6.4 Outcomes of UI

6.4.1 Increased demand for services and higher profitability

A study of Standard and Poors 'S&P 500 companies' (Hillman and Keim, 2001) showed that there was a positive correlation between stakeholder management and share value. Stakeholder management was defined as ongoing relations with primary stakeholders, including customers.

When IKEA wanted to create a more compelling customer experience they assembled nine groups of twelve customers from their Chicago store and asked them to design their ideal store (rather than merely come up with an improved version of the company's existing stores). They came up with a number of ideal specifications and a design for the Chicago store that fulfilled their list of requirements. Resulting sales at the store were twice as high as those that had originally been predicted (Magidson and Brandyberry, 2001).

British Airways made changes to business class services, including the introduction of flat beds on long-haul flights and changes to services provided at arrivals lounges, on the basis of a series of satisfaction surveys and in-depth interviews. These changes coincided with a 9 per cent increase in the number of business class passengers using the airline (Weiser, 1995). We encountered several reports that detailed increased sales of personal software following the involvement of service users in the design of new products (Day, 1999; Prahalad and Ramaswamy, 2000; Thomke and von Hippel, 2002).

6.4.2 Higher levels of user satisfaction

Following in-depth surveys of customers' views about rides at Disneyland (USA), changes were made to 'The Tower of Terror', a ride that simulates a runaway lift with a series of two big drops and one short drop. Customers thought that the ride too short, and that their preferred part of the ride was the 'hang time', the period of 'weightlessness' in the ride. Disney used this feedback to provide a different sequence of seven long and short drops taking the same amount of time as the previous ride. Satisfaction ratings for the ride increased from mean ratings of 'exciting' to 'excellent' (Ford *et al.*, 2001).

Enterprise Rent-A-Car uses their customer questionnaire and its results as the yardstick by which they measure the success of their employees, and field managers must perform above average to qualify for promotion. Enterprise Rent-A-Car attribute their US market leadership position in the car rental market to this focus on achieving year-on-year increases in 'completely satisfied' customers (as a percentage of total customers). Using in-depth interviews, Rent-A-Car

have found that 'completely satisfied' customers are three times more likely to choose Enterprise again, over 'somewhat satisfied' customers (Taylor, 2002).

Following data derived from surveys of staff and patients at the Medical College of Virginia Hospitals, a system of staff training aimed at improving customer relations was introduced. These changes coincided with a 17 per cent increase in patient satisfaction ratings (Holland *et al.*, 1990).

6.4.3 Increased customer retention

Having understood their controllable defection ratios, British Airways was able to understand and rectify the issues around customer defection through their customer service department. They discovered that this process easily paid for itself, in that for every £1 spent on customer retention, they received £2 in future custom. Focusing on complaining customers, they were able to increase the retention rate from 50 per cent to 80 per cent, and also increased the percentage of customers who were willing to comment on services (Prokesch, 1995).

Dholakia and Morwitz followed customers of an American financial services institution after a telephone customer satisfaction survey over a two-year period. They found that those customers that had been telephone surveyed were three times more likely to open new accounts, half as likely to defect, and more profitable than those customers who had not been surveyed (Dholakia and Morwitz, 2002). This was without changing the products or services offered to the surveyed group, or making them aware of additional products or services offered by the company. MBNA America reduced their defection rate to 5 per cent – half the industry average – following an eight-year programme of empowering staff to manage customer complaints and introducing bonuses for staff related to the defection rates of the customers they worked with (Reichheld and Sasser, 2000).

6.4.4 Product development/redefining the product

We identified several examples where the involvement of service users had led companies to redesign or redefine the nature of the product they were selling. This process has been described in detail by Vandermerwe who suggests that companies that develop a better understanding of their customers' needs have found that factors prior to and following the purchase of a service are often as important as the product they purchase (Vandermerwe, 1997). This led firms that previously sold personal insurance to develop a more complete range of services to help customers at the point at which they make their claims, and led airlines to provide transfers to and from airports for their business customers (Vandermerwe, 1997).

British Airways found, through a survey and in-depth interviews with their most frequent flyers, that passengers wanted a space to recover

following long-distance and early morning arrivals. This led BA to develop a range of other services in their arrivals lounge at Heathrow including showers, immediate laundry service and office facilities (Kotter and Leahey, 1993). Xerox has redefined the service it provides from supplying office technology to delivering a more comprehensive after-sales service (Jones and Sasser, 2001).

Chapter 7 Equality of access and opportunity

7.1 Consumer protection

There is widespread recognition that all consumers can make poor decisions when purchasing goods or services (Department of Trade and Industry (DTI), 1999), because of 'difficulty in obtaining or assimilating the information needed to make decisions about which goods and services to buy', or the disproportionate loss that might be incurred as a result of making inappropriate choices (Office of Fair Trading, 1998b). Frail older people entering the largely privatised residential care sector are a good example of the second category of vulnerability (Office of Fair Trading, 1998a). Elderly and young people, people on low incomes, unemployed people, people with poor education, members of ethnic minorities and people with limiting, longstanding illness are the seven categories singled out as intrinsically vulnerable consumers (Office of Fair Trading, 1998b). However, in each case, the status of vulnerability (largely the limiting aspects of low income, which limits choice in areas such as credit, and limited education and articulacy) is attached to the consumer, thus ignoring the inadequacies of markets, manufacturers and retailers of goods and services. Regulatory bodies are empowered to investigate market sectors and companies in cases of monopoly, price fixing, and other anti-competitive practice (Department of Trade and Industry, 1999). The DTI is also responsible for consumer law, promoting public confidence (for example, in internet trading) through appropriate accreditation systems, the promotion of rights of redress, prosecution of rogue traders, product labelling, regulation of advertising, consumer credit, consumer education, etc. Consumers do not have a single government-sponsored regulatory or advice body, but may take advice from Citizens' Advice Bureaux and Community Legal Services. The 1999 white paper (Department of Trade and Industry, 1999) recommended the setting up of a single access helpline to guide dissatisfied consumers to appropriate services, but it is unclear how such a service might be used to influence further reform.

Some sectors – transport, utilities and communications – offer so little power of 'exit' to dissatisfied consumers that the government funds consumer bodies to receive and promote consumer complaints and causes, and to otherwise regulate providers in sectors where there is no or little competition. The DTI white paper (Department of Trade and Industry, 1999) suggests that 'utility regulators should be given a primary duty to protect consumers', illustrating that industry regulation, rather than consumer advocacy, is their primary remit. In the telecommunications industry, at least 10 different agencies have regulatory responsibility (National Consumer Council, 1999a), with no

single body representing consumer interests. The National Consumer Council (National Consumer Council, 1999a, 2001b) argues for a single regulatory body 'to ensure open access, real choice and diversity, quality and fair terms and conditions'. The report on Ofcom (National Consumer Council, 1999a) suggests that, whatever else rapid advances in technology may deliver, they are unlikely to promote universal access in broadcasting and telephone services: the cost of such services will promote, rather than reduce, social exclusion. The National Consumer Council therefore recommends that an independent body, a Communications Consumer Panel, be set up to work independently of Ofcom, to represent the interests of domestic consumers and small businesses, to consult publicly on its work programmes, canvas and monitor consumer views, and publish its recommendations. Such a body (described in detail in National Consumer Council, 2001b) would expect to establish influence through the credibility of its involvement practice, carrying out targeted research, internet discussion groups, establishing networks of consumers and deliberative panels; it would be consulted by regulatory bodies, and would have no formal powers.

The National Consumer Council has (at request of DTI) drawn up guidelines for persons seeking appointment to consumer bodies (National Consumer Council, 1999b), which advocate research as the primary means of establishing consumers' views about particular topics. Prioritising research (qualitative and quantitative) as a basis for establishing the views of consumers and lay people generally, and supporting such activity with dedicated budgets for involvement and research investigations (National Consumer Council, 2002), could be good advice for public sector services, deflecting preoccupation with the representativeness of service users, clients and citizens with whom they engage.

Enabling poor and/or disadvantaged people to use and afford private sector goods and services is therefore the concern of the government, targeting much the same population as does public sector regeneration funding: those suffering social exclusion. Within competitive market systems, the balance of such activities is likely to be more with redress for actual consumers, rather than enablement to consume, except where better information is the barrier to consumption.

7.2 Involving 'hard-to-reach' service users

Reports from service managers, and accounts of involvement projects, suggest that particular groups of people are difficult to access and engage in service management and development (Audit Commission, 1999; Office for Public Management, 1993a). Literature on four groups – carers, young people, older people and people of black and/or ethnic minority background (BME) – is described in further detail in the following sections. These examples are not exclusive or comprehensive: other groups which are commonly described by providers as difficult to engage are homeless^, travellers and (though less commonly cited) people with learning difficulties. All the examples we discuss come from the public and voluntary sectors; we did not identify any literature that specifically examined involving these groups in the literature on UI in the private sector.

Despite our use of the title 'hard to reach', our review of the literature accessed for this section does not suggest that these service users are intrinsically 'hard to reach', but that they may lack structures of representation (such as school councils, BME patient groups), they may find it difficult to meet with service users and managers (for example, carers, older people), or they may be hampered by attitudinal and legislative deficiencies which fail to promote their rights to involvement (all groups discussed).

7.2.1 Carers

The experience of carers is very different from that of people in direct contact with services. Carers themselves have needs, as acknowledged in the Carers' (Recognition and Services) Act, 1995: some carers (including spouses) have found that their own health needs are neglected both as a result of their own, and the services', concentration upon the person cared for (Henwood, 1998). Carers have a paradoxical status in user involvement in health and social care: the views of carers providing essential support to patients are likely to be the best available guide to the views of patients who lack the capacity to express themselves, although the carer's perspective is clearly not identical to the patient's. Carers, for example, may find it hard to bear the suffering of patients, and request more pain relief, while patients themselves may prefer to remain conscious, though in pain (Small and Rhodes, 2000). Since carers have distinctive needs (personal and also related to their continued capacity for caring) and distinctive views, they are likely to require different but parallel contexts for involvement, and may find, as an event organised by the London Forum of Carers in May 2002 concluded, that 'only lip service or token notice is taken of the requirements of carers'.

Carers are themselves potentially 'hard to involve': unlike patients and service users, they may have no official status or contact with health and social care providers. They are often isolated and unsupported, particularly if very young or very old, as well as in need: devising services which address their own needs and are valued by them is a means of engagement (Princess Royal Trust, 2002), as well as a means of support and a potential means of recruiting them for ongoing involvement in service development. Commenting on the implementation of the All Wales Strategy (for needs-led service planning for learning-disabled clients), McGrath and Grant (1992) identify three possible relationships between carers and providers:

- carers as resources (but resources independent of providers)

- carers as co-workers (with providers)

- carers as co-clients (with their own needs, as recognised by Carers Act, 1995).

In implementing the Strategy, carers were treated as substitutes for learning-disabled clients, introducing confusion about whose needs were being considered. According to calculations made by the organisation Carers UK (Carers UK, 2002: available at www.carersonline.org.uk), carers save the state £57 billion per year. Involvement in planning services which would both facilitate their caring roles, and at times substitute for them, seems obvious. Yet the major legislation affecting carers, the 1996 Carers' (Recognition and Services) Act, deals mainly with individual carers' rights to have their individual needs assessed through care management (Olsen *et al.*, 1997), which has no direct impact on service development.

Most caring takes place in the home, so carers do not automatically associate with others: they have fewer opportunities for mutual support than patients may encounter in inpatient or other service settings, and lack of engagement with services results in less opportunity for policymakers who seek to involve them (Olsen *et al.*, 1997). They may not define themselves as 'carers' in relation to the object of their care, but as daughters or husbands, with culturally defined responsibilities to care (Olsen *et al.*, 1997): a leaflet about consulting carers will not then reach them. It has been argued that the view that carers can be seen as a distinct group, with a common set of interests, 'is partially manufactured by pressure groups and public officials charged with making a reality of community care' (Olsen *et al.*, 1997). However, carers are strongly advised to get together to form organisations to promote both their own interests and those of the people they care for (Carers Northern Ireland, 2000). Difficulties in coming together, and 'unwelcoming bureaucratic structures', together with poor understanding on the part of professionals, may often mean that individual carers are forced to campaign alone, unable to demonstrate how representative their views may be. 'Existing models of consumer involvement may not transfer easily to the changed circumstances of service provision in individuals' homes'; and many of

the services delivered in homes (by diverse agencies from different sectors, whose origins may be unknown to users and carers) are not easily managed, let alone monitored with input from users and carers (Olsen *et al.*, 1997).

In local authorities (such as Lewisham, Sutton), parallel carers' meetings 'shadow' the work of planning teams and committees, borrowing their agendas, and feeding back issues pertinent to them (Olsen *et al.*, 1997). Through this approach, carers have a distinctive voice in relation to active issues and developments; on the other hand, depending upon other opportunities to participate, they may be merely reacting to the authorities' agenda, with sparse opportunity to influence it. Consultation overload – and the amount of work which may be expected of participants – is a particular problem for a group defined by other responsibilities; it also suggests that not enough carers are being enabled to participate to share out the workload. Thornton and Tozer (1994) advocate a model of community development which would allow carers to move in and out, since, like the careers of some patients, their caring commitments can be very variable. Olsen and colleagues (1997) highlight initiatives in East London to promote carer support in primary care.

The Birmingham Community Care Special Action Project described by Barnes and Wistow (1994a, 1994b, 1994c; Wistow and Barnes, 1993) took exceptional measures to consult with BME carers, many of whom did not identify themselves as such. Meetings to draw in ethnic minority carers were organised within the context of community functions and centres; a large variety of languages were supported, with meetings facilitated by members of the community (Olsen *et al.*, 1997). Outcomes of the wider carers' consultations, however, were generally disappointing, as managers decided which of the carer 'demands' to adopt, and then failed to act upon them (Barnes and Wistow, 1994b). Participants suggested that the meetings were intrinsically useful in enabling mutual support, companionship and respite; the opportunity to learn about service systems was also important, as 'you can't be influential unless you're in the system and you know what goes on behind closed doors'. Because of the nature of caring, carers who do take part in consultations are generally self-selected, with wider 'representative' views sought through an additional postal questionnaire, a useful model for people who may be confined to the home.

The London Forum of Carers (LFC) is currently lobbying Chief Executives/Directors of primary care trusts and social services in London for meaningful participation in planning services, and meaningful consultation in relation to provision for individual support (London Forum of Carers, 2002). While LFC's demands (for training, expense payments, jargon-free briefing, communication and representation structures) are similar to those of patients, they express concern that the new involvement arrangements (PALS, Patient and Public Forums,

etc.) do not explicitly concern them, while their own needs for individual assessment and support remain largely unmet.

7.2.2 Young service users

Some 10 million people in England and Wales are under 16 (Audit Commission, 1999), with the majority receiving public services: education, health, and care in place of parental supervision. A survey of local authorities published in 1999 showed over 70 per cent of them specifying young people as 'difficult to consult', second only to homeless people (Audit Commission, 1999). At the same time, comprehensive project reports aimed at improving consultation with users and carers about community care may neglect to mention children and young people at all (Goss and Miller, 1995; Bewley and Glendenning, 1994; Stevenson and Parsloe, 1993; Office for Public Management, 1993b). Our search found little material on the direct involvement of children and young people in NHS services or in other areas of direct interest, with the exception of limited work in the field of education (see Section 7.2.2.5).

The case for consulting children about particular services may be urgent. 'Looked-after children' – those taken into care by the local authority and placed in a residential or foster-family setting – are vulnerable to abuse which they alone may know about.

> *Care has frequently been characterised by instability, disruption and sometimes abuse … Disabled children experience patterns of care which would never be tolerated for non-disabled children.*
>
> (Masson *et al.*, 1997)

Children 'looked after' by the local authority have rights to be consulted about their care under the Children Act (1989), including the right to participate in judicial and administrative proceedings affecting them, either directly or through an intermediary. Where such proceedings involve an infant, a Guardian Ad Litem may be employed to establish and represent (as best as possible) the child's viewpoint.

People growing up in local authority care have been shown to suffer comparatively poor (educational, social, psychological) outcomes (Searle, 2002). The Utting Report (HMSO, 1997), which reviewed the adequacy of safeguards against the abuse of children living away from home in the wake of several investigations of serious abuse in children's institutions, recommended that children in care have access to confidential advice and support independent of the local authority. The government called upon local authorities to implement a programme based upon Utting's recommendations, Quality Protects, Standard 8 of which requires them to:

> *… actively involve users and carers in planning services and in tailoring individual packages of care, and to ensure effective mechanisms are in place to handle complaints.*

Children's involvement should then, since 1997, move beyond individual care planning and complaints to involvement in service planning.

The National Children's Bureau (NCB) (www.ncb.org.uk) has championed the involvement of looked-after and other children, both in service development and in individual care planning. It is closely linked to the Council for Disabled Children (which can be accessed via the NCB web site). While research studies have often led to clearly stated recommendations, there has been little discussion about what changes, if any, to service these have resulted in.

7.2.2.1 Examples of consultation with children

In the course of identifying a sample of 62 children and young people in care whose parents were 'lost' to contact either with their children or with social services, Masson *et al.* (1997) approached 29 authorities, of whom 17 (57 per cent) refused to participate, with some indication that they feared criticism. The project interviewed practitioners, parents and some children in the course of identifying 'problems' which contributed to loss of contact between parents and looked-after children. While there were no particular problems identified in conducting interviews with young people (9 were interviewed, aged 11–20), the hostility between some parents and social services led the research team to employ independent sessional interviewers to interview parents, so as to assure them of the absolute boundaries of confidentiality between the two sets. The project confirmed the importance of maintaining parental contact for the children, who themselves confirmed its significance in forging and maintaining their own identity.

For various reasons, including the relative isolation and vulnerability of a child in institutional or familial care, advocacy is the preferred model for accessing young people's views about their own care. Several of the NCB's publications (see the 'Publications' section of the web site at www.ncb.org.uk) highlight peer support as an acceptable form of advocacy for looked-after and disabled children, although there are acknowledged issues around peer support schemes relating to confidentiality, and care of the supporting partner (Searle, 2002). Most of the £9 million spent on Objective 8 of Quality Protects in 2001 is thought to have gone into advocacy services (Harnett, 2002). Harnett argues (after others) that local authorities cannot directly provide confidentiality (a safe space) for children to give their views on their own care because employees work in a culture where information is shared. As with older people in residential care, children living in 'total' care settings are vulnerable to repercussions from caregivers if they openly criticise them. In the children's advocacy service evaluated by Harnett, 37 per cent of referred children wanted advocacy in order to either stay in their current placement, or to be moved to another: direct complaints against the local authority amounted to 7 per cent of referrals. In the majority of cases, advocates were required to

represent the young person's view in a formal context such as a review: it may be that children's aggregate views could also be ascertained and represented in formal planning contexts.

NCB's advocates involvement of children as informants in a range of services. For example, in a regular newsletter available from the web site entitled 'Children and violence', it laments the fact that 'the British Crime Survey does not collect regular data from citizens (sic) under 16', so they are not involved in either defining or addressing problems which some sections of the media may largely (in the recent coverage of anti-social behaviour orders) attribute to them. The NCB has developed initiatives on violence which feed into discussion and adoption by students of PHSE and citizenship modules (part of the National Curriculum). While it is beyond the scope of this account to review in detail NCB publications, there is good evidence of: commitment to reviewing *existing* services with participation by children and young people (Knight, 1998); of guides promoting and exemplifying involvement (Willow, 1996; Olle, 2002); and of educational materials for young people developed by young people (for example, 'HIV: Crush the Myths', an A4 poster available free via the web site).

In a description of North Derbyshire Health Authority's 1985 consultation with the intended beneficiaries of its proposed 'Young Disabled Unit' (Department of Health, 1994a), it was concluded, to the commissioners' surprise, that there was little support for such a unit: but those consulted proposed that more would be accomplished if more disabled people were employed in the running of local services. The conclusions of a review in 1993 showed that this demand had not been met. The limited literature available suggests that children receiving health and social care services are more likely to be consulted than children who are not. Exceptionally, Lambeth Council has won an IPPR award for establishing a Youth Council for 11–24 year olds to work with statutory services. Examples cited (*Guardian*, 11 December 2002) include Council members working with the police to develop stop-and-search guidelines, and with teachers to design peer-led education targeting the reduction of teenage pregnancies. Direct involvement with decision makers and having a clear view of outcomes is said to be important to maintaining motivation. Consulting children about generalised services need not require formal settings. The Fire Brigade, for example, report the use of short, face-to-face structured questionnaires from stalls set up at regional/community events to consult with all sections of the community (Audit Commission, 1999).

7.2.2.2 Children and young people as carers

Dearden and Becker (2000) suggest there may be 50,000 people under 18 providing substantial care in the UK, which may have 'a restrictive or negative impact on their childhood'. Profound disquiet about the burden carried by young carers has allegedly discouraged any professional focus on their views and needs. In a report by the Princess

Royal Trust (2002), the experience of members of the Young Carers' Network in Scotland is used as the basis for advice on how to set up a young carers' service, maintaining elements of a service run by and for service users. Legally children cannot manage a service, and the recommended practice is to form an advisory group to the management committee of young carers. Given the caring responsibilities of these children, desire for involvement in the service may be limited, but young people should take part in the evaluation of the primary aim of meeting their needs. The guidance directs detailed attention to complaints procedures, which may be a way of reinforcing a professional organisational culture in which client needs are met, rather than a 'charitable' ethos, where recipients should be grateful. Young carer organisations in Scotland have been outreaching potential beneficiaries through schools, involving teachers and children through personal and social education classes. Another key area considered in the guidance is policy and practice involving parental abuse. Young carer organisations have the responsibility to make child protection referrals if they consider a child under 16 may be at risk: but parents must also, according to suggested practice guidelines, be made aware of the agency's policy to refer in such cases. An abusing parent may then forbid the child's engagement with the service. Children are far from free agents, but this may make it all the more important that they are involved in services aimed at meeting their needs.

The Young Carers' Schools Development Project based in Lewisham conducted detailed research in schools to look at the incidence of young carers, and consider ways in which they could be supported (Baker, 2002). The account (which can be downloaded from www.carers.org) demonstrates the accessibility of children through schools: informing and consulting schoolchildren about young carers became a means to identify those in need of such a service. The early work of the Young Carers' Research Group (Dearden and Becker, 2000) also centred around qualitative interviewing. Multi-agency steering groups helped to identify potential interviewees. Although those under 16 and those with learning difficulties were not interviewed without parental consent, the group has always insisted that interviews take place without parents being present. Interviewees are assured that they can leave the venue, or refuse any questions: some have been encouraged to work the tape recorder, giving them greater control over the interview process. Early work suggested (as is true of adult studies) that interviews could be cathartic; that children were able to identify needs but were less competent to suggest services which might support them; and that parents often felt guilty and grieved about the responsibilities laid upon their children. There was a high incidence of educational underachievement in these children. In policy terms, outcomes of research conducted with young carers may include the Social Services Inspectorate (SSI) directive of 1995 to local authorities to take responsibility for young carers; the acknowledgement that young carers can be classified as children in

need under Section 17 of the Children Act (but of lower priority than children at risk); and the new entitlement to assessment of their own needs under the Carers (Recognition and Services) Act 1995. Local support projects for young carers have risen from 2 in 1992, to over 100 by 1998; and by 1998, 11 per cent of young carers had had an assessment of need, though whether the identified needs were met is not stated (Dearden and Becker, 2000). There is apparently no legal duty to address need, unless perhaps the child/children are identified by social services as being 'at risk', which is a highly stigmatised label for a family to attract.

7.2.2.3 Children and young people with chronic disease

Sufferers of specific diseases and disabilities may be predominantly children, who have a shortened life expectancy. The Cystic Fibrosis Trust (CFT) (www.cftrust.org.uk) publishes information booklets and tapes directed at parents, children, adolescents and teachers, and campaigns at national level for more appropriate treatment and wider screening programmes. In common with other similar societies for chronic disease sufferers, the CFT publishes comprehensive quarterly magazines, through which members communicate: self-management tips are exchanged, and children seek pen pals through its pages. This is important since children with cystic fibrosis are discouraged from meeting because of their mutual susceptibility to airborne infections. The newsletter is also a 'virtual' forum for campaigning, and for disseminating scientific information about the disease, and seems to have no difficulty in communicating at several different levels of literacy and intellect. The Trust also has patient advisory and advocacy telephone lines.

7.2.2.4 Obstacles to involvement

'Families' may be perceived as the proper level of involvement for service providers to target. In the Home IV service for cystic fibrosis children evaluated by Atkinson and Farshi (1998), the child as end user was not understood to be separable from the family, which is perceived as the 'client' to be involved in service evaluation. Services provided for the welfare of children under statutes such as the Children Act 1989 specifically direct local authorities to work actively with parents and others. Even where children are 'accommodated' and will not return to live with them, parental authority may continue to be held jointly with the mother or married parents (although the distribution of power is far from equal (Masson *et al.*, 1997)). Legal competence for children to make decisions independently of parents varies according to context: especially variable are the rights of children to act independently of parents between the ages of 16 and 18.

Consulting children may be difficult: provider organisations may resist their involvement. Providers may fear criticism from clients, or may suggest that involvement will be too taxing or upsetting for individual

clients (Masson, 1997). It may be thought that children should not be consulted – nor perhaps informed until necessary – about issues which they cannot affect, such as the closure of residential homes in which they lived (Payne, 1995). It may however be particularly unrealistic for adult professionals to believe they can anticipate the life factors to which children attach value, and therefore over which they may want to be consulted. Parents as advocates for children fear that complaints made to children's services may put their children at risk of retaliation:

> *… it is very hard to criticise because they are looking after our children.*

> (Mother, quoted in Kumar, 1997)

Providers may also neglect complaints from parents, since:

> *at the end of the day I'm accountable to the child*

> (SSD manager, quoted in Kumar, 1997)

Finally, policies designed to protect adult users of services may not recognise the need to protect children. An SSI inspection of services for ethnic minority children and families (Social Services Inspectorate, 2000) found that there were no policies to address racial discrimination against child clients, and strong evidence that abuse directed against ethnic minority children was neglected by practitioners.

7.2.2.5 Children in educational settings

Around one-third of all (primary and secondary) schools have a school council (Ashworth, 1995), with reports suggesting councils influence matters such as school uniforms, behaviour and anti-bullying policies and strategies, and equal opportunities. Wyse (2001), considering the role of councils in promoting children's rights, concluded from studies in four schools that true participation of children in all matters relevant to their education is constrained by adult expectation and management, and issues raised by pupil councillors (rather than teachers) were rarely addressed (a view shared with many patient groups). Wyse's account associated low student expectations of influence with children's perception that fair treatment from teachers was not a right, but conditional on their own behaviour and the teachers' predilections. All the surveys and publications we accessed were written up by adults, predominantly teachers, and we found no experimental studies showing the effect of introduction of a school council. Davies (1999) carried out case studies in 10 state schools with functioning pupil democracy (in 9 out of 10 cases through a school council) and low/declining rates of exclusion, and retrospectively attributed the latter to the former. A number of other strategies were in place to promote inclusion, such as pastoral, mentoring and target-setting systems, but councils were said to have had: direct impact through peer advocacy and monitoring of children at risk of exclusion; semi-direct impact through generating anti-bullying/conduct policies which were owned by the pupils; and indirect impact through conveying ideas about respect for children, mutual support and problem resolution. Other concrete outcomes of

councils described by Davies as demonstrating a 'sense of agency' include fund-raising, a student newspaper and the acquisition of a drinks dispenser and telephone for student use: all outcomes which probably do not challenge existing school management. As in health services, unsubstantiated claims of intangible benefits are made, with Ashworth (1995) citing increased responsibility, caring, commitment, and motivation among pupils as the major outcome of introducing councils.

Obstacles and issues described in the literature cited above are strikingly similar to those raised by patient groups: doubts about the representativeness of pupil councillors; the need to build in routes of involvement for other pupils; the ambiguous role of councillors (between pupils and teachers); and the schools' tendency toward 'over-dependence' on school councils.

A report from the Advisory Centre on Education (ACE, 1995) points out that very few councils have links with the Board of Governors, and that councils that want to express a view on important decisions affecting the school will first have to find out what they are, and when they are being discussed. Using a construct highly reminiscent of Arnstein's ladder of public participation, Holdsworth (2000) discusses the limitations of student 'voice' in Australian schools, and the need to realise outcomes from participation. Elton (1994) suggests that the role of the council should only ever be consultative, and the council should be chaired by the headteacher who has the final veto. No relationship with the governors – the real decision makers – is advocated. Involving the council in the disciplining of named pupils is treated with some caution, although Elton's account of one school's experience suggests that naming, shaming and minuting can be a powerful way to curb anti-social behaviour. In a survey of staff and students of over 200 secondary schools, Baginsky and Hannam (1999) found that 54 per cent of councils explicitly banned topics from discussion, most frequently matters relating to staff (44 per cent of councils) and individual pupils (19 per cent). Of the staff surveyed, 50 per cent said it was difficult for staff to find time to attend, or to develop councils according to their full potential, a conclusion reiterated by Ashworth, whose survey (Ashworth, 1995) found staff 'blaming' the demands of the National Curriculum for their failure to develop school councils. Limited time, lack of resources, and the tendency of staff to disregard council decisions if they were opposed by teachers were identified by 50 per cent of surveyed students as impediments to council work. Both staff and students identified staff resistance as an obstacle to development, as well as apathy among students and staff. While 73 per cent of student respondents thought councils could improve relationships between students, only 50 per cent thought they would secure improvements in staff–student relationships.

Davies and Kirkpatrick (2000) carried out a study of pupil democracy in Denmark, Germany, the Netherlands and Sweden for comparison with

the UK. In these four European countries, they identified multi-layered strategies of involving pupils in decision making.

- Extensive legislation to ensure that pupils are involved in all decision making (local, regional, national): this is not left to individual schools.

- Children participate in curriculum planning (their own and their schools').

- Children sit on school governing bodies, as well as having pupil councils and a national school student union, linked to a pan-European association.

- Unions are financed by Education Ministries, with training for pupil councillors, guidance and information and conferences.

- In schools, councils have their own rooms, computer, telephone, etc.

- All schools have formal channels for complaints and grievances.

We conclude that the rights of children to influence the educational system in the UK are comparatively poorly developed.

7.2.3 Older service users

With almost one in three of the population over 50 in 2000 (Hayden and Boaz, 2000), the claim that older people are hard to consult is of concern. In evaluating the 'Better Government for Older People' project, Hayden and Boaz suggest that effective engagement requires, alongside attitudinal change: resources to support existing groups to develop activities and broaden membership; more older people's groups and forums (capacity-building); funding to enable participation (logistical and practical support); and staff development to engage with older people. Appendix 3 shows some of the concrete outcomes of the project.

7.2.3.1 Attitudes to older people

Wells (1990) suggests that our low expectations of elderly patients' involvement in decision making reflects a combination of outdated assumptions of welfare charity ('they should be grateful'), the emphasis on incapacity among elderly and disabled people, which equates physical frailty with disability and dependence in all areas, and older people's fear of reprisals in the event of complaints, which inhibits their ability to criticise services they receive (Barnes and Walker, 1996; Thornton and Tozer, 1994).

> *Most collective action with empowerment objectives presupposes the involvement of fitter older people.*

However, the range of project reports describing the successful involvement of older people suggests that attitudes, institutional barriers (such as the 'need' for residential homes to authorise resident participation, see Raynes, 1998), and the confusion of physical and mental frailty) are more injurious to successful participation than any intrinsic characteristics of elderly people. Barnes and Walker (1996) and Thornton and Tozer (1994), reporting on the Fife User Panels, comment on the willingness of older people to take part in critical analysis and development, with high rates of response (70 per cent) to a self-completion questionnaire designed by a user panel. Elderly service users identified personal benefit from increased opportunities for association, and improved self-worth and optimism.

> *That's been one of the best things that's ever happened to me, is getting to go there and voice my opinion … you feel you are getting somewhere by doing that'.*

A 90-year old woman summarised her experience of being a panel member: 'It's given me courage'. Barnes and Bennett (2002) reiterate the personal benefits of participation and association for isolated elderly people. The project did raise suspicion from providers that self-selection of the elderly disabled participants suggested lack of representational mechanisms, though 'self-selection' among such a group appears inevitable. Some staff also thought that the

Development Manager was 'using' clients' views to promote her own opinions: again, this may be inevitable if this manager was committed to advancing user perspectives. Professionals also expressed disappointment about the 'negativity' of expressed opinions, while:

> *Officials seemed more comfortable with the idea of soliciting views on matters of immediate concern to them than with responding to the user panels as a pressure group (a term which they introduced …).*

These are telling expressions of not uncommon professional attitudes.

Small and Rhodes (2000) examine methods of involving patients receiving palliative care in service planning. Despite the uncertainty with which such patients inevitably live, they found users willing and able to contribute to future planning, though they might not themselves expect to benefit. With much palliative care administered in the home, the outcomes of technical interventions often cannot be predicted by 'professionals'. Qualitative individual interview techniques exploring individual experience are advocated for the most frail.

Around 95 per cent of people aged over 65 in the UK live in their own homes, with the GP and primary health care team providing most health cover. Evaluating primary care services from the perspective of elderly patients in Buckinghamshire, Bartlett (1999) accessed older people through pre-existing groups, often linked to services (lunch clubs, sheltered housing, etc). This left those who were not engaged with social activities unrepresented, though they may be the most needy of intervention. Although the project identified a range of strategic needs (such as the need for ongoing participatory mechanisms in health care planning) and specific service gaps (such as in podiatry and chiropody, services which were commonly discarded in primary care trusts as relatively insignificant, but were seen by older people as vital to their comfort, health and mobility), the report of the research does not identify changes made as a result of recommendations. A project (sponsored by Age Concern and the National Charities Lottery Board (NCLB)) to involve older people in GP practices (Sheppard, 2000) found that most GPs did not want to participate personally. Some saw the meetings as of limited relevance to the development of services, describing meetings as 'a safety valve rather than as a source of useful ideas'. No evidence is presented to suggest that any recommendations of participants were adopted, though the report adds that GPs all 'felt the meetings should continue'.

7.2.3.2 Service users with dementia

The Alzheimer's Society project 'Learning to live with dementia' has ambitious aims to involve sufferers in service development and decisions about their own life and care. With the advent of diagnosis at an earlier stage, Alzheimer's patients are changing an organisation which traditionally supported 'those caring for people with dementia' (Litherland, 2001).

Allan (2001) offers a detailed account of methods of communication used with this group: the views and comments of patients on their experience of taking particular drugs to inhibit the disease are rightly central, in the absence of conclusive trials, to their submission to NICE to gain support for free prescribing (Alzheimer's Society, 2000). Youll and McCourt-Perring (1993) describe structured questionnaire approaches developed for use in a residential home with residents who were unable to communicate verbally. Staff, and members of the village community who were invited to take part as 'researchers' in the evaluation, found the exercise extremely valuable, even though only two factual comments were elicited from the eight home residents, because it enabled them to focus on the resident perspective, and consider the motives behind non-verbal forms of communication.

7.2.3.3 Residential care

Payne's (1995) accounts of private residential care homes for older people details the choices available to residents:

> *… people must take the available bed, in a room that may be shared with a stranger. This seems acceptable if such provision is compared with a hospital ward … but not if it is compared with the privacy of a home.*

Particular concerns were raised by the Office of Fair Trading (OFT) regarding the ability of older people entering or living in residential homes to play an active part in the organisation and delivery of the care they receive (Office of Fair Trading, 1998a). The OFT research was commissioned because of concerns that increasing numbers of older people reliant upon residential care (some 500,000 in 1998) are vulnerable consumers, even when supported by relatives. The project involved semi-structured interviews with 965 people. Most homes are managed by private and voluntary sector providers. Explicit concerns were raised about their performance in four respects: provision of adequate information to potential 'customers'; provision of contracts to the residents, enabling them to assess compliance with contract in the services delivered; financial protection for residents; and powers of redress, if residents wish to question or complain of practice. The report's recommendations can be summarised as attempting to give each resident some of the rights of an individual consumer, including standardised and comparable information on which to base choice of care home, information about how to complain (as only 17 per cent of 155 brochures examined by the OFT outlined the process), and contracts between resident and provider, even when the local authority, rather than the older person, was paying for and/or commissioning the individual's care under bloc contract. The report recognises elderly people in residential care as both reluctant (the majority of a resident sample reporting no choice in the decision) and ill-informed 'consumers', easily intimidated by fear of those they may wish to complain of. Residents also reported that they were prevented from forming residents' committees to combat intimidation of individual

complainants. One-quarter of them had no one outside the home whom they could enlist to help them pursue complaints, with only 3 per cent citing a social worker as a possible support in this instance.

Standards in care homes are enforced by the National Care Standards Commission: neither the Commission, nor the legislation it enforces, requires the consultation or involvement of users of care homes (Kerrison and Pollock, 2001). The Social Services Inspectorate is under-resourced, and there is no provision for redress, as there is in the retail, utilities and financial services sectors, where residents make a valid complaint against a home. In the USA (Kerrison and Pollock, 2001), Federal government have facilitated the provision of outcome data and regulatory deficiencies in US care homes on the worldwide web, so that new consumers have information on which to base choice.

7.2.4 Black and minority ethnic (BME) service users

We found very little evidence of comprehensive involvement of minority ethnic groups in any sector, one exception being the consultation carried out by Leicester Royal Infirmary (National Consumer Council *et al.*, 1999d), which concludes that organised groups (often based on religion) were relatively easy to identify, but not always easy to contact or communicate with. Of the many suggestions gleaned from consultation, the Infirmary decided to concentrate on the relatively narrow goals of improving skin care for African–Caribbean patients, and piloting a new interpreting service in two community clinics, as well as continuing to invest in communication and contact (itself expensive when written communication is inappropriate).

The use of link-workers (Tang and Cuninghame, 1994), and of health advocates (Neuberger and Coker, 2002; Rai-Atkins, 2002) have both been recommended as methods to improve communication with BME service users. Advocacy provided through BME voluntary sector organisations can be used as a model for the involvement of service users in directing change: but advocacy services are more commonly established to ensure that the individual is not disadvantaged in his or her dealings with existing services. Successful advocacy services run by the voluntary sector may be used by providers as an alternative to reforming their own systems to enable direct collaboration between providers and black users, leading the author to conclude (of mental health services) that 'black services users and their carers have virtually no participation or influence … in overall service development'.

Comparative analyses of minority influence over health services conclude that both the USA and UK need to recruit a more representative range of health professionals, both to make services more acceptable and accessible, and to support and adapt (rather than dismiss or ignore) indigenous 'informal' care and lifestyle practices for better health outcomes (Trevino, 1999; Chen, 1999; Ferguson, 1998). Improving social services was also linked to the recruitment and support of BME staff at all levels of the organisation, but there was little discussion of the possible benefits of involving users of services directly in service design and management. Commenting on the only two social services departments which had credible facilities for consulting with local BME groups at the time of the 1999 inspection, a report from the UK Social Services Inspectorate (2000) notes that these also had black workers' groups, which brought together workers from different levels of the organisation.

7.2.4.1 Do BME persons want to collaborate with services?

Allen (1997) argues that coalitions based around the health of BME persons may be primarily concerned with political identity, with sharing common experiences of discrimination, and a desire to construct

positive images of self within a context that may emphasise deviance and pathology. Organisations formed to campaign for the screening and treatment of sickle cell anaemia inevitably concerned themselves with the reasons why a disease affecting 50 in 10,000 babies of African–Caribbean origin attracted far fewer resources than phenylketonuria, affecting one in 10,000 white babies, for which there was a national screening programme (Allen, 1997). Black and minority ethnic groups may have difficulty in subordinating their objectives to the narrow agenda of the health services, and may be unwilling to act as collaborators with health service managers. In a report produced by the Campaign for Racial Equality, it is argued that for some people previous attempts to influence health and social care services have proved so unsatisfactory that separation is less demoralising (Commission for Racial Equality, 1997).

7.2.4.2 BME people and involvement techniques

Rudat (1994) explores some of the pitfalls of conducting surveys with minority ethnic groups: terms of either medical or English derivation (stress, healthy foods, cervical smear tests) may not have a shared meaning, a problem which the use of bilingual interviewers may not overcome. Survey staff found it difficult in some contexts to identify the 'head of household' respondent from among extended families, and the lack of privacy in which interviews were conducted made it unlikely that questions on smoking, drinking and sexual practices were truthfully addressed. Rudat's survey (for MORI, with Health Education Authority as clients) was preceded by in-depth, qualitative interviews which allowed respondents to identify their health concerns, but the validity and relevance of the survey content remained problematic.

> *The major dilemma when considering the format of the questionnaire was to find a balance between acknowledging 'community' priorities, as identified in the qualitative research, whilst at the same time maintaining a degree of comparability with questions which had been asked of the general population in the UK-wide Health and Lifestyles Survey.*

> (Rudat, 1994)

This problem may be reduced when the scope of surveys is more specific: for example, the Terrence Higgins Trust and UK Coalition of People Living with HIV and AIDS (2001) report on a national survey (conducted by post and through personal interview) in which only 60 per cent of the 430 respondents described themselves as White UK. A subsequent report by the Terrence Higgins Trust (2002) suggests 'patient shadowing', where a staff member or researcher accompanies as observer a patient negotiating health care, as a useful tool in investigating the experience of people who do not have good communication skills or English.

Involvement is also potentially damaged by the expectation that individuals are dominated by community elders, relatives or persons of particular ritual/political status or office. Involving potential patients or

beneficiaries of health interventions by proxy may distort the true nature of need, particularly if the health problems (HIV; over-use of alcohol among Asian women) are highly stigmatised. In such cases, it may be more beneficial to conduct small-scale interviews with a very few potential service users (Shaikh and Naz, 2000) to investigate service needs than to engage with 'the community', or the 'power-brokers' in the community, in more superficial ways. Service users may also be 'stereotyped' according to the expectations of providers. The London East AIDS Network (Robson *et al.*, 1997) now finds its clients are (contrary to the earlier stereotypes of AIDS patients as young, middle-class and gay) predominantly unemployed, speak English as a second language if at all, and are of cultures where HIV is highly stigmatised, making its commitment to involve service clients in its management rather more challenging.

7.2.4.3 Involving BME service users in health service research

Johnson (2002) has recently completed a literature review of over 200 health-related research projects that have involved BME service users. In most cases, service users have been involved in research as informants, rather than as commissioners or investigators. The majority of examples of good practice located by the study came from initiatives directed specifically at BME concerns, including ethnically specific disease, perpetuating 'a perception that minority cultures and practices are themselves unusual and potentially problematic or pathogenic'. At the same time, Johnson concludes, the failure of health bodies to ensure that BME groups are involved in all research (the 'colour-blind' approach) is effectively denying BME people their right to express views on general health issues. The largest single category of research and development involving black and minority ethnic consumers identified by Johnson was 'needs assessment' exercises, often conducted as part of Community Care strategic planning under the NHS and Community Care Act, and therefore driven by changing requirements for producing strategic documents and demonstrating consultation. Johnson's review does not comment on the extent to which identified needs were addressed. Feedback available to Johnson from practising researchers noted that inclusion of a minority consumer perspective tended to draw attention to other areas and victims of discrimination in health, housing and employment.

7.2.4.4 Involving BME organisations in health and social services

Johnson (2002) also notes that the needs of black organisations have barely been recognised within the mainstream voluntary sector. In adult health and social services, users who feel marginalised or inadequately provided for by mainstream or statutory services may move toward establishing voluntary sector services, aiming to provide mutual support and advocacy against discriminatory practices and institutions.

> *Black projects saw most of their work as advocacy … The black voluntary sector lacks the appropriate infrastructure to support and maintain its development.*

(Rai-Atkins, 2002)

The Home Office has recently funded an initiative to link such organisations with non-BME 'mainstream' voluntary sector partners, with whom they can share expertise and experience (Gaskin, 2003). However, there are at least 5,500 established BME groups (who may provide support in legal, professional and other areas of life, as well as health and social care) which are not affiliated to the National Council for Voluntary Organisations (Plowden, 2001). Making up 6 per cent of the population of the UK, they have received only 2.3 per cent of National Lottery funding, prompting the NLCB to conduct an internal review to consider how best to offer support. Plowden comments that the expertise of BME organisations is unclear, though they are now able to access capacity-building support from a new agency, the Council of Ethnic Minority Voluntary Sector Organisations (CEMVO). Existing membership of CEMVO is not representative of the diversity of the BME population. Fundraising is an essential function for voluntary sector organisations: capacity for bureaucratic procedure and resources to cushion uncertainty are features which grassroots organisations originating in mutual support do not find easy to develop. Ferguson (1998) describes the role played by the Manchester Action Committee on Health Care for Ethnic Minorities (MACHEM), a Manchester-based consortium, in trying to promote the 'assimilation' of vulnerable black organisations into 'mainstream' funding, and to promote partnerships between, for example, local statutory service providers and black voluntary sector organisations.

Becoming a recognised player in local services, who should be consulted about service development, depends upon establishing status:

> *… the smaller projects are thought of at the last minute or missed altogether … 'consultation' can often mean nothing more than a last-minute dissemination of information about impending service developments.*

(Rai-Atkins, 2002)

The Social Services Inspectorate found that links between local authorities and black voluntary groups were 'fragile', and authorities 'did not generally have strategies to use ethnic minority groups as service providers or to help them to compete in the "contract" culture' (Social Services Inspectorate, 2000). The BME voluntary sector is hampered by 'insecure funding, inadequate premises, lack of equipment, shortages of staff and lack of training and support' (Ahmed, 1998), and there is broad scope for collaborative support in any one of these areas by statutory services.

7.2.4.5 Involving BME people in service development and management: lessons for policymakers

Discussing the involvement of BME persons in community care and social housing plans, the Commission for Racial Equality (1997) suggests that services have recently shifted toward needs-led definition, but that consultation strategies may stop at needs assessment, with professionals planning how needs should be met, often within traditional institutional frameworks. Where activities, and supporting documentation, are separated into needs assessment, commissioning and planning, each may require independent consultation arrangements. Underlying themes of the guide are the pros and cons of separate BME specialist planning groups (which may be marginalised) versus inviting one or two black people onto broader planning groups (which may be tokenistic); and the commissioning of separate BME services (perhaps across boroughs) versus the provision of racial equality and choice in mainstream services. As Gunaratnam's (2001) discussion of food and ethnicity in a South London hospice suggests, individuals (of minority or majority culture) may alternate between preference for 'ethnic' food and 'English' food:

> *The fundamental challenge is to leave behind the apparent security offered by categorical approaches, in favour of more temporary and incomplete processes of policy and service development that will mark a significant departure from 'traditional' forms of bureaucratic management.*

Chapter 8 Discussion

8.1 Results of the literature search

In the course of the study we examined abstracts of over 3000 papers from a variety of different sources. Most of the literature we found came from searching electronic databases, but hand searching libraries, hand searching for references cited, and contact with experts also generated significant numbers of papers. The majority of reports that we identified were discussion papers that explored the rationale for involving users and, in relation to health and social care sectors, the policy context of UI. We found relatively few detailed accounts of user involvement in the private and voluntary sector for reasons that are discussed elsewhere (see Section 8.2). Reports that described the process and outcomes of user involvement were generally in the form of case studies of user involvement initiatives. We found very little evidence of empirical research in any of the sectors that we examined. Where empirical research had been conducted, this was generally in the field of health and social care and other social services such as housing and welfare.

Throughout the sectors that we examined, a common factor motivated service providers to involve users in the process of change: the view that service users had knowledge and expertise of the process of receiving services and that through harnessing this expertise the quality of services could be improved. Discussion of the motivation for involving service users in the private sector was limited to describing the need to achieve customer loyalty and increase profitability. The motivation for involving service users in health care and other public sector services is more complex. Pressures to involve users have been both bottom-up, from an increasingly organised and vocal user movement), and top-down, from national governments keen to increase democratic accountability, effectiveness and satisfaction with public services. The relative absence of choice that users of most public services have means that service providers are not dependent on satisfying the needs of service users in order to remain operational. While recognition of the fact that most people in Britain are not able to choose the organisation that provides their health care services has been important in the development of systems for consulting service users, pressure to implement changes based on users' views has been limited.

Surveys and focus groups have been used extensively across the sectors that we examined. Systems for monitoring and responding to complaints were also widely reported. Within health, social care and voluntary sectors we identified numerous examples of meetings

between service providers and groups of local service users, and the appointment of representatives of service users on to management committees of organisations. We did not find evidence of users being involved in management structures of service providers within the private sector. Within the private sector we found greater discussion of factors, other than the direct involvement of service users, that are required to develop user-focused services. Limited financial and other resources, and more general problems encountered in managing change within organisations, have reduced the impact that the involvement of service users has had throughout the sectors that we examined. Ambivalence or opposition of front-line staff to involving users in change within the NHS and other public sector services has also been documented.

8.2 Limitations of the review

In setting out to review literature on user involvement in change management we were restricted to examining examples of involvement that have been documented. Throughout the course of the review, people we spoke to about the study repeatedly suggested examples of involvement for which we could not find written accounts. This leads us to conclude that the reports we identified are a sample of the small proportion of user involvement initiatives that have resulted in written reports. We believe this to be especially true for the private sector where identifying the expectations of service users and changing service provision to meet these expectations is an integral part of the management of most businesses. We also found few published examples of involvement in the voluntary sector, although 'incorporated' user-led organisations themselves derive from this context. Published material may be only a partial guide to the extent and scope of user involvement.

As our aim was to examine user involvement in different sectors in order to reflect on user involvement in change management within NHS hospital and primary care trusts, we focused on top-down change management in which service providers manage change at a local level. It was not our intention to try to account for other aspects of user involvement. These include national campaigning and political activity that have been central aims of many within the user movement over the last 50 years (Barnes and Shardlow, 1997). Service users have been involved in other related activities, such as promoting self-advocacy and attempting to change public attitudes to health and illness. These activities have played a central part in supporting the development of 'top-down' user involvement and, particularly in relation to services for disabled people, have led to the development of new models of service delivery (Priestley, 1999; Hales, 1996). It is significant that in other areas where users have been particularly involved in changes to health and social services, such as psychiatric services, maternity services, and services for people with HIV/AIDS,

users have been part of wider social movements that have campaigned around other related issues. While these activities form an important part of the context of user involvement in change management in NHS trusts, a detailed exploration of these social movements is beyond the scope of this report.

When examining the context for involving users we attempted to identify and comment on reports from countries outside of the UK but the search strategy we used meant that far greater emphasis was placed on user involvement initiatives in Britain. Despite making concerted efforts to identify grey literature, the papers we have included in this report are dominated by academic reports. Discussions with steering group members leads us to the view that there is a large amount of grey literature that we did not identify and that has not been covered in this review. Rather than attempting to provide an exhaustive account of user involvement in change in these different sectors we have therefore used the reports we identified in order to illustrate the scope and breadth of user involvement in these different sectors.

At an early stage in the review it became clear that much of the literature that had been published in this field was in the form of discussion articles and commentaries written by people with experience of working in user involvement initiatives. Had we restricted the scope of this review to papers which had used research methods to explore specific hypothesis, we would have excluded the majority of the papers that we have referenced in this report. While we believe that our attempt to synthesise a broader range of material has helped us to identify factors that promote successful user involvement, we acknowledge that the validity of the claims made in some of these reports, and therefore our conclusions, need to interpreted with caution. Despite these limitations we found considerable consensus about process factors that can promote successful user involvement. Significant differences in the aims of involving users, and the methods which are used, did emerge, and these are explored further in Section 8.7.

Although we used a systematic approach to identify literature for this review, we have not attempted in this report to account for all the examples of UI that we found. During the course of the review we reached a point where we were continuing to identify new material that was relevant to the aims of the study but did not add to the information in the reports that we had already examined. Rather than referencing these papers in this report we therefore decided to purposively select papers in order to illustrate key themes that emerged in each of the sectors that we examined (see Section 1.3.4.1). While we believe that it was necessary to adopt this approach in order to produce a readable report, we acknowledge that notable examples of UI in change management are not included in this report.

8.3 Aims of UI in the NHS

While increasing emphasis has been placed on involving users in change within health care over the last 30 years, the rationale for involving users appears to have varied during this period. Commentators describing these changes have used a variety of different models to present thesm, including democratic and consumerist approaches to user involvement (Barker *et al.*, 1997). During the 1970s, the setting up of Community Health Councils was viewed as a means of increasing democratic accountability of health services, while in the 1980s emphasis was placed on strengthening the role of service users as consumers of health care. More recently user involvement has been seen in terms of promoting partnerships between service users and providers in order to develop services that focus on meeting the needs of service users. While aspects of each of these motives for UI have been present throughout this period, these changes in emphasis have had a powerful effect on the context for involvement and influenced the methods that have been used:

1   to increase accountability (democratic approach) – patients and the public as citizens who have a right to voice their opinions of services and contribute collectively to service developments

2   to promote the interests of service users (consumerist approach) – patients as consumers who should be enabled to receive the type of service that they want (with which they are satisfied)

3   to improve the effectiveness of services (patient expert approach) – patients and members of the public have expertise in their experience of health problems, and in trying to access or use services, and can use this expertise in order to contribute to the development of services that are better at improving health.

These three motives for involvement are not mutually exclusive. At present, elements of each contribute to UI in the NHS: through users voting for a government which makes decisions about the resourcing and organisation of health care; through patients contributing to surveys aimed at increasing patient satisfaction with services; and through patient representation on Community Health Councils and other bodies which present the views of patients and the public to health service providers. Current changes to the methods through which users may contribute to change within health care also reflect these different motives. Plans for service users to be involved in electing boards of governors of Foundation Trusts are aimed at increasing accountability of local services (Department of Health, 2002a), and plans to allow patients greater choice regarding the time and place at which they receive treatment seek to strengthen the role of users as consumers of services (NHS Executive, 2000). The development of new bodies such as 'Patient and Public Forums' are underpinned by a range of motives, including the belief that patient involvement can lead to the development of more effective services (Department of Health, 1999).

While much has been written about the differing philosophical and political theories that underpin these different models of involvement, they all share the aim of reorienting the development of services around the perceived needs of service users. In the NHS Plan, user involvement is seen as a means of developing more 'effective' services (NHS Executive, 2000), though whether from the perspective of service users, or from that of clinicians and other providers, is unclear. Services that better meet the perceived needs of users may not necessarily be those that deliver optimal outcomes in terms of morbidity and mortality. There is therefore a potential conflict between plans to promote and address the perceived needs of service users, and the aims of a service that has traditionally sought to increase people's health and productivity. Should service providers be responsible for judging the value of users' views and acting on those they believe will help the service deliver health care priorities? Should service providers have a responsibility to identify the self-defined needs of local service users and make changes to services that aim to satisfy these needs whether or not it is believed that they will deliver improved health outcomes? National policy documents have failed to engage with these fundamental conflicts. The impact of this and other potential obstacles to UI are discussed further in the following section.

8.4 Barriers to UI in the NHS

Barriers to UI in the NHS include the tension between national policies and locally defined needs, tensions between the different priorities of service users and providers, and issues related to the willingness and ability of users to contribute to the process of change. Professional power, assumptions about expert knowledge, professional defensiveness and lack of organisational expertise in engaging with service users also impede this process.

Much of the recent pressure for change in the organisation and delivery of NHS services has emanated from central government, national assemblies and other national bodies. Decisions about which treatments will and will not be made available by the NHS have been taken on by the National Institute for Clinical Excellence, and local hospital and primary care trusts have come under pressure to ensure that recommendations of National Service Frameworks, and targets to reduce waiting times, are implemented. While such bodies have consulted with representatives of service users at a national level, there is evidence that centralisation of the decision-making process may have limited the potential for local service users to influence change at a local level (Rutter *et al.*, 2001). Current proposals for devolving power to a limited number of Foundation Trusts suggest that the scope for local variation in practice may increase (Department of Health, 2002a). However, while the agenda for development of health care remains centrally located, groups of service users that have the capacity to organise at a national level may choose to focus their energies on influencing national policy rather than becoming further engaged in change at a local level. Health service managers must implement national policy and are also responsible for allocating scarce resources wisely. Implementing changes suggested by users that are not congruent with national priorities may be felt to be impractical.

Professional resistance to UI from doctors and other groups within the NHS has also been reported to be an important obstacle to UI. User involvement has been seen by some as undermining their professional status or competing against their own limited ability to contribute to changes within services (Pritchard, 1993). It is generally recognised that in recent years the rights of patients to choose their treatment have been strengthened, and that partnership rather than paternalism is becoming the basis for relationships between individual patients and their carers (British Medical Association Secretariat, 1994). This development has been strengthened by the recognition that users of services may judge their needs and response to treatment differently from those providing the services (Cay, 1975), and evidence that patients want to be more involved in decisions about the care they receive (Little *et al.*, 2001). While partnership is increasingly seen as the method most appropriate for planning individual care, service

providers remain concerned about the impact of strengthening the role of service users in the process of change management within the NHS. Achieving successful changes to the organisation and delivery of services requires the support of front-line staff who are asked to implement these changes. Managers, clinicians and others working within the NHS may be reluctant to support user-led changes in health care unless it can be shown that these improve the quality of care that is provided (White, 2000). Further clarification about the rationale for, and expected scope of, UI at a local and national level may help to change professional attitudes to service users' involvement. Research exploring the impact of UI may also help to develop greater support for UI among those delivering health care services.

Concerns have repeatedly been expressed about the willingness and ability of service users to contribute to the development of better health care services. The broad range of reports that we identified that document changes resulting from UI challenges these concerns. While public meetings and surveys may not have large response rates, careful planning can increase the support of service users, and the combination of different methods can enable service providers to obtain the views of a wider range of users (Maxwell and Weaver, 1984; Bradford Health Authority, 2000). Concerns about representativeness are particularly pertinent if UI is seen in terms of either increasing democratic accountability, or making services more acceptable to all service users. Service providers can and do implement changes on the basis of an individual complaint (Crawford *et al.*, 2003) without any consideration being given to the representativeness of the concern when they feel it is warranted. When user perspectives diverge from those of service providers, providers have a greater incentive to consider whether these are more generally held before taking action. Under these circumstances, the onus is on service providers to obtain the views of other users, rather than undermine the contribution of those users who are raised the concern. While consideration needs to be given to the logistics of involving older people, children and others, we did not find substantive evidence to support the notion that these or other groups of service users are 'hard to reach'.

8.5 Factors that promote UI in the NHS

A central aim of this review was to identify factors that facilitate user involvement in change within the NHS. We identified a variety of reports that described such factors, but many of these were specific to particular methods for involving service users (such as how to conduct a survey or organise a public meeting). References that provide further details of organising and implementing these specific methods of involving users are presented in Sections 2.2 and 2.3. Several factors that we identified were not specific to the method that is used. Generic factors in the involvement of users of health and social services are summarised in Table 5.

Table 5 Factors that service providers should consider when planning and implementing user involvement in change management

1	**Be clear about the aims and scope of involvement before contacting service users.** Is the primary aim of UI to improve accountability, improve satisfaction with care, service utilisation or are there other aims? Ensure that there is scope for users to influence services before consulting them. Clarify the extent to which services can be changed on the basis of user views; are resources available to implement user views?
2	**Make the aims and scope of involvement clear to users and carers who participate.** Service users should be told how they can contribute to change and the basis on which decisions on whether or not to implement changes suggested by users will or will not be made: Are resources available to support the implementation of suggestions from service users? Do requirements of central government or other bodies, or health improvement priorities and targets, mean that some elements of change are non-negotiable?
3	**Ensure that there is organisational commitment to act on the views of service users before user involvement begins.** The impact that users have will depend less on the methods of involvement than on the willingness of decision makers to act upon the advice and suggestions that service users generate.
4	**Before embarking on new involvement initiatives find out what has already taken place.** Experience of previous local UI will help in planning and implementation of new initiatives.
5	**Ensure that UI is responsive to the aims and demands of local service users.** Successful user involvement needs to be bottom-up as well as top-down and the commitment of local service users to achieving the changes they want will facilitate successful involvement. As well as issues service providers want to consult on, is there capacity for users to introduce concerns?
6	**Make sure that there is adequate time and resources to support involvement.** Involving service users may make the decision-making process slower and more costly.
7	**Consider how feedback will be presented to service users who participate.** Service users are unlikely to make a sustained contribution to user involvement unless their involvement results in visible and meaningful changes to services. If change is hampered, users must be told why.
8	**Consider how important the representativeness of service users who participate is to the process of involvement.** Is representativeness important? Asking 'why?' should help you arrive at suitable strategies for accessing a range of views. Combining different methods will allow a greater range of service users to be involved than relying on a single method. Avoid criticising users for not being 'representative'.
9	**Ensure that adequate information, time, administrative and financial support is available for service users.** Discussing the needs of service users who contribute to the process will maximise their ability to contribute to the process of change. Will involvement be equally accessible and comfortable for people of minority ethnicity or background? Will expenses be paid and support/training offered?
10	**Ensure that staff involved in the process are committed to making it a success** Staff involved may be ambivalent about the value of UI. Defensiveness on the part of service providers can damage UI initiatives. Staff training may be required; finding ways to make staff feel *their* views are also influential may be even more important.

While these recommendations are based on the case reports and qualitative studies that we identified in the course of the review, they have much in common with toolkits produced by health service practitioners (McIver, 1991; Kelson, 1997; Barker *et al.*, 1997) and recent recommendations for service user involvement produced for the Department of Health (Transition Advisory Board, 2002; www.doh.gov.uk/involvingpatients; North Tees Community Health Council, 1999; www.doh.gov.uk/pub/docs/doh/toolkit1.pdf).

8.6 Outcomes of involving service users in the NHS

In Appendix 3 we present the findings of reports that have described changes to services resulting from user involvement. These reports support the view that UI has contributed to changes to services, including attempts to make services more accessible through simplification of appointment procedures, extending opening times, improving transport to treatment units and improving access for people with disabilities (Crawford *et al.*, 2002). Several reports describe new services being commissioned at the request of service users, including advocacy, initiatives aimed at improving opportunities for employment, complementary medicine, and fertility treatments. Another frequently stated outcome of user involvement is the development of information material for new and existing service users. A further common outcome is that users involved in the process welcomed the opportunity to be involved and experienced improved self-confidence as a result of their contribution. This observation is supported by the findings of surveys and interviews with service users (Wistow and Barnes, 1993; Barnes and Bennett, 2002; Lord *et al.*, 1998). However, we also identified reports where users and staff alike described dissatisfaction with the process. Concerns were expressed by some who found evidence that UI was used to legitimise decisions that would have been made whether or not service users had supported them (Kirk *et al.*, 1997; Harrison and Mort, 1998; Taylor, 1994; Summers and McKeown, 1996). Others concluded that the decision-making process was slower as a result of involving service users (Todd *et al.*, 2000). Several reports stated that the culture of an organisation influenced or restricted the implementation of UI.

Very few case studies of UI have reported no or negative effects on services or their users. However, findings from surveys of users and providers suggest that difficulties do arise and that there are many occasions when changes to services do not result from UI (for example, Harrison *et al.*, 2002; Crawford *et al.*, 2003). Publication bias may help to explain the difference in findings reported in case studies and surveys; there may be less incentive for service providers to write up accounts of UI that did not achieve their aims.

We found very little evidence of empirical research in this field. Qualitative research has helped to examine process factors that support and hinder the development of successful UI. However, quantitative research methods have not been used to examine the effects of UI on service use, patient satisfaction, health, or quality of life of those in contact with services. The effects of UI are likely to be complex, affecting different aspects of services, users and staff in different ways. The views of service users are among many factors that influence change in health services, and health care providers remain the final arbiter of how much weight is attached to them. Separating out change specifically attributable to the participation of users is a difficult task (Smith, 1998). Despite these problems, the literature discusses factors such as the extent of service utilisation, satisfaction with care, and impact on health and quality of life that are amenable to formal evaluation. User involvement is not without its costs and the inclusion of outcome measures in future evaluations of UI could enable comparisons of different approaches to take place, and the effects of suggestions made by service users on service outcomes to be evaluated.

8.7 Similarities and differences in approach to UI in different sectors

In Table 6 we have attempted to summarise some of the similarities and differences in the aims, methods, processes and outcomes of user involvement across different sectors. Our attempt inevitably simplifies the complex issues involved, but we believe that it illustrates real differences between these sectors that may help explain some of the findings that we detail elsewhere in this report.

Table 6 Comparison of user involvement across public, voluntary and private sectors

Sector	Public			Non-Public	
	Health care	*Social services*	*Other public services*	*Voluntary*	*Private*
Pressure for UI	External and internal	External and internal	External and internal	Internal and external	Internal
Aims	Effectiveness Accountability Impacts on self-esteem, stigma, exclusion, etc.	Accountability Effectiveness Impacts on self-esteem, stigma, exclusion, etc. Encouraging citizenship	Accountability Managing public expectations Value for money Effectiveness	Self-management To represent the views of members To support applications for funding	Higher profitability/ market share Increased customer satisfaction/ retention
Methods	Surveys Representation at meetings Complaints Contact with user groups	Complaints Surveys Public meetings Representation at meetings	Surveys Public meetings Representation at meetings Co-production	Representation on management committees User advisory groups	Surveys Focus groups Complaints Co-production
Barriers	Representative-ness Staff opposition Resources Organisational culture	Representativeness Resources Organisational culture Staff opposition	Resources Organisational culture Staff opposition Changing policy at national level	Organisational development Professionalisation Lack of resources/time Legal obstacles	Resources
Factors that promote UI	Clarity about aims and limits Staff support Providing feedback to users who take part	Clarity about aims and limits Staff support	Using local knowledge Combining different methods Clarity about aims	Resources Time (to consult and respond to external partners) Setting specific objectives	Consider the 'whole' customer experience Use of multiple methods Staff incentives
Outcomes	Changing attitudes to UI User empowerment Information for service users Accessibility of services Expansion in range of services	Changing attitudes to UI User empowerment Information for service users Development of new services	Increased satisfaction with services Changes in service priorities Improved effectiveness	Impact on statutory providers' policies/services	Higher profitability/ market share Increased consumer satisfaction Increased customer retention

8.7.1 Motives for involvement

An important distinction between user involvement in the public and private sectors is that responding to the needs and expectations of service users in the private sector is seen as an essential task of service providers, which is evidently necessary for their profitability and growth. Within the public sector, user involvement has been promoted as benefiting service providers through supporting managerial objectives: but public sector managers and other staff charged with implementing user involvement are not always convinced of its benefits.

8.7.2 Aims of involvement

Throughout the different sectors, providers agreed that involving service users could impact on the quality of services by making them more 'user-friendly', more accessible and acceptable to users. There was also widespread support for the view that users could assist in making services more effective and cost-efficient. While these appear to be the overriding aims of user involvement within the private sector, we found a greater range of aims for involving users in the public sector. Reports of UI in the public sector have sometimes placed equal or greater emphasis on involvement as a means of improving democratic accountability. In health and social care sectors, user involvement is also seen as an important means of raising the confidence and self-esteem of vulnerable or socially excluded service users. From the perspective of those planning and delivering local NHS services, user involvement may therefore be a response to national and local demands and an attempt to obtain the views of local users in order to achieve a variety of local and national aims and imperatives.

Aims of user involvement in the public sector may in some instances be incongruent or even incompatible with other service imperatives: likewise, implementing the suggestions of some, perhaps socially excluded, service users may not be compatible with quality improvements for other types of service user. Private providers can choose to provide different services and products in different price ranges to suit different customers: public sector services, based upon equity of access and free treatment, and struggling to make resources meet demand, cannot disaggregate services in this way.

8.7.3 Methods of involvement

We identified a broad range of methods for involving service users across the different sectors that we examined. There was general agreement that there is no 'gold standard' approach to involving service users but that using a range of methods can help to obtain as complete a picture as possible of the views of current and potential service users. Surveys and focus groups were frequently used

throughout the sectors as methods for identifying expectations and levels of satisfaction with services. Similarly complaints from service users were viewed as providing an important source of information on potential deficits: organisational response to complaints was accorded great weight by some companies in the private sector, as complaints were an opportunity to determine more precisely what customers wanted, and so improve retention and profitability. Satisfaction and other surveys of users are seen throughout all sectors as a means of consulting users about services. As a method of involvement in the process of change, satisfaction surveys have been criticised in the health and social care sectors because they offer a very 'passive' form of involvement (Crawford and Kessel, 1999), but they may be more useful as a measure of impact of change (applied before and after). We found no evidence of such concerns in the private sector, possibly because customers do not have any 'rights' or expectations of involvement.

Health and social care organisations utilised more complex methods for involving users at all levels than was apparent within the private sector. These methods included bringing service users into the management structure of organisations through representation on management committees. We were unable to find examples of the recruitment of service users into the management structures of private sector businesses. While non-executive directors and others within private sector businesses play an important role in their management, they are not selected on the basis of being end users of the company's products or services.

Examples of involving users through co-production were found across sectors. Patients are frequently involved in co-production of their own treatment, but this phenomenon is less evident at organisational level. Co-production of services is more widely recognised within the non-health and social care components of the public sector, and in the private sector, where it is most common in product design and customisation.

8.7.4 Barriers to UI

Across the public and voluntary sectors, resource restrictions (money, staff, time) limited the scale and scope of involvement activities. Accounts from the private sector tended to justify costs of involvement (where mentioned) by reference to resultant increases in profits. We found little discussion of the issue of representativeness of service users outside the public sector. While representativeness may be considered to be an important issue if user involvement is seen as a mechanism for enhancing democratic accountability and social inclusion, within the private sector the proposals/suggestions of articulate, innovative or high-spending customers for improving service quality may be valued more than those of 'typical' service users.

Reports of staff resistance which are commonly encountered in the literature on user involvement in health care settings are also found within other areas of public services. This observation suggests that staff resistance in the health care sector owes less to the perspectives of these particular professionals than to more general issues concerning the motives and outcomes of user involvement. A recurring theme throughout the different sectors that we examined is that organisations that embrace user involvement need to be open to criticism. Concerns have been expressed that many health care providers and other public services have a defensive attitude to complaints and feedback from service users that is not conducive to successful UI.

8.7.5 Factors that promote UI

There is widespread agreement that, in order to achieve successful UI, service providers need to be clear about the aims and scope of the initiative before it is started. We found reports that suggested that service providers within the public sector may have undertaken user involvement in order to demonstrate compliance with local or national policy without having given sufficient consideration to the aims, process and outcomes of user involvement (for example, Snary, 2002). We have referred earlier in this chapter to the ambiguities of policy guidance, focusing as it does upon aims and processes of involvement. False expectations may be raised when the aims and limits of involvement initiatives are not made clear; conversely, we suggest they can be avoided if providers have thought through and communicate these terms at the outset. Giving users an honest account of what to expect can help to sustain the support of users for future involvement initiatives.

Within the private sector, reports stated that in order to achieve successful user involvement staff working within provider organisations needed to feel empowered to respond to the suggestions (or complaints) of service users. We also identified examples where staff were rewarded on the basis of achieving standards that had been found to improve user satisfaction with services.

8.7.6 Outcomes of UI

Differences in reported outcomes of user involvement in different sectors reflect differences in the aims of UI (see Appendix 3). Customer satisfaction, customer retention and profitability were referred to in the private sector, with changes in the nature, range and effectiveness of services being discussed in the context of public sector services. Beneficial effects for users who participate in user involvement initiatives have been reported in the health and social care sectors.

As will be discussed in Section 9.2, the nature of evidence to support claims of benefits resulting from user involvement need to be in taken into consideration when considering their validity. With the exception of evidence from qualitative research in relation to health and social care sectors, together with some experimental evidence that has explored the effects of employing service users in order to deliver care, the effects of user involvement have not been tested empirically. Clearly the ways in which user involvement may contribute to changes within services are complex and not readily amenable to empirical investigation. The paradigm of evidence-based practice has far greater influence in the health care sector than elsewhere. While the limitations of this approach to examining the impact of complex processes such as user involvement need to be acknowledged, the 'evidence base' for benefits resulting from user involvement is not strong (White, 2000; Crawford *et al.*, 2002). The potential value of comparative research in this field is discussed further in Section 8.10.

Interpreting evidence presented in case reports that have been written up on user involvement in the private sector presents even greater challenges. As Pendleton and King recently stated:

> *Research in business organisations is notoriously poor, because it often uses little other than correlation evidence, without any controls or attempts to establish causality.*

(Pendleton and King, 2002)

Despite this, we encountered many reports that described how private sector companies had changed services in response to the expectations and needs of service users and how these changes had led to customers becoming more satisfied and less likely to defect to other service providers. While we did not identify empirical research on the impact of user involvement in the private sector, the substantial resources that companies devote to identifying the views of customers suggests that this process can deliver improvements in customer-defined service quality.

8.8 What can the NHS learn from UI in other sectors?

At the start of the project we hoped to identify factors that promote user involvement in other sectors which could be applied to UI in the NHS. However, our review identified few such factors. In relation to both the methods for involving service users, and awareness of process factors that are important in achieving successful user involvement, we found very little that had been written in other sectors that has not also been considered in the literature on UI in the NHS. Several factors that have been discussed in relation to health care appear to have greater prominence in other sectors. These include:

•   the opportunity that co-production can provide for involving service users in the delivery of more effective services

•   the role that responses to complaints can play as a method for highlighting deficiencies in service provision

•   the role that local media can play in increasing awareness of and participation in user involvement initiatives

•   the potential that extending the opportunities that people have to choose elements of the services they receive can have in enabling people to receive the service they want

•   the expansion of systems through which users can deliver feedback (such as use of the internet), and general simplification of the methods by which users can register their views about existing services.

Co-production, which was highlighted in our review of UI in the private sector, is increasingly employed within health care settings as patients are more actively engaged in deciding and implementing treatment. Future efforts to extend the development and application of mechanisms for involving patients and carers in self-care/self-management and the co-production of their health are likely to be valued by service users and result in more effective use of available resources.

In the private sector, social care sector and other (non-health) public sector services, considerable emphasis has been placed on systems for utilising complaints made by service users as a the basis for changes in the organisation and delivery of services. While complaints procedures have operated in the NHS for some time, it is envisaged that the development of Patient Advice and Liaison Services (PALS) will improve the way that complaints are managed in the NHS (Department of Health, 2002d). Plans for developing PALS highlight the important role that they should play in feeding back the concerns of service users to managers within trusts. Ensuring that PALS services are sufficiently well resourced to be able to follow up responses from trusts to

complaints would seem to be a valuable way to facilitate this important aspect of user involvement.

Current changes within the organisation of UI in the NHS also involve service users becoming members of the trust Board and the requirement of trusts to set up and consult with Patient and Public Forums made up of local service users. Reports from social and voluntary care sectors suggest that it is difficult for lay people to have an influence in higher managerial settings, and that sustaining the involvement of service users in a voluntary capacity to act in this role is a difficult task. Process factors highlighted in Section 8.5 are likely to be important in ensuring that Patient and Public Forums make a full contribution to service development.

In considering the relevance for the NHS of 'lessons learnt' in the private sector, it is important to consider significant differences in the context in which the public and private sector services operate. These differences were explored in detail by Legge (1995), and include:

- *choice:* an absence or limited range of choices often faced by users of public sector services

- *response to demand for services:* private sector service providers may seek to increase demand, while public sector services may need to control or limit demand

- *profit motive:* while private sector services may ultimately be motivated by the need to maximise profits, public sector services do not need to profit from their interactions with service users

- *length of relationship with service user:* while many relationships between customers and suppliers of private sector services are short-term, public sector organisations may be responsible for providing long-term or lifelong services such as housing and health care, etc.

Within the private sector the rationale for providing the customer with what they want is that the customer pays for the service they receive. Within the context of the NHS, members of the public as taxpayers finance the service. Some users of NHS services do not pay tax and others who do pay tax choose to opt out of state-funded healthcare and use private sector services. This distinction highlights the need for members of the public, whether or not they are current users of NHS services, to contribute to the process through which NHS resources are set and services are prioritised.

As previously discussed, the aims of health care and other public services go beyond meeting the self-defined needs of service users. Differences may exist between self-defined needs of service users and those defined by service providers. For private sector services the need to achieve profitability and growth trumps that of meeting the needs of service users. If profitability and growth can be achieved without meeting the needs of service users then these needs are unlikely to be met.

Private sector services have no statutory requirement to consult current and potential users. Their primary motivation for doing so is to retain existing customers, and to increase their market share. Draper and colleagues (2001), discussing UI in health care in the United States, comment that:

> *Hospitals that compete for paying customers have strong commercial reasons for obtaining consumer feedback … and acting on those results. Tax-funded health services of open access … do not share the same concerns about retaining or expanding their market share.*

Similarly, NHS hospitals, with the current problem of under-capacity to treat increasing demand, do not have a clear interest in increasing the volume of patients needing or wanting treatment.

Differences in the values and organisation of private sector services and those provided in the NHS limit the generalisability of findings from one context to the other. Despite this, we believe that by paying greater attention to the organisational factors that are required to develop user-focused services in the private sector, more could be done to provide patient-focused services within the NHS. These factors are discussed further in the following Section 8.9.

8.9 User involvement and the development of user-focused services

Over recent years the involvement of service users has been championed as a means of developing patient-focused services (NHS Executive, 2000). The importance of developing services that are focused on the needs of users has also been highlighted in other sectors, notably within the private sector. When examining literature from the private sector it soon became apparent that compared to UI in the NHS there has been less attention paid to exploring factors associated with the *process* of involving service users than with achieving an *outcome*: user-focused services. In Figure 3 we illustrate the current context, process and outcomes of UI in the NHS.

Figure 3 The context, process and potential outcomes of UI in the NHS
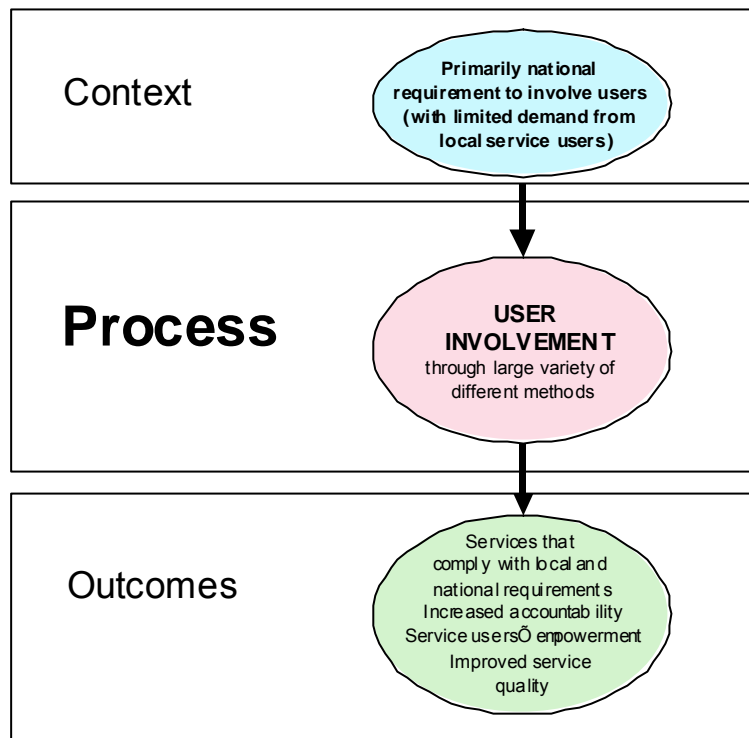
The focus of Figure 3 is on the process: user involvement, which is where current efforts to respond to the needs of service users have been concentrated. In Figure 4 we represent those factors considered necessary for the development of user-focused services. In contrast to the previous model of user involvement, the focus for this model is on the outcome of delivering user-focused services.

Figure 4 The context, process and outcomes of delivering user-focused services
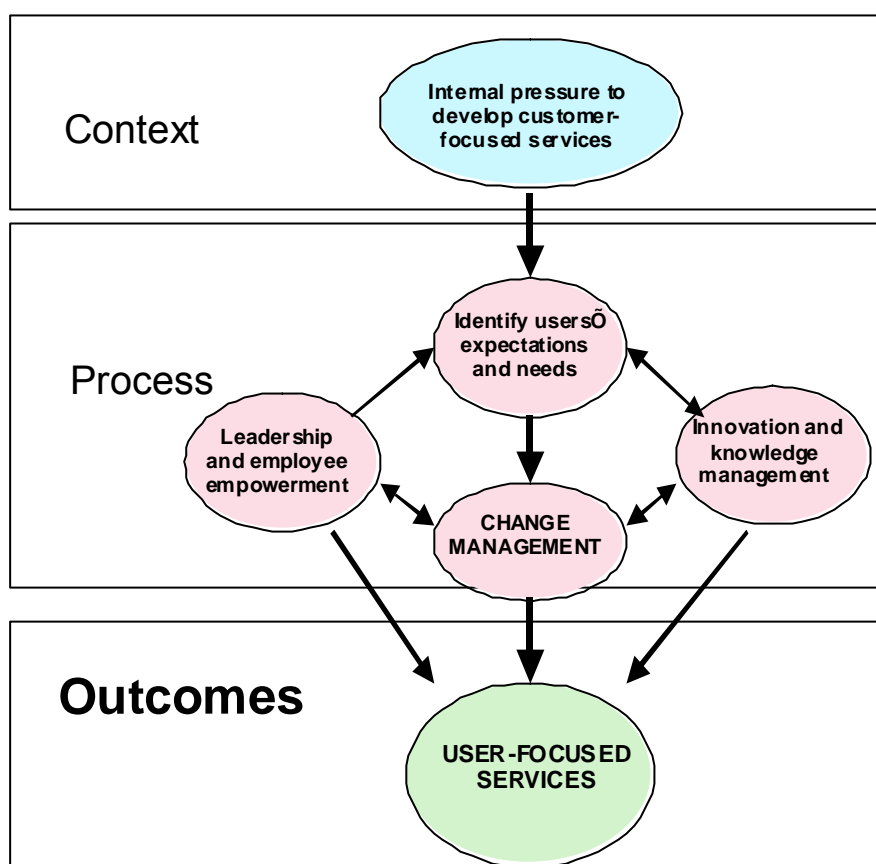
In this model the role that users primarily play is in providing information about their expectations and satisfaction with services. Some initiatives aimed at developing user-focused services do not directly involve users at all. In these examples service providers, especially front-line staff who have the greatest contact with service users, are asked to identify changes that need to be made and structures are then put in place that aim to deliver these (Basch, 2002). Within the private sector we identified other methods through which senior management repeatedly expose themselves to the experience of service users through observation and interactions with customers (Reichheld, 1996; Kotter and Leahey, 1993; Parasuraman and Berry, 1997; Band, 1995).

Our search strategy led us to identify large numbers of papers that reported the results of surveys of users of health services. Most of these are not included in this report because they gave little or no indication of how their results were used to change services. Themes such as users wanting more information about the care they are offered, the cleanliness of wards and clinics, and dissatisfaction with

delays in treatment occur repeatedly (for example: Walsh, 2001; Department of Health, 2002c; Airey *et al.*, 2001). The literature we examined on the development of user-focused services emphasises that obtaining the views of users is only one component of a larger process that is required if services are to better meet the expectations and needs of its users (Draper *et al.*, 2001). Key among these factors is the role of front-line staff, because these are the people in organisations who have direct contact with service users. Services that aim to be user-focused ensure that front-line staff are enabled to manage the needs of service users, and are encouraged to contribute to changes within organisations based on their first-hand knowledge of what service users want. Emphasis is also placed on ensuring that staff have financial and other incentives to deliver services that are valued by users. This in turn requires that systems be put in place that measure and provide feedback on user-focused measures of service quality.

Leadership is another factor that is of central importance in the development of user-focused services. Senior managers in organisations need to continually expose themselves to the experiences of service users through direct personal contact with users (Parasuraman and Berry, 1997; Reichheld, 1996; Kotter and Leahey, 1993; Parasuraman and Berry, 1997; Band, 1995). Senior managers of user-focused services lead by example by prioritising user-focused goals, showing commitment to the organisation through using the services that they provide, etc.

Organisations that seek to become more user-focused also need to be able to successfully manage change. Concerns have been raised about the ability of the NHS to manage change (Plamping, 1998) and ongoing initiatives aimed at improving change management in the NHS would increase the ability of the organisation to develop more user-focused services (Iles and Sutherland, 2001).

Discussion of process factors that support the development of user-focused services are not restricted to the private sector. Foster's (2000) report on modernising public services within the Department of Environment, Transport and the Regions highlighted similar themes of leadership and employee involvement as being essential in order to develop customer-focused services. Reports detailing efforts made by public sector health care providers to develop patient-focused services also highlight the need to set clear organisational goals (Capitulo and Silverberg, 2001; Newman, 1997), have the full support of senior managers (Spiers, 1996), and the involvement of front-line staff (Laing, 2002; Bate, 2000).

A model that combines those factors considered necessary for the development of user-focused services with current methods for involving service users is illustrated in Figure 5. This model differs from Figure 3 in that the outcome of producing patient-focused services has

replaced the process of involving service users as the focus of the model. In contrast to the private sector model, bodies representing the views of service users not only generate information concerning the expectations and needs of service users but also influence management processes within trusts through representation at trust Board and other meetings. An important difference between this model and Figure 3 is that clinical and other staff within trusts are seen as playing a central role in identifying the problems that their patients experience: the knowledge and expertise of front-line staff is utilised in the process of developing patient-focused services.

Figure 5 A model illustrating the development of patient-focused services

Context

PALS and trust Board rep.

External AND internal pressures to develop customer-focused services

Elected Board of Governors

Process

Identify usersÕ expectations and needs

Leadership and employee empowerment

Innovation and knowledge management

CHANGE MANAGEMENT

Outcomes

PATIENT-FOCUSED SERVICES
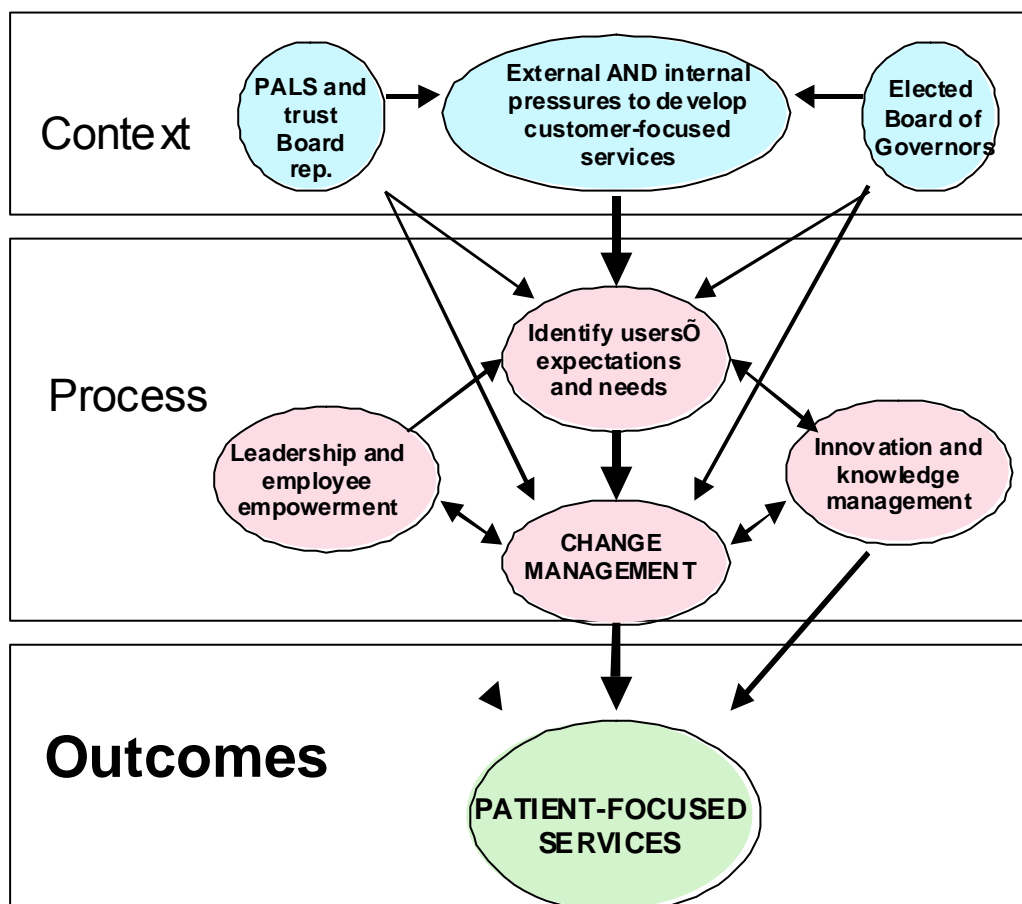
The overarching factor that provides the incentive for private sector businesses to develop user-focused services is that if customers are dissatisfied with what they receive they may seek the services of another provider. Health care systems that enable users to choose their service provider have been criticised for failing to cater adequately for the poorest patients, who are often those in the greatest need (Wistow and Barnes, 1993). Others have argued that previous attempts to expand choice within the NHS failed because many were unwilling or unable to exercise their right to choose (LeGrand *et al.*, 1999). While choice will continue to be limited under the present structure of the NHS, providing choice to users (such as delivery at home or in hospital, or the extension of complementary therapies) has the potential to act as a steer to change in the organisation and delivery of services, as patients, and subsequently resources, will gravitate toward the most receptive services.

8.10 Areas for future research

Our review of literature on user involvement in change management revealed that the vast majority of reports to date have been in the form of discussions or case studies written by people involved in the projects they are describing. We found very little evidence of independent or empirical research in this field. Notable exceptions to this are experimental studies that have evaluated the impact of employing service users to deliver health care (Simpson and House, 2002) and examples of qualitative research exploring the process of user involvement in the development of health and social care services (for example, Wistow and Barnes, 1993; Harrison and Mort, 1998; Sheppard, 2000). Evidence from case studies has generated valuable information about factors that facilitate the process through which service providers can obtain the views of service users. Far less has been written about the process through which these views can influence change within organisations. Case studies provide poor evidence on which to make judgements about the impact that user involvement has had.

8.10.1 Independent evaluation of the impact of implementing changes based on users' views

The effects of UI are likely to be complex, affecting different aspects of services in different ways. The views of service users are among many factors that may influence change in health services and separating out changes specifically attributable to the participation of users is a difficult task (Smith, 1988; Elizabeth, 1998). Despite these problems, possible effects of user involvement have been discussed at length and these include factors such as the extent of service utilisation, satisfaction with care and quality of life that are amenable to formal evaluation (Beresford and Croft, 1993). Failure to explore the impact of UI may have contributed to professional ambivalence about acting on the views of service users. We believe that studies which can demonstrate the impact of service users' views on services have the potential to encourage both staff and users to commit to such initiatives.

Studies comparing the effects of different methods and contexts of involvement may enable more effective methods to be developed. One approach would be to compare organisational factors in those provider organisations where there is a consensus that successful user involvement takes place with those organisations judged to perform poorly in this area. However, such services are likely to differ in ways other than their responsiveness to users, and these differences may also affect the outcomes being examined. While randomised evaluations of interventions aimed at changing the organisation and delivery of services are often problematic (Ferlie, 2001), we believe that randomised studies of the impact of UI are feasible and would help generate important information about the relationship between the process and outcomes of UI. Such studies should also include economic evaluation in order to allow the costs and cost-effectiveness of different methods of involving users to be compared.

8.10.2 Identifying service users' preferences for when and how they should be involved

Numerous reports have concluded that patients want greater involvement in their care, particularly in relation to the amount of information they are given about their treatment. While there is also evidence that service users want more accessible and convenient services, we know very little about the extent to which users want to be directly involved in contributing to changes to the organisation and delivery of health care services. Several reports have suggested that identifying service users who are willing to participate in this process is difficult. Research in the public sector suggests that public desire to contribute to the development of local government services is low (Lynn, 1992, quoted in Office of Deputy Prime Minister, 1998). At a time when the number of methods and occasions when service users

are being asked to participate is increasing, information about when and how service users are willing to contribute to this process needs to be obtained. It is likely that this will be different in different contexts. While much previous consideration has rightly been given to the involvement of people with chronic conditions, future research also needs to consider the views of service users who have less prolonged contact with services, such as users of emergency and palliative care services.

8.10.3 Action research examining the process and outcome of new methods for involving service users

New methods for involving service users are currently being implemented including Patient Advice and Liaison Services and Patient and Public Forums. While these build on existing methods for involving users, independent research should evaluate factors that maximise their effectiveness. Mechanisms need to be established that enable patients' views and concerns, as conveyed to PALS workers, to feed into change processes in primary care and hospital trusts. Systems also need to be identified for supporting patients and carers on Patient and Public Forums to identify and present the views of wider groups of service users. Action research has been recommended as a method that ensures that findings inform future service developments. We believe that this form of research may be particularly valuable in ensuring that information about the process and outcomes of users' involvement leads to changes in practice.

Plans for the development of Foundation Trusts emphasise the importance of devolving power to local communities (Department of Health, 2002a). It is envisaged that local patients and the public will help elect Boards of Governors of Foundation Trusts. Action research could play a useful role in ensuring that systems for patient and public involvement are supported by service users and are sustainable.

8.10.4 Investigating innovative methods for developing patient-focused services

In our investigation of factors that support the development of customer-focused services we identified a variety of factors, in addition to obtaining the views of service users, that appear to be necessary if this aim is to be realised. It follows that research into change management and leadership in health and social care services, commissioned by the National Co-ordinating Centre for Service Delivery and Organisation R&D programme and by other bodies, should also support the development of patient-focused services. The costs and benefits of extending patient choice in the NHS, employee empowerment, and the feasibility and desirability of performance-related pay for staff based on user-defined targets also require further evaluation.

Chapter 9 Conclusions

Efforts to promote user involvement in change within the NHS over the last 30 years have been accompanied by increased emphasis on UI within other public sector services in Britain and elsewhere. Meanwhile commercial and other pressures within the private sector have stimulated efforts to develop customer-focused services. These developments are based on the premise that by finding out what service users want, and what they think of existing services, changes can be made that will improve the quality of services and better meet the users' needs.

User involvement in the NHS has been the subject of a large number of papers and reports in which the context and process of involvement have been extensively discussed. A far smaller number of reports have described the outcomes of UI. Available evidence suggests that UI in the NHS has contributed to changes in services and that service users often value the opportunity to take part in this process.

Motives for involving users in change within the NHS have altered during this period. These have included increasing democratic accountability within services, improving user perceptions of the quality of services they receive and enhancing the ability of services to deliver improved health. Pressures for involving service users have generally come from outside organisations that deliver care, predominantly national government and occasionally service users themselves. While service providers have been under increasing pressure to consult with users, there has less emphasis on implementing changes based on user views.

A large number of different methods for involvement have been used within the NHS. There is general recognition that there is no 'best' method for involving users, but that methods need to be selected on the basis of the aims of involvement, the capacity of local users and providers, and financial and other constraints. Factors that promote successful user involvement are thought to include organisational commitment to act on the results of consultation with service users, clarity about the scope and aims of involvement, ensuring that sufficient time and other resources are available to obtain the views of service users, and providing feedback to users involved in the process.

Centralisation of decision making within the NHS limits the influence that local service users can have in changes within local services. Ambivalence or opposition of clinical staff has also been identified as an obstacle to successful user involvement. Front-line staff may see the empowerment of service users as a threat to their own limited ability to influence change within services. Some are concerned that diverting limited resources towards meeting user-defined needs may limit the

capacity of services to concentrate on delivering improved health outcomes. Users of NHS services have limited incentives for contributing to change within health care. While providing administrative support, training and financial remuneration have been recommended as methods for rewarding service users who participate, ensuring that users are provided with feedback about the impact of their contribution is also important when trying to build sustained involvement. Utilising feedback from complaints procedures through Patient Advice and Liaison Services, and regular contact with local pressure groups, provide readily available sources of information on the needs and concerns of some service users.

The involvement of service users in social care and other public sector services has much in common with UI in the NHS. Motivation for involving users and methods used are similar in both contexts. Local elections may provide greater incentives for providers of local government services to respond to the views of local users, but obstacles such as limited financial and other resources and resistance of front-line staff parallel those described in the NHS. Complaints procedures have been used extensively within social care and other public sector services as a spur to changes in service delivery. User involvement in the voluntary sector illustrates the tension faced by service users who become more involved in service delivery between remaining in touch with the experiences of users and developing the skills that are required to make an effective contribution to organisational change.

The greatest contrast in the context and process of user involvement in the sectors that we examined was between those in the public and private sectors. The aims of UI within the private sector are more simply stated: to achieve customer loyalty and growth. The opportunities that users of private sector services usually have to choose their service provider acts as a powerful incentive for businesses to identify and try to meet the needs of current and potential users. Methods employed for involving users tended to focus on those required to identify the needs of individual service users. We did not find examples of users becoming involved in management structures within public sector organisations. Outcomes of user involvement in the private sector have rarely been quantified, but the view that successful businesses are those that are better at understanding and meeting the needs of service users was frequently and vigorously stated.

Another apparent difference between reports from the public and private sectors was that within the private sector there has been less discussion about how to involve service users and why, than of how to deliver services that are centred on the needs of users. Literature on the development of user-focused services suggests that factors other than user involvement are necessary if this is to be achieved. Chief among these are staff empowerment, leadership and knowledge

management. Businesses that have attempted to develop user-focused services have recognised that front-line staff often have a good understanding of the problems experienced by service users. Enabling staff to respond to the needs of users in a flexible and timely manner is considered important, as are financial and other incentives that are linked to feedback from service users.

Current plans for changing systems for user involvement in the NHS will affect methods for obtaining the views of service users. Patient Advice and Liaison Services have the potential to facilitate organisational learning through feedback from dissatisfied service users, Patient and Public Forums should provide ready access to the views of local service users, and the appointment of service users to trust Boards should ensure that users' views are represented at senior management meetings. However, the results of this review suggest that methods for obtaining the views of service users are only one element among several that may be required if the NHS is to fulfil its aim of becoming a patient-focused service.

Appendices

Appendix 1 Details of search terms used to search electronic databases

In most instances terms related to 'user involvement' were each combined, in turn, with terms related to 'changes to services'. When searching European Association for Grey Literature Exploitation (EAGLE) and Social Science Citation Index, the number of references obtained by searching terms related to user involvement alone was sufficiently small for us to examine all titles retrieved using these terms.

Terms in BLOCK CAPITALS relate to subject headings, those in lower case to free text searches.

Database	Search terms		
	Terms related to user involvement	And	*Terms related to change management or service provision*
European Case Clearing House	User (OR) Customer (OR) Client (OR) Involvement (OR) Participation (OR) Representation	(AND)	CITIZEN ORIENTATION (OR) CUSTOMER FOCUSED (OR) CUSTOMER ORIENTED (OR) CUSTOMER OWNERSHIP (OR) CUSTOMER RELATIONS, (OR) CUSTOMER SERVICE, (OR) KNOWLEDGE MANAGEMENT (OR) ORGANISATIONAL DEVELOPMENT (OR) ORGANISATIONAL CHANGE (OR) MANAGEMENT OF CHANGE (OR) MASS CUSTOMISATION (OR) MARKET FOCUSED (OR) SERVICE DELIVERY (OR) SERVICE DEVELOPMENT (OR) SERVICE INDIVIDUALISED (OR) INDIVIDUALISATION (OR) SERVICES MANAGEMENT (OR) SERVICE QUALITY (OR) TOTAL QUALITY MANAGEMENT
Harvard Business School	User (OR) Customer (OR) Client (OR) Involvement (OR) Participation (OR) Representation	(AND)	CITIZEN ORIENTATION (OR) CUSTOMER FOCUSED (OR) CUSTOMER ORIENTED (OR) CUSTOMER OWNERSHIP (OR) CUSTOMER RELATIONS (OR) CUSTOMER SERVICE (OR) KNOWLEDGE MANAGEMENT (OR) ORGANISATIONAL DEVELOPMENT (OR) ORGANISATIONAL CHANGE (OR) MANAGEMENT OF CHANGE (OR) MASS CUSTOMISATION (OR) MARKET FOCUSED (OR) SERVICE DELIVERY (OR) SERVICE DEVELOPMENT (OR) SERVICE INDIVIDUALISED (OR) INDIVIDUALISATION (OR) SERVICES MANAGEMENT (OR) SERVICE QUALITY (OR) TOTAL QUALITY MANAGEMENT
McKinsey & Company	User (OR) Customer (OR) Client (OR) Involvement (OR) Participation (OR) Representation	(AND)	CITIZEN ORIENTATION (OR) CUSTOMER FOCUSED (OR) CUSTOMER ORIENTED (OR) CUSTOMER OWNERSHIP (OR) CUSTOMER RELATIONS (OR) CUSTOMER SERVICE (OR) KNOWLEDGE MANAGEMENT (OR) ORGANISATIONAL DEVELOPMENT (OR) ORGANISATIONAL CHANGE (OR) MANAGEMENT OF CHANGE (OR) MASS CUSTOMISATION (OR) MARKET FOCUSED (OR) SERVICE DELIVERY (OR) SERVICE DEVELOPMENT (OR) SERVICE INDIVIDUALISED (OR) INDIVIDUALISATION (OR) SERVICES MANAGEMENT (OR) SERVICE QUALITY (OR) TOTAL QUALITY MANAGEMENT

Database	Search terms		
	Terms related to user involvement	**And**	*Terms related to change management or service provision*
EBSCO Information Services	User (OR) Customer (OR) Client (OR) Involvement (OR) Participation (OR) Representation	(AND)	CITIZEN ORIENTATION (OR) CUSTOMER FOCUSED (OR) CUSTOMER ORIENTED (OR) CUSTOMER OWNERSHIP (OR) CUSTOMER RELATIONS (OR) CUSTOMER SERVICE (OR) KNOWLEDGE MANAGEMENT (OR) ORGANISATIONAL DEVELOPMENT (OR) ORGANISATIONAL CHANGE (OR) MANAGEMENT OF CHANGE (OR) MASS CUSTOMISATION (OR) MARKET FOCUSED (OR) SERVICE DELIVERY (OR) SERVICE DEVELOPMENT (OR) SERVICE INDIVIDUALISED (OR) INDIVIDUALISATION (OR) SERVICES MANAGEMENT (OR) SERVICE QUALITY (OR) TOTAL QUALITY MANAGEMENT
European Association for Grey Literature	Client empowerment (OR) Client involvement (OR) Client participation (OR) Client representation (OR) Consumer empowerment (OR) Consumer involvement (OR) Consumer participation (OR) Consumer representation (OR) Patient empowerment (OR) Patient involvement (OR) Patient participation (OR) Patient representation (OR) User empowerment User involvement (OR) User participation (OR) User representation		
Social Science Citation Index	Client empowerment (OR) Client involvement (OR) Client participation (OR) Client representation (OR) Consumer empowerment (OR) Consumer involvement (OR) Consumer participation (OR) Consumer representation (OR) Patient empowerment (OR) Patient involvement (OR) Patient participation (OR) Patient representation (OR) User empowerment User involvement (OR) User participation (OR) User representation		
Medline	Client empowerment (OR) Client involvement (OR) Client participation (OR) Client representation (OR) Consumer empowerment (OR) Consumer involvement (OR) CONSUMER PARTICIPATION (OR) Consumer representation (OR) Patient empowerment (OR) Patient involvement (OR) PATIENT PARTICIPATION (OR) Patient representation (OR) User empowerment (OR) User involvement (OR) User participation (OR) User representation	(AND)	Change management (OR) DELIVERY OF HEALTH CARE (OR) HEALTH PLANNING HEALTH SERVICES (OR) ORGANISATIONAL INNOVATION (OR) OUTCOME AND PROCESS OF CARE

Database	Search terms		
	Terms related to user involvement	And	*Terms related to change management or service provision*
Embase	Client empowerment (OR) Client involvement (OR) Client participation (OR) Client representation (OR) Consumer empowerment (OR) Consumer involvement (OR) Consumer participation (OR) Consumer representation (OR) Patient empowerment (OR) Patient involvement (OR) Patient participation (OR) Patient representation (OR) User empowerment (OR) User involvement (OR) User participation (OR) User representation	(AND)	Change management (OR) HEALTH CARE DELIVERY (OR) HEALTH CARE ORGANISATION (OR) HEALTH CARE PLANNING (OR) HEALTH CARE DELIVERY HEALTH PLANNING (OR) HEALTH SERVICE (OR) ORGANISATION AND MANAGEMENT
PsychINFO	Client empowerment (OR) Client involvement (OR) CLIENT PARTICIPATION (OR) Client representation (OR) Consumer empowerment (OR) Consumer involvement (OR) Consumer participation (OR) Consumer representation (OR) Patient empowerment (OR) Patient involvement (OR) Patient participation (OR) Patient representation (OR) User empowerment (OR) User involvement (OR) User participation (OR) User representation	(AND)	Change management (OR) HEALTH CARE DELIVERY (OR) HEALTH CARE SERVICE (OR) MANAGEMENT PLANNING (OR) ORGANISATIONAL CHANGE PARTICIPATIVE MANAGEMENT

Database	Search terms		
	Terms related to user involvement	And	*Terms related to change management or service provision*
CINHAL	Client empowerment (OR) Client involvement (OR) Client participation (OR) Client representation (OR) Consumer empowerment (OR) Consumer involvement (OR) CONSUMER PARTICIPATION (OR) Consumer representation (OR) Patient empowerment (OR) Patient involvement (OR) PATIENT PARTICIPATION (OR) Patient representation (OR) User empowerment (OR) User involvement (OR) User participation (OR) User representation	(AND)	Change management (OR) DELIVERY OF HEALTH CARE (OR) HEALTH PLANNING HEALTH SERVICES (OR) ORGANISATIONAL INNOVATION (OR) OUTCOME AND PROCESS OF CARE
HMIC and HELMIS	Client empowerment (OR) Client involvement (OR) Client participation (OR) CLIENT REPRESENTATION (OR) CONSUMER EMPOWERMENT (OR) CONSUMER INVOLVEMENT (OR) CONSUMER PARTICIPATION (OR) Patient empowerment (OR) Patient involvement (OR) PATIENT PARTICIPATION (OR) Patient representation (OR) USER EMPOWERMENT (OR) USER INVOLVEMENT (OR) USER PARTICIPATION (OR) USER REPRESENTATION	(AND)	Change management (OR) HEALTH CARE (OR) HEALTH CARE DELIVERY (OR) HEALTH CARE MANAGEMENT (OR) HEALTH SERVICE (OR) HEALTH SERVICE DELIVERY (OR) HEALTH SERVICE ORGANISATION (OR) HEALTH SERVICE PLANNING (OR) HEALTH SERVICE PROVISION MANAGEMENT PLANNING (OR) TOTAL QUALITY MANAGEMENT

Appendix 2 Copy of the literature coding sheet

A ID Reference number [   ]

B TYPE OF PAPER

1 **Editorial/commentary** ☐   2 **Case study** ☐

3 **Qualitative research** ☐   4 **Systematic review** ☐

5 **Quantitative research (numerical data)** ☐

C CONTEXT (tick more than one box if needed)

1 **Health care (public)** ☐   2 **Health care (private)** ☐

3 **Social care** ☐   4 **Public sector** ☐

5 **Private sector** ☐

D CENTRAL THEME OF PAPER (tick more than one box if needed)

1 **Motivation for UI/Aims of UI** ☐   2 **Describes a method of UI** ☐

3 **Obstacles to UI** ☐   4 **Factors that promote UI** ☐

5 **Negative outcomes of UI** ☐   6 **Positive outcomes of UI** ☐

7 **Other (*Please state*)** [   ]

E GLOBAL QUALITY RATING

1 Paper provides clear and detailed information that ***must be highlighted*** ☐

2 Paper provides clear and detailed information that ***may need to be highlighted*** ☐

3 Paper provides useful information that ***should be included*** ☐

4 Paper has relevant information that ***should be considered for inclusion*** ☐

5 Paper does not address study questions and ***should be excluded*** ☐

General comments and details of any reference cited in the report that needs to be chased may be added to the reverse of this sheet.

Appendix 3 Reported outcomes of user involvement

A3.1 Public sector health, social care and community care contexts

Study	Nature of service	Location	Model of involvement/ context investigated	Stated outcomes	Nature of evidence
Airey *et al.*, 2001	Coronary heart disease patients	Throughout UK (10 CHC networks)	Large-scale surveys based on indicators established through qualitative work	New rapid access diagnostic and day care clinics; improvements in pain control; improved patient information (services; healthy lifestyles); stronger links with primary care; empowering patients to manage heart failure and rehabilitation	Summary of case reports from surveys
Atkinson and Farshi, 1998	Community paediatric	UK	Audit involving structured interviews with 32 service users	Changes to dissemination of information	Audit analysis of patient questionnaire responses
Audit Commission, 1999	Cataract surgery (most patients elderly), Oxford Radcliffe Hospitals	UK	Questionnaires completed by service users	Day case surgery volunteers increased after service replaced the requirement for next-day attendance with telephone follow-up; better patient info on what to expect; evening appointments increased to suit accompanying carers and relatives	Summarised case report
Audit Commission, 1999	Maternity services, Trafford Health Care Trust	UK	Audit (change for service users); survey of random sample of new mothers	Restructuring by midwives for improved continuity, shift patterns changed to cover whole labours; new (fast) ante-natal protocol for low-risk mothers, reducing hospital attendance and saving consultant time	Summarised case report
Barnes, 1993	Community care for physically disabled	UK	User committee	No changes implemented	Case study, qualitative research methods
Barnes and Shardlow, 1997	Mental health	UK	3 user groups	Improved self-esteem	Case studies, qualitative research methods

Study	Nature of service	Location	Model of involvement/ context investigated	Stated outcomes	Nature of evidence
Barnes, 1993a Barnes and Wistow, 1994a	Community care for disabled, learning-disabled and mentally ill clients of one local authority	UK	Mixed consultation methods (public/open meetings, service-based reviews; developing users' councils; surveys, interviews, clients invited onto planning boards)	Improvements to local authority information about community care; carer out-of-hours helpline; day centres made links with training colleges; new service to get employment for disabled people; mobility task force set up to implement environmental and transport changes.	Case studies, qualitative research methods
Berger *et al.*, 1996	HIV	Australia	Consumer network; users' research views of residents of group homes; peer education; user-run clubhouse	User-friendly services and support; improved self-esteem/confidence	Report
Bowl, 1996a	Community care for mental health service users	UK	31 social services departments (survey); 3 case studies (involving 6 user forums, 9 provider agencies, three local authorities)	Confusion of objectives; slower decision-making process; user dissatisfaction	Telephone survey of social service managers; qualitative case studies
Broderick, 1997	General health	UK	Survey of 140 people by CHC	Reversal of plan to close hospital	Case report
Carlson and Rosenqvist, 1990	Diabetes management in primary care	Sweden	Consultation meetings with 34 patients	Changes to organisation of care, patient information	Retrospective review of records
Checkoway *et al.*, 1984, Checkoway, 1982	General health	USA	User representation at meetings	Increased confidence of users who participate; changes to services provided	Survey of 154 service provider organisations
Clarke and Herinckx, 2000	Mental health, ACT team	USA	Employment of users as case managers	Fewer clients of user-employees needed hospital, and emergency, admission; those that did stayed out longer	Randomised controlled trial
Crawford *et al.*, 2003	Mental health trusts	London, UK	Survey of London mental health provider trusts, to ascertain methods and outcomes of UI: trusts used mixed methods of involvement	Improvements to ward environments; improved access to outpatient services; development of crisis services; changes to policies and procedures	Self-report by survey

Study	Nature of service	Location	Model of involvement/ context investigated	Stated outcomes	Nature of evidence
Department of Health, 1994a	General health	UK	Mixed methods of consultation by health authorities (surveys, meetings) with local people	Impact on strategies unclear: some service improvements, better communication with local residents	Summarised case reports
Dixon *et al.*, 1994	Mental health	USA	2 users employed as consumer advocates in assertive outreach team	Improved engagement with patients and staff awareness, but problems with boundaries	Case study
Elizabeth, 1998	General health	UK	3 Citizens' Juries	Increase in participants' self-confidence and interest in local democracy	Case studies
Felton *et al.*, 1995	Mental health	USA	User-employees in intensive case management team	Clients of users reported improved satisfaction with living situation and finances; less decline in contact	Controlled trial
Gummer and Furney, 1998	Mental health	UK	Staff/patient forum: patients represent six user groups	Improved design of new services; plan for advocacy; improved information, training and recruitment; culture shift; increased user self-esteem	Case report
Harris, 1989	Mental health	UK	User forum	Promoted further UI	Case report
Harrison and Mort, 1998	General health	UK	Health panels run by CHC	Little evidence of changes to services	Case studies, qualitative methods
Harrison *et al.*, 2002	Primary care organisations	UK	Survey of PCGs/PCTs; qualitative interviews in three health authority districts with range of stakeholders	Around 30% (of survey respondents; of interviewees) reported unspecified changes to services or policies as result of UI: around one-third of changes involved new services, another third relocation or reconfiguration.	Self-report survey; case studies
Hayden and Boaz, 2000	Services for elderly people: range of initiatives from government-funded project, local pilot sites	UK	Advisory and user groups, and qualitative (face-to-face) or telephone interviewing	Statutory sector managers encouraged to engage with older people, set up ongoing forum; better understanding by staff of value of face-to-face information; new outreach approaches; better information on services; increased benefits take-up; new forms of services, more flexible, delivered differently, while maintaining independence; more take-up of lifelong learning, ICT; more awareness of contributions older people make to communities, challenging ageism; improved access to decision making forums	Summary of case studies (mixed methods); two-year evaluation

Study	Nature of service	Location	Model of involvement/ context investigated	Stated outcomes	Nature of evidence
Heginbotham, 1993	Broad range	UK	Range of initiatives including campaign by CHCs	Reversal of plan to close hospital	Summarised case report
Hendessi, 1994	Broad range	UK	London-based user groups and forums	Changes in policy, quality and methods of service delivery	Surveys with follow-up interviews
Hogg, 2002	Mental health; CHD; older people; diabetes	UK	Expert Reference Groups (ERGs) with users, activists, experts; with resources to consult and research (mixed methods)	Development of National Service Frameworks (national service standards and models; implementation strategies and performance measures)	Case study, qualitative research methods
Kennelly and Bradburn, 2000	Breast care services	UK	Semi-structured telephone follow-up interviews with 16 service users	Staff training and development needs to be addressed; additional clinical supervision in pain control; new post of discharge nurse agreed; telephone helpline for patients started	Qualitative telephone interviews with service users
Kirk *et al.*, 1997	Primary care	UK	Range of initiatives including interviews with service users	Supported existing plans for expansion of services	Case studies using qualitative methods
Klein *et al.*, 1998	Mental health	USA	Users employed as peer supporters alongside case managers	Clients supported by users had fewer inpatient days and improved social functioning	Comparative pilot study (4 centres)
Lord *et al.*, 1998	Mental health	Canada	Stakeholder meetings including service users	Shift in service delivery toward individualised care; broader-based ownership and control	Case study with qualitative methods
Milewa, 1997	Mental health	UK	5 patient forums	Unspecified changes to organisation and delivery of services	Retrospective review of records
Millett, 1999	Medical outpatients	UK	Survey of 120 patients and 3 focus groups	Development of information and shared care record book	Patient questionnaires and focus groups

Study	Nature of service	Location	Model of involvement/ context investigated	Stated outcomes	Nature of evidence
National Consumer Council *et al.*, 1999d	Community groups of ethnic minority backgrounds, patients of infirmary	UK	Mixed methods of consulting with groups and with individuals	Infirmary decided to promote better skin care for African–Caribbean patients; pilot new interpreting services in two community clinics (chosen from range of issues identified during the project)	Project report
NHS Executive, 1996	Range of hospital and community settings	UK	Mixed involvement initiatives	Simplified procedures, provision of new services	Self-report survey of service providers
NHS Executive, 1998	Maternity services, Changing Childbirth national projects	Throughout UK: many projects	Mixed methods, mostly involving users in evaluating outcomes of established goals: large surveys favoured	Include radical reorganisation of midwifery to improve continuity of care; guidance for providers on involvement disseminated; MSLCs trained to evaluate and monitor services; evaluation (by survey of 3000) of GP scheme	Summarised case reports
Nutt, 1976	Primary care	USA	User representation at 12 planning meetings	Broad range of suggestions for changes to services	Retrospective review of records
Pagett, 1994	Medical outpatients	UK	Service users panel	Patient information and appointment cards revised; disabled facilities improved	Summarised case report
Pecarchik *et al.*, 1976	General health care	USA	Health and welfare council	Pressure from service users speeded up changes to organisation of blood banks	Summarised case report
Pilgrim and Waldron, 1998	Mental health	UK	User group convened, 8–14 members	Extension of CMHT hours; advocate funded; service information for users published	Action research report
Raynes, 1998	Nursing and residential homes, UK	UK	Off-site focus groups with sample of elderly residents	Social services' service contractual specification/outcome indicators amended to reflect resident needs/wants; care home bought minibus, employed leisure therapists; group of homes requested training in initiating activities	Case report
Richardson and Bray, 1987	Primary care	UK	Patient participation groups	Reorganisation of waiting rooms; development of new clinics; changes to opening times	Postal survey

Study	Nature of service	Location	Model of involvement/ context investigated	Stated outcomes	Nature of evidence
Sheahan, 1999	General hospital care	Australia	Survey of discharged patients	Development of information booklet	Case report
Sheppard, 2000	Primary care, elderly people	UK	Meetings with service users: patients at 5 GP practices	UI appreciated by users and providers: no concrete outcomes	Action research qualitative methods
Silva, 1990	Mental health	USA	Client group to plan respite facility	Clients directed service design; became volunteer staff; reduced dependency	Case report
Smith, 1984	Mental health	USA	Ex-client representation at meetings, survey of current clients	Promotion of rehabilitation through enhanced self-worth, self-reliance	Case report, use of mixed methods
Summers and McKeown, 1996	Maternity services	UK	Mixed – focus groups, consultation, interviews, user survey and CHC	Strategy reflects call for more link-workers; better catering; staff interest in user views stimulated	Case report
Summers and McKeown, 1996	Mental health	UK	Mixed – focus groups, consultation with user forum, survey of voluntary organisations and CHC	Improved self-esteem for users; staff interest in user views stimulated	Case report
Taylor, 1994	General health; learning difficulties	UK	Range of consultation projects across all sectors and stakeholders	Researching, implementing documenting service standards; revised patient information; user input into major overhaul of learning difficulties services	Action research report
Thornton and Tozer, 1994	Services for elderly people: range of initiatives reported in directory format	UK	Standing advisory groups; focus groups facilitated by development workers; lay elderly inspectors appointed to monitor care homes; qualitative interviews; user campaigning and advice groups formed, etc.	Many activities concern development of agenda for change; development of user-led 'cascade' training programme for self-management of arthritis; selection and training for representation on statutory bodies; gaps in services identified; information needs and quality of life issues addressed; instigation of plan for sheltered housing and clinic; events for elderly people organised; plans to close services stopped; day care project for elderly Bengalis established; broader population researched and informed (surveys, newsletters); local campaigns (re retention of concessionary fares; launderette closures; library fines); financial, legal, security advice and support disseminated	Series of summarised case reports: overarching issues discussed

Study	Nature of service	Location	Model of involvement/ context investigated	Stated outcomes	Nature of evidence
Tischler, 1971	Mental health	USA	Consumer board overseeing service providers	Training for staff on patient needs	Case report
Todd *et al.*, 2000	Community learning disability services	UK	User and carer representation on strategic planning boards	User and carer dissatisfaction: involvement slow and expensive	Interviews with qualitative analysis
Williams, 1994	Outpatient services	UK	Patient and staff interviews; survey	Waiting times, notes retrieval, patient information and feedback to patients improved	Case study, qualitative methods
Wistow and Barnes, 1993 Barnes and Wistow, 1992 Barnes and Wistow, 1994a, 1994b, 1994c	Community health and social care	UK	Survey, citizen advocacy, meetings	Improved access to services, enhanced self-esteem of users who participated; service provider became more open to UI	Case study with qualitative methods
Woods, 1994	Surgical inpatient	UK	Questionnaire survey	Revised admissions and discharge procedures/information; improved ancillary services; complementary medicine; liaison group established	Case report supported by survey
Young, 1975	Primary care	Canada	Lay board of directors controlling a primary care clinic	Physicians left the clinic, alleging interference	Case report

A3.2 reported outcomes of user involvement in public sector (non-health/ social care) contexts

Study	Nature of service	Location	Model of involvement/ context investigated	Stated outcomes	Nature of evidence
Alford, 1998	Postal service	Australia	Co-production – introduction of optical character reading technology	Cheaper postal services	Example supporting expert opinion
Alford, 1998	Social security and job search	Australia	Co-production – increase in skills prior to work	Individual job skills plans	Example supporting expert opinion
Brock and Harknett, 2002	Social security and job search	USA	Co-ordinated service provision Single point of contact Co-production – increase of skills prior to work	20% higher participation in 'preparation for work' programmes; 2.2% higher wage earned by 'integrated' cases; increased referrals to social services for vulnerable clients in need	Case report
Broussine and Wakefield, 1997	Probation	UK	Interviews and focus groups with offenders, magistrates, etc.	Organisational change, move from geographical to functional units; major evaluation of hostels; more resources into accommodation and employment, linked to NVQs; more IT for staff to convey information to offenders	Case report
Buchy and Race, 2000	Land management	Australia	Devolution of authority Public meetings Media briefing Public education	Control of Aus$1 billion revenue/annum budget devolved; local people involved in revising regional infrastructure development, including expanded railway network	Case report
Davies, 1999	Primary and secondary schools	UK	School councils	Reduction in exclusions from school and bullying identified, anecdotal (not audited); some limited impact on policy concerning student behaviour; increased sense of personal responsibility	Case studies, qualitative methods
Foster, 2000	Employment service	UK	Mystery shopping (by bogus customers actually investigating customer experience)	Customer-focused quality standards and measures introduced, resulting in shorter response times (to phone calls; for appointments and replies to letters); greater care in displaying up–to-date vacancies	Summarised case report

Study	Nature of service	Location	Model of involvement/ context investigated	Stated outcomes	Nature of evidence
Foster, 2000	Driving Standards Agency; Driver and Vehicle Licensing Agency; Highways Agency	UK	Mystery shopping; customer surveys and market research; analysis of complaints	Longer opening hours; customer-focused quality standards and measures introduced for shorter response times; easier procedures for customer transactions (e.g. through internet) introduced; consideration of alternative supplier (other than BT) of telephone lines because of local insufficiency at peak times; better customer information; new arrangements for swift re-licensing of fleets, new vehicles and drivers introduced; complaints analysis improved, and linked to regular staff briefings; staff development improved; customer surveys improved	Evaluation drawing upon independent audit techniques, output data and staff consultation
Johnson, 1993	Public utilities	USA	Public meetings Invited special interest groups Media briefings	Reduction of threat of litigation; reduced power of public scrutiny body	Self-report of leaders
National Consumer Council *et al.*, 1999a	Clients of Cheshire Benefits Agency, especially people in rural areas, people with literacy problems and those hostile to services	UK	Mixed methods, visiting existing groups, financing independent meetings facilitated by voluntary sector, surveys conducted by telephone or interview, flyers and posters, media coverage and confidential telephone commentary line	Independent meetings found to be most productive, with written materials least productive. User views formed basis for a new format and charter for Benefits Agency service standards	Project report, supported by mainly qualitative methods
Nielsen and Vedsmand, 1999	Fishing industry	Denmark	Devolved decision making Invited user groups	Agreement on historically contentious issue; increase in quality of data available to government	Case report

Study	Nature of service	Location	Model of involvement/ context investigated	Stated outcomes	Nature of evidence
Office of Deputy Prime Minister, 1998	Oadby and Wigston Council: planning for site of new cemetery	UK	Publicity in local newspaper of 12 possible sites; letters to nearby households. 100 responses from public considered by planning committee. Decision made, with further invitation for objectors to address committee	Site most popular with residents not selected, but council proposes site which complies with public's expressed priority (desirable it should be distant from residential areas)	Summarised case report
Scharitzer and Korunka, 2000	Public housing services	Austria	Process change; local empowerment/ accountability; customer-based incentives; quality systems introduced	Single point of contact; improvement in speed of handling cases	Case report
Snary, 2002	Environmental impact assessment	UK	Invited special interest groups	Distrust increased and support for scheme weakened, but service complied with compulsory consultation	Case report
Steelman, 2001	Land management	West Virginia, USA	Public meetings Invited special interest groups	Consensus on contentious issues	Case report
Thody and Punter, 2000	Education services	UK	Inclusion of business leaders in school boards	Better school governance/objectivity	Self-report survey of governors
Tunstall, 2001	Local authority estate management	UK	Devolution of housing estates management to tenant management organisations (sample of 16)	Improvements in repair services almost universally; benefits in *some* estates in voids, rent arrears and cleaning/caretaking services; changes in policies, practices and attitudes in LA staff re tenant participation; increased competence/confidence in active tenants.	Case studies
Walters *et al.*, 2000	Land management	Utah, USA	Public meetings, Media briefings On-line chat rooms/bulletin board	Consensus on contentious issues; population educated	Comparative case study

A3.3 Reported outcomes of user involvement in voluntary sector contexts

Study	Nature of service	Location	Model of involvement/ context investigated	Stated outcomes	Nature of evidence
Goss and Miller, 1995	1 Disabled people, community care clients 2 Day services for disabled people	1 Sheffield, UK 2 Sutton, UK	1 Consultation with user-led network 2 5 meetings held to consult with 100 users, who also filled in 70 questionnaires	1 User-led business plan to provide consultation services under contract to local authority; development worker employed 2 Day centre turned into learning resource centre, managed by user-led board	Case reports
Poole, 2000	Neurological disorder	UK	User-focused monitoring	Users and staff found UI rewarding	Case report

A.3.4 Reported outcomes of user involvement in private sector contexts

Study	Nature of service	Location	Model of involvement/ context investigated	Stated outcomes	Nature of evidence
Day, 1999	Consumer software	USA	Behavioural analysis User testing (25% existing users, 75% non-users)	Increase in sales (to 75% of US personal finance software market); new products for small businesses	Examples supporting expert opinion
Dholakia and Morwitz, 2002	Retail financial services	USA	Telephone interview	Three-fold increase in new accounts/products purchased	Case report
Ford *et al.*, 2001	Travel services	USA	Customer survey	Company focus on cost-cutting and punctuality	Examples supporting expert opinion
Ford *et al.*, 2001	Entertainment services	USA	Customer survey Behaviour studies	Cleaner parks; better, more satisfying rides	Examples supporting expert opinion
Helfat and Raubitschek, 2000	Consumer goods	Japan	Customer complaints	Inclusion of missing or incorrect product functionality in product development	Examples supporting expert opinion
Jones and Sasser, 2001	Office products	USA	Interviews Satisfaction surveys On-line feedback Customer complaints	Company (Xerox) retained market share	Examples supporting expert opinion
Kotter and Leahey, 1993, Prokesch, 1995	Travel services	UK	Surveys Customer complaints User groups Process re-orientation Usage analysis	9% increase in business class usage; defection rate of complaining customers reduced from 60% to 20%; financial rate of return on investment in customer relations at 200%; increase in reporting and resolution of customer complaints; changes in peripheral services on board (food, beds, arrivals lounge)	Examples supporting expert opinion and leadership comment
Magidson and Brandyberry, 2001	Consumer goods	USA	Focus group	Doubling of sales in new store	Examples supporting expert opinion
Myer, 1989	Consumer goods	USA	Interviews	Changing in packaging/handling/ delivery of goods to suit final customer as well as retailer	Examples supporting expert opinion

Study	Nature of service	Location	Model of involvement/ context investigated	Stated outcomes	Nature of evidence
Paliwoda and Osing, 1992	Utilities	USA	Invited special interest groups Interviews Co-production – innovative ways for customers to generate power and spread risk	Greater customer satisfaction and user lock-on	Case report and leadership comment
Prahalad and Ramaswamy, 2000	Consumer software	USA/global	User testing	Increased number of applications user-ready by the launch of Windows 2000 smoothing the way for launch (equivalent to $500 million testing costs)	Examples supporting expert opinion
Prahalad and Ramaswamy, 2000	Telecoms equipment	USA/global	User community/customer support desk	Reduction in in-house support costs; user fault resolution service more accessible to users	Examples supporting expert opinion
Reichheld, 2001	Fast-food services	USA	Customer satisfaction surveys Employee promotion based on survey	Managers retained total focus on customer satisfaction	Examples supporting expert opinion
Sculley, 1987	Consumer goods	USA	Interviews Behavioural study	More repeat purchase compared to equally available similar products	Examples supporting expert opinion
Seybold and Marshak, 1998	Research grant application	USA	User advisory group User testing of solutions On-line comments On-line use analysis	Transparency of process improved; application formats more user-friendly, more applications made	Example supporting expert opinion
Seybold and Marshak, 1998, Gilmore and Pine, 1997	Travel services	USA	Survey Interviews	Club Gold service established, easing frequent users' path to car hire	Examples supporting expert opinion

Study	Nature of service	Location	Model of involvement/ context investigated	Stated outcomes	Nature of evidence
Seybold and Marshak, 1998	Electronic supplies	USA	Focus groups User testing On-line feedback Automated on-line usage analysis Co-production – taking order processing inside major customers' organisations	Customer tools based on customer activity cycle; major departments reorganised around customer profiles	Examples supporting expert opinion
Seybold and Marshak, 1998	Consumer products	USA	Co-production – incorporation of definition/ordering within internal procurement processes	Lowered cost of traditional PC manufacturers (changed model to commodity); customer choice increased; user support service improved	Examples supporting expert opinion
Seybold and Marshak, 1998	Office products	USA	Co-production – providing design tools and pro forma documents to customer	Reduces overheads (in-house design/proofing team) passing cost cutting on to customer	Examples supporting expert opinion
Taylor, 2002	Travel services	USA	Interviews Surveys Linking employee bonuses and promotion directly to customer satisfaction	Company (British Airways) retained market share	Examples supporting expert opinion
Thomke and Nimgade, 2001, Thomke and von Hippel, 2002	Food manufacture	USA	Co-production – R&D mechanism delivered to customer	Customers can design their own flavours, which are manufactured by BBA	Examples supporting expert opinion
Thomke and von Hippel, 2002	Electronic supplies	USA/global	Co-production – R&D mechanism delivered to customer	Creation of $15 billion market; customers can design their own chips which are manufactured by LSI	Examples supporting expert opinion
Vandermerwe, 1997	Travel services	UK	Survey Interviews	Limousine service to/from airport established; luxury departure lounges	Examples supporting expert opinion

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This document was published by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) research programme, managed by the London School of Hygiene & Tropical Medicine.

The management of the Service Delivery and Organisation (SDO) programme has now transferred to the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton. Prior to April 2009, NETSCC had no involvement in the commissioning or production of this document and therefore we may not be able to comment on the background or technical detail of this document. Should you have any queries please contact sdo@southampton.ac.uk.

Addendum:

This report was amended on 29th September 2011 to update the correct copyright statement and/or correct the publication date. The content of the report has not been changed.