Designed to Involve: public involvement in the new primary care structures
This publication is part of an initiative designed to encourage a greater degree of public involvement in primary health care. The initiative is a joint project between the NHS Management Executive, the Scottish Association of Health Councils and the Scottish Consumer Council.

**Steering Group**
Dr Kevin Woods, (Chairperson)
Dr Tricia Donald, Royal College of General Practitioners
Dr JD Watts, Scottish General Medical Services Committee
Mr David Bolton, Director of Primary Care Development, Lothian Health
Dr Eleanor Guthrie, GP, Glasgow
Ms Liz Cooke, Queen’s Nursing Institute Scotland
Mr John Turner, Chief Executive, Borders Community Health Service NHS Trust
Ms Yvonne Dalziel, Lothian Health Promotion
Ms Anne Clark, Highland Community Care Forum
Dr Scott Murray, Dept of General Practice, University of Edinburgh
Mr Rob Brown, Director of Nursing and Quality, Argyll & Bute NHS Trust
Mr Brian Smythe, Project Manager, Dundee Alliance
Mrs Anne Conlon, Drumchapel Community Health Project
Dr Gordon Peterkin, Grampian Healthcare NHS Trust
Christine Campbell, Chief Officer, Argyll & Clyde Health Council
Professor Gerard Hastings, Centre for Social Marketing, University of Strathclyde
Professor J Cromarty, Clinical Pharmacy Practice Unit, Robert Gordon University
Dr David Steel, Health Gain Division, NHS Management Executive
Dr Hugh Whyte, Primary Care Directorate, NHS Management Executive
Mrs Sue Plummer, Primary Care Directorate, NHS Management Executive
Mr Hector MacKenzie, Health Gain Division, NHS Management Executive

**Editorial Group**
Mrs Patricia Dawson, Director, Scottish Association of Health Councils
Mrs Liz Macdonald, Scottish Consumer Council
Mr David Black, Communicable Health
Ms Pauline Craig, Communicable Health
Ms Jane Hopton, Primary Care Research Group, University of Edinburgh

The project editorial group would like to thank the following people for their help with, and comments on the draft publication: Barbara Abbot: Highland Community Care Forum, Nick Zappa: Greater Glasgow Community and Mental Health Services NHS Trust, Mike Winter: Lanarkshire Health Board, David Carse: Greater Glasgow Health Board, Ian Kirkton: Forth Valley Local Health Council, Hugh Stewart: ENABLE, Brian Clegg: GP, Clydebank, George Wilson: Woodburn Action Group, Pat Taylor: University of the West of England, Antonia Ineson: Lothian Health Promotion, Susan von Reusner, Highland Community Care Forum.

Publication written and produced by Communicable Health

Published by the Scottish Consumer Council 1999
ISBN 0907067 689
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preface</td>
<td>4</td>
</tr>
<tr>
<td>Introduction</td>
<td>5</td>
</tr>
<tr>
<td>Policy context</td>
<td>5</td>
</tr>
<tr>
<td>Clinical governance</td>
<td>5</td>
</tr>
<tr>
<td>Primary care trusts: new organisations, new opportunities</td>
<td>6</td>
</tr>
<tr>
<td>Overview of Public Involvement</td>
<td>7</td>
</tr>
<tr>
<td>Benefits of involving the public</td>
<td>7</td>
</tr>
<tr>
<td>Levels of involvement</td>
<td>8</td>
</tr>
<tr>
<td>Who should be involved?</td>
<td>9</td>
</tr>
<tr>
<td>Good practice in involvement</td>
<td>9</td>
</tr>
<tr>
<td>Appropriate methods and support</td>
<td>11</td>
</tr>
<tr>
<td>Health Councils</td>
<td>13</td>
</tr>
<tr>
<td>Approach to a Public Involvement Strategy</td>
<td>14</td>
</tr>
<tr>
<td>Steps to a strategy</td>
<td>14</td>
</tr>
<tr>
<td>Vision/Policy</td>
<td>15</td>
</tr>
<tr>
<td>Steering and managing a strategy</td>
<td>17</td>
</tr>
<tr>
<td>Audit of current practice</td>
<td>17</td>
</tr>
<tr>
<td>Development and support</td>
<td>19</td>
</tr>
<tr>
<td>Monitoring, evaluation and feedback</td>
<td>21</td>
</tr>
<tr>
<td>Examples of Public Involvement in Primary Care</td>
<td>23</td>
</tr>
<tr>
<td>Appendix 1</td>
<td>36</td>
</tr>
<tr>
<td>Bibliography</td>
<td>38</td>
</tr>
<tr>
<td>Sources of Further Information</td>
<td>41</td>
</tr>
</tbody>
</table>
There is general agreement that public services should be responsive to the needs of those who use them. The changes which are currently being made to the health service offer an opportunity to develop public involvement in primary care. This publication seeks to encourage and enable primary care trusts (PCTs) to make public involvement central to their work.

Target audience and use of the document
The document has been designed primarily as a practical tool for senior clinicians and managers coming into post in primary care trusts. It gives clear guidance on how to ensure that public and patient involvement is developed. It is also targeted at primary care trust boards who will need to support this work. In addition the publication provides ideas and guidance for the designated member of the executive team with responsibility for public involvement.

It will also be useful for members of local health care co-operatives (LHCCs) and service providers who are working towards developing public involvement within their practice, and to the members of the public and communities who participate in this work.

Shape and content
The shape and content of the document has been developed in consultation with a steering group of people from a wide range of backgrounds and diverse experience.

It begins with an overview of the benefits and scope of public involvement and outlines elements of good practice. It then sets out the building blocks for developing a strategic approach to public involvement in the planning and delivery of services.

The final part of the publication is a set of examples of good practice with contacts for further information. The examples have been structured to illustrate public involvement in relation to the functions of the new primary care organisations. These have been gathered both from Scotland and elsewhere. There is a bibliography of relevant texts and sources of information.

Throughout the publication, boxed sections are used to address key points and give useful checklists and tips. Many of these boxes contain quotes from other work, and, where this is the case, the source of the work is identified.
Developing primary care through new collaborative working methods is at the heart of the government’s commitment to the National Health Service in Scotland (NHSiS). The involvement of the public as partners in the development of primary care is integral to this.

**Policy Context**
The context for this publication has been set by the Government’s White Paper *Designed to Care*, the White Paper *Towards a Healthier Scotland* and the Priorities and Planning Guidance for the NHS in Scotland 1999-2002. By placing patients at the centre of health service delivery and planning, *Designed to Care* sets out the following basis for providing better services to patients:

- providing information to patients;
- improving the co-ordination and reliability of services;
- promoting the involvement of individual patients in their own care and treatment;
- improving the effectiveness of care;
- making health services more accountable and responsive to the public; and
- promoting openness.

It also seeks to develop the role of the NHS in areas which have previously been less well developed by setting core objectives to:

- improve health and reduce inequalities in health and access to services; and to
- promote partnerships between the NHSiS and other organisations whose work can help improve health and the quality of services.

**Clinical governance**
In *Designed to Care*, the government stated that trusts would be given a statutory duty for the quality of care provided: this is known as clinical governance. Trust boards will have to satisfy themselves that there are systems in place within their organisations which ensure that staff have the necessary qualifications and skills, that good practice is shared and put into practice, and poor performance recognised and acted upon.

Trusts will be required to ensure that patients and the public are fully involved in quality activities at every level (NHS MEL (1988)75 on clinical governance). Definitions of quality must include the views of patients, carers and other health service users, including:

- defining standards against which quality will be measured;
- monitoring service provision; and
- evaluating outcomes.

*Designed to Care* to redesign services from the perspective of patients - and to reflect this in all aspects of health service planning - requires finding out what patients and communities want; and consulting them over proposals for change.

*Health Bill 1999*

It shall be the duty of each Health Board, Special Health Board and NHS trust to put and keep in place arrangements for the purpose of monitoring and improving the quality of health care which it provides to individuals.
Primary care trusts: new organisations, new opportunities

The development of primary care is an essential part of meeting the objectives of the health service as a whole. A crucial feature of primary care is the close on-going relationship between staff and the local community, both as patients and as members of the public. The challenge is to develop the full potential of public involvement in primary care in the new organisational context of the primary care trusts.

Progress towards more effective involvement of the public will be a key feature of the performance management of boards and trusts. The new primary care trusts and local health care co-ops supporting their constituent general practices have a pivotal role in encouraging public involvement. Their development offers a chance to be imaginative about structures and ways of working, and to build in the mechanisms and develop the culture of effective public involvement from the outset. There has never been more potential to develop an integrated approach to public involvement and partnership within primary care.

The potential of the emerging new organisations exists within a context of organisational uncertainty and diversity. In particular, local health care co-operatives are still developing and will reflect local situations, which differ across Scotland.

We have used the key functions of the trusts to look at how to make public involvement central to their organisation. The final section, giving practical examples of how to involve the public, seeks to build on this approach and reflects these functions, which are inter-related and overlap.

Designed to Care describes the roles of the PCTs as follows:

- providing support to general practice in delivering integrated primary services;
- formulating primary care policy and directing future development of services;
- working with others to develop Health Improvement Programmes, to implement local health strategies, through LHCCs, and to deliver their Trust Implementation Plan;
- developing integrated care pathways between primary and secondary care;
- stimulating improvements in quality and standards of clinical care;
- addressing health inequalities; and
- developing teamwork within primary care.
Benefits of public involvement

The benefits of public involvement in primary health care are wide ranging, and of considerable significance both to NHS staff and to patients and the public. They include the following:

**Appropriate, responsive and effective services**
Responsive services are more likely to be appropriate and effective.

**Accountable services**
Mechanisms which increase or promote dialogue between service providers and service users encourage a greater accountability and openness on the part of the service provider.

**Improvements in staff and patient morale**
Professionals gain confidence from knowing that services have taken account of the views of service users, and those users feel more positive about a service which they feel they have some influence over.

**Developing alternatives**
Public involvement can be one way of challenging the traditional or accepted view of what is important in health services, and can be an agent for change. It can also support and facilitate change.

**Addressing health inequalities**
Involving local communities in decisions about the planning and delivery of services is one of the most effective ways of identifying and addressing health inequalities.

**Empowerment and strengthening communities**
When people are encouraged to participate in decision making, they have a clearer sense of local ownership and commitment to health services.

---

**Overview of Public Involvement**

**Box 1: Benefits of Public Involvement**

**Benefits to patients**
- Better outcomes of treatment and care
- An enhanced sense of self esteem and capacity to control their own lives
- A more satisfying experience of using health services
- More accessible, sensitive and responsive health services

**Benefits to the NHS**
- Restoration of public confidence
- Improved outcomes for individual patients
- More appropriate use of health services
- Potential for greater cost effectiveness
- Contribution to problem resolution
- Sharing responsibilities for health care with the public

**Benefits to public health**
- Reduction in health inequalities
- Improved health
- Greater understanding of the links between health and the circumstances in which people live their lives
- More healthy environmental, social and economic policies

**Benefits to communities and society as a whole**
- A greater sense of ownership of the NHS
- Improved social cohesion
- A healthier democracy - reducing the democratic deficit
- A health service better able to meet the needs of citizens
- More attention to crosscutting policy issues and closer co-operation between agencies with a role to play in health improvement.

_Amended from In the public interest NHS Executive et al 1998_
Levels of involvement

Building a successful partnership with the public will involve different levels of activity, all of which can be beneficial. The simplest way to describe these levels is to think of three stages: communication, which is about engaging in a meaningful dialogue with service users; consultation, where service users are asked for their views; and partnership, where service users and carers work as equals with professionals.

To avoid confusion, it is always best to explain clearly what type of involvement is to be undertaken.

Box 2 shows the range of involvement in more detail.

<table>
<thead>
<tr>
<th>Box 2: Working with the community may mean a whole range of different activities and levels of involvement</th>
</tr>
</thead>
<tbody>
<tr>
<td>• <strong>Information giving</strong>: publishing information on the existing services and structures of decision making, for example, information sheets, a helpline, service directories or regular media information slots.</td>
</tr>
<tr>
<td>• <strong>Gathering information</strong>: getting people’s views on existing services and listening to their views on their wider health needs and concerns, for example, surveys, focus groups or attending community meetings.</td>
</tr>
<tr>
<td>• <strong>Consultation</strong>: asking people to comment on a particular plan or proposal, for example, a hospital trust application or the plans for developing a hospital-based service into community-based premises.</td>
</tr>
<tr>
<td>• <strong>Involvement in policy development and decision making</strong>: getting user or community involvement directly within the management of the organisation, for example, a user panel set up to develop training and quality standards for professional staff, user representatives on service committees.</td>
</tr>
<tr>
<td>• <strong>Joint working</strong>: working with users or local people on an equal basis to develop joint projects or new forms of services, for example, designing a new mental health information pack, a local health forum initiating a community health project.</td>
</tr>
<tr>
<td>• <strong>Community or user control</strong>: the service provides a grant or enters a service agreement with a user or community organisation to develop their own initiative, for example, a grant is given to local parents to set up a helpline.</td>
</tr>
</tbody>
</table>

*P Taylor 1996*
**Who should be involved?**

People relate to the health service in many ways. Service users have direct experience of service provision which provides a unique and often essential input into the process of planning and monitoring of services. Citizens have an interest in the ways in which public money is spent and the pattern of services which is potentially available to them and others. Carers and parents bring their own perspectives and concerns.

It is important to be clear about who the participants are in different settings, and why attempts are being made to involve them. People can be involved as individuals or as representatives of groups and, depending on the initiative, you may wish to involve:

- the local community;
- people with a long term medical condition;
- carers;
- occasional service users;
- community groups;
- communities of interest (for example disabled people, people from minority ethnic groups, residents of a particular area);
- or
- the population using a health care or other service.

**Good practice in involvement**

Any public involvement exercise should be underpinned by the following values:

- Transparency
- Social inclusion
- Partnership
- An understanding of representative participation

**Transparency**

It is important that the aims of particular initiatives are clear and transparent to all those involved. The organisation should develop a clear policy and strategy for public involvement. The partners in any particular activity should understand the reason for their involvement, the scope of the exercise, the issues to be addressed, the decision making process and the subsequent use of outcomes.
Box 3: Representativeness

Do Attempt to engage a range of views

Do Maintain up-to-date lists of local groups, their membership profile, interests and expertise so that you can call on a range of views to inform an initiative

Do Look at whether the issues raised, even by individuals or a minority group, indicate a problem that needs further investigation and action

Do Monitor who is involved in your organisation’s initiatives and attempt to identify groups who may not be represented, or only poorly represented within routine public involvement activities

Do Carry out special targeting of under-represented groups to ensure that they have appropriate and adequate opportunity to inform individual initiatives and wider organisational decision-making strategies.

Don’t Use the issue of representativeness to deny public input

Don’t Criticise single individuals or groups for “failing” to embrace all view points

Don’t Rely on a very small number of patients, local people or user/community groups to participate in your organisation’s user involvement initiative

Don’t Reject suggestions or criticisms by questioning the authority or representativeness of their source

Kelson 1997

Social Inclusion
Involvement initiatives should be inclusive. This means taking account of the social and structural barriers which affect people’s ability to participate. These could include issues of physical access, for people with a physical disability, and resources may be needed to enable people who cannot afford transport or child care to take part. Information should be provided in clear and accessible language, in appropriate formats for a range of needs. Procedures should be designed to encourage involvement, and this may mean avoiding formal procedures. Events should be held in local or neutral venues.

Partnership
Work on developing healthier communities depends on working in partnership with others. Within the NHS partnerships must be developed between health boards, trust and primary care providers. Health service staff also need to build relationships with other organisations in both the statutory and the voluntary sectors. There are many other bodies working on issues that affect public health. For example, many local authority services have clear health implications, and involve collaborative working. Community Planning Partnerships and Social Inclusion Partnerships have health components, and Healthy Living Centres are being encouraged with funding from the Lottery. Participative approaches are particularly important in areas of deprivation where the factors that impact on health are complex and wide ranging.

It is important the primary care trusts support partnership working at all levels, and provide training where this is needed.

Representative participation
People as patients, carers, parents and citizens have a range of experiences and bring unique perspectives to the development of health services.

Many service providers express concern about whether participants are representative. While some participants can claim to be representative, others should be included simply because their experience is likely to be typical of that of other service users, carers or parents. Lay knowledge is a form of expertise in its own right. Concern that individuals and members of users groups are not representative is never a reason for denying involvement but may be a reason for reconsidering the purpose and process of involvement (see box 3).
### Appropriate methods and support

Appropriate methods and support are key to the effectiveness of this type of work. They include:

- adequate resources and support
- the selection of appropriate methods
- time and timing
- action on the outcomes of involvement.

### Adequate resources and support

Public involvement needs resources. Even the simplest consultation exercise involves staff and participant time and costs money and effort: this time has to be allowed for in work and family schedules.

Patients, their representatives or members of the public may need support to play an effective part. This might involve providing interpreters for people from ethnic minority groups, or advocates for those with learning difficulties. Where people are taking part in committees as lay representatives they need training and support. These concerns are also important to remember when working with voluntary agencies. They may need support and funding to increase the level of public involvement. The support needs of health service staff who may be asked to develop new ways of working also have to be considered.

In summary, the development of involvement as an integrated and ongoing part of the organisation means that the support, training and development of workers, stakeholders and voluntary organisations should be part of the overall strategy and must be realistically resourced.

### Appropriate methods

A wide range of approaches to public involvement exist. To be effective, initiatives which involve the public or patients must be extremely clear about what their aims are. Methods must be chosen carefully to ensure their appropriateness, both to the aims and to the particular group of the public involved.

Existing groups such as community health projects, local health councils or community care forums can be used and developed as facilitators of local involvement.

There is a growing body of literature and material available exploring appropriate methods of working with particular groups, for example children, those with learning difficulties and frail older people. Examples are given in Appendix 1 and in the bibliography.
**Time and timing**
Always try to involve the public as early as possible. Involving people in agenda setting increases transparency.

Remember, when organising meetings and deadlines, that participants and voluntary organisations have lives and structures of their own. As representatives of other organisations, the participants may have to report back to committee structures, which may then have to refer to their membership before responding to the consultation. While consultation may be slow, the breadth and quality of the consultation makes it worthwhile. Not allowing enough time for consultation can lead to poor feedback and complaints about inappropriate services. Community organisations need to know the timescales of trust planning cycles to allow them to participate effectively.

The time of meetings can also be important. It should not be assumed that everyone can attend meetings during working hours, and school holidays are often times when involvement of the community becomes difficult.

**Outcome**
It is important to be clear about what the outcomes of the involvement will be. The results of the activity should be fed back to participants along with a description of action which has resulted from the work. Reinforcing participation through publicising developments in practice is very important.

Conversely, failure to report back can create cynicism about the process. Even if no action is, or can, be taken, people should be kept informed.
Box 4: Health Councils

Health councils are committed to effective public and patient involvement. They are key stakeholders in this agenda. They have a statutory duty to “represent the interests of the public in the NHS”. They do this in many ways including:

- developing influential strategic relationships with health boards and NHS Trusts;
- establishing and maintaining consultation pathways and community networks;
- providing information and advice about the NHS; and
- keeping under review NHS services.

Health councils are engaging with PCT boards and with emerging LHCCs. Some health councils are able to sustain active involvement with LHCCs while the larger health councils have a more facilitative and strategic role. Local responsiveness means the island health councils have different, but no less effective, relationships with primary care.

Health councils are also a major resource of patient and public involvement know-how - what works best, where and why. This is built upon their extensive local knowledge and networks with other community and patient groups.

From their experience they know:

- that there is a requirement for high quality accessible information which presents a “joined up” picture of the NHS;
- effective public involvement must be an ongoing two way process which builds on existing successes and structures, is ongoing and sustainable;
- time and resources need to be safeguarded and directed to this function; and
- all agencies need to work collaboratively.

Most health councils also have a wealth of experience in:

- research and survey work - from the patient’s perspective;
- writing and editing patient/public information;
- assisting complainants; and
- presenting a lay perspective to professionals.
Public involvement cannot be viewed as an add-on to existing work. It must be integral to the ethos of the organisation, built into the culture and responsive to both the public’s needs and to those of the organisation. Examples of involvement already exist in different forms in the services which will in future be provided by PCTs. If public and user involvement is to make a difference it has to be more than just a collection of projects and experiments. It has to be part of the core set of beliefs of the agency, central to its mission statement and actions.

Within the PCT, a culture should be developed and sustained which is committed to public involvement throughout the organisation. A vision of effective involvement should be actively promoted, and this vision should be complemented by a recognition of the need for allocated resources in terms of staff time and budget to sustain and develop activity.

Whilst it is important that the strategic development of public involvement reflects local circumstances, the core elements of the strategy, its principles and values, and the process of its development will be common to all trusts. This section provides a framework for developing and implementing a strategy for public involvement.

Steps to a strategy
Planning for public involvement should be a dynamic process involving many partners. The development of participative work can be an educational process for organisations, patients, public representatives and communities. It can create new links, develop larger projects and collaborations from the successes of smaller ones, and from these build confidence in the ability of collaborative work to provide useful new policy directions and models.

New approaches to primary care will gradually develop within PCTs, and the exact shape of services within the areas of general practice and primary health care services are still unclear. It is, therefore, difficult to lay down a rigid framework for the development of public involvement. There are however a set of steps that can provide the framework to allow this work to develop (Box 5).
Developing the vision, building the policy

Developing a vision about the benefits of public involvement within an organisation requires a development team led by a senior manager. Designed to Care requires all health boards and trusts to give a designated member of the executive team the responsibility of ensuring that the public and patients are involved in the planning of services. This person needs the support of the PCT board, and should work closely with any non-executive trustee with a particular responsibility or interest in this area.

The vision should be shared between the trusts, health board, local authority, the public and communities. Because the PCT will be developing policy which underpins the way primary care

---

**Box 5: Steps to public involvement**

**Vision / Policy**
An identified vision of public involvement to which the organisation is committed. A policy which lays out the concepts and principles has to be developed to build this work upon.

**Steering and developing the strategy**
To support the strategy, a multi-disciplinary, participative steering group is needed to develop the work. The membership should reflect the ethos of participative involvement and be drawn from a range of organisations for example LHCs, voluntary and community groups.

**Audit of current practice**
Audit of practice in the organisations and communities that are involved with the trust. A preliminary audit will help to map skills, experience and activities.

**Development and support of a range of activities**
Building on the work already taking place, supporting early winners and reflecting the work back into the organisation and the community at all times. Identify organisational arrangements for taking involvement forward, the levels at which it takes place and who will be responsible. Outline a training program to make staff aware and to develop their commitment to the policy.

**Monitoring, evaluation and feedback**
Monitoring structures for regularly reporting the work have to be set up and used. The evaluation of progress towards targets will require the use of a range of qualitative and quantitative measures. The successes and failures of the work should be aired and discussed and used to shape the next arm of the planning process.
services are provided locally, it is important that the vision of public involvement is promoted with primary care providers. It will develop and evolve as the organisation and community become more skilled in involvement.

The following approaches can be used in developing a vision for public involvement:

- consultation documents circulated to service organisations and community groups;
- briefing seminars for management and workers;
- public seminars to explore new visions for primary health care;
- community-based vision workshops for both community members and service providers;
- discussion of public involvement in local mass media;
- developmental workshops across agencies to explore the benefits of collaborative work;
- seminars synthesizing ongoing work already using this approach.

The policy that will emerge in each PCT, based on this vision, will reflect local circumstances. However common elements of policies can be identified. A public involvement policy should have:

- a statement of commitment;
- a broad definition of users;
- why users are being involved;
- how users will be involved; and
- principles which should govern user involvement, for example equal opportunities and principles of good practice.

An example of a policy might be as follows:

This organisation is committed to ensuring that internal and external users are involved in the planning, delivery, development and evaluation of services.

Our aim is to............. (define level of user involvement, for example inform, consult, empower)............. in order to ensure that our services are responsive to users.

We aim to ensure that everyone who wishes to be involved can become involved in ways which are appropriate and responsive to their needs, eg. .............

Fleming and Golding 1997
Steering and developing the strategy

The clear direction given by senior management in the vision statement and policy document has to be matched by the development of an effective framework to put the vision into practice.

To develop and support this framework, a multi-disciplinary, participative steering group should be set up. The membership should reflect the ethos of participative involvement and be drawn from a range of sectors and organisations, for example, primary care staff, health promotion, local health councils, voluntary and community groups.

Development team

Putting the framework into effect and actively promoting patient and public involvement will be the responsibility of the development team which developed the vision. It is crucial that the team has effective input into strategic development across the whole trust, and direct links with senior managers. Line management of the team should be by the chief executive or the director responsible for planning.

It should have clear terms of reference with scope to link into and between participating agencies and the community. The skills, contacts and support provided by this team can be drawn on by LHCCs and other primary care providers as required. The team should have a set of specific tasks, these could include:

• taking responsibility for developing public involvement across the organisation;
• organizing the development of consultations;
• coordinating the consultation process;
• organizing a communication and public relations strategy for the policy and carrying it out;
• educating participants about the aims and goals of the plan;
• developing pilot projects;
• responding to difficulties;
• evaluating initiatives.

Audit of current practice

One of the first steps for the development team should be to carry out an audit of the extent of public involvement within the trust area, at health board or community level, in relation to primary care, more general health projects and initiatives of the
local authority. It should identify gaps and opportunities, as well as the scope for development at all levels. The team should consider how the structures and processes of the new trust and its constituent LHCCs can facilitate and encourage public involvement and access.

In particular, the audit should review, at the very least:

- existing procedures for working with the local health council;
- existing procedures for involving the public by locality or care group;
- existing user or care groups;
- local government consultative procedures and mechanisms;
- local health council activity; and
- community health projects.

**Box 6: Organisational checklist for promoting effective user involvement**

Does the organisation have a written strategy for public involvement?

Is there a budget for public involvement?

Are there named, trained personnel with responsibility for public involvement and clear lines of accountability and responsibility for public involvement?

Is the organisation committed to, and can it demonstrate evidence of:
- acting on the results and recommendations of public involvement initiatives?
- providing full and timely feedback to participants?
- explaining, when necessary, why recommendations could not be implemented?

Is public involvement an ongoing and integrated component of organisational activity (rather than a series of occasional “one off” initiatives)?

Does the organisation maintain comprehensive, up to date lists of local user representatives, user and community groups and organisations?

Does the organisation liaise with existing local resources (for example local authority, local health councils, the Council for Voluntary Services, Citizen’s Advice Bureau) to identify local groups and complementary projects to inform the organisation’s own activities?

Do public involvement initiatives within the organisation complement and inform:
- each other?
- other relevant policy and decision-making activities at all levels?

Is training available for staff and involved users? (for example in the issues and principles public involvement; in public involvement methodologies, networking and consultation skills?)

Are user trainers involved in training health service professionals (for example to raise professional awareness of issues of key relevance to users and carers)?

*M Kelson 1997*
Development and support of activities

Based on the trust’s vision and policy, guidelines should be produced for different sectors. They should clarify the trust’s position on public involvement, identify organisational arrangements for taking involvement forward, the levels at which it applies and identify who will be responsible for this. They should give clear guidance about expected actions and outcomes and show how this work fits into an overall plan. They should also explain to members of the public what it means for them.

The guidelines will only be part of the overall activity in the area of involvement. By providing support and training for staff, the trust will reinforce the understanding of this issue across the organisation. The fact that participation and involvement are a meaningful part of the organisation’s outlook will become clear as staff and community are trained and supported. The time, planning and support needed for this work will be made clear in the guidelines.

Involving the public means a real change of culture for the health services in general. The NHS has a fine record of working for people, providing expert services and care: moving towards working with the public will need changes in organisational culture and new skills for managers and staff.

Most public involvement work takes time to develop and achieve success. The work should not be jeopardised by failing to provide support or by demanding too much too early.

Don’t raise the public’s expectations and don’t put too much pressure on the lead workers. Plan for small and early successes to gain support both within the organisation and the participating groups.

The development of activities does not necessarily mean new work. There will be examples of involvement and participation happening within the health board area, and the support and development of this work should be seen as part of the broader development of activities. Local community health projects and work with local health councils are examples. A range of projects tackling inequalities in health in collaboration with the local authority will also be fruitful grounds for the development of good practice. The trust should forge links with all such projects.

Taylor et al 1998

Crossing professional boundaries and making contact with a wide range of people may not be easy, but it is essential to success and management support is important here.
In communities where this infrastructure is not developed, an important step in the development of an involvement strategy is community and organisational development to support it. The trust can play an important role in developing this community infrastructure in collaboration with other agencies.

The hierarchy of health outcomes shown here plots community-based work which can tackle issues that communities identify as important. Working with communities on these appropriate issues is a good way to develop partnership and involvement skills for all participants.

**Monitoring, evaluation and feedback**

All the systems, procedures and initiatives which develop need to be regularly monitored and reviewed with service users and members of the community. There is no single model for public involvement and therefore the types of evaluation and monitoring strategies will vary.

**Monitoring**

Monitoring in the context of public involvement is the on-going checking of progress against a plan. Information must be collected to provide a regular check on what is happening compared with the intention of the project or initiative. Monitoring is a value-free activity concerned with assessing what has happened over time.

**Evaluation**

Evaluation, on the other hand, is concerned with making an assessment of the processes and the outcomes of initiatives or projects. It judges the value of an activity according to criteria which are established at the start of the activity. The outcomes expected, and the methods of evaluating projects should be made clear at the start. The views of all the stakeholders should be taken account of in developing these criteria, and in carrying out the evaluation.

**Feedback**

It is important to be explicit about the results of the public involvement. This is not only a matter of courtesy to those who have invested time and effort in the process but also promotes the confidence and trust which is the basis of a sustainable relationship. Feedback can be achieved through newsletters, press releases, and regular reports to all those taking part. This process should be seen as an important part of the trust’s communication strategy, both internally and with members of the public.
Box 7: Criteria For Successful Public Involvement

Be clear
You should ensure that you, your colleagues and the partner organisations with whom you work (for example LHCs) know precisely the meaning of the words you use to define the purposes of specific public involvement initiatives mean (for example consult, inform etc.). This can be accomplished by:

- clear and consistent definitions
- clear understanding of the rationale, scope and scale of the work.

Develop a policy
You should possess a strategic public involvement policy. You will know you have one if:

- public involvement is seen to be built into all strategic processes
- you have ways of measuring the impact of public involvement
- there are clear lines of accountability and responsibility for this area of work.

Know the big picture
You should appreciate that successful public involvement is not a series of stand-alone or one-offs, but an interlinked, ongoing body of work embracing many types of activity.
You will know that this is happening if:

- there is evidence of a continuum of different activities
- there is an overview of public involvement activity—a ‘big picture’ which spans a reasonable time frame

Define outcomes
You need to be clear about what you want to get from public involvement and how its findings will be acted on. This will happen if:

- its rationale is written down and understood
- there are clear statements on: time frame, outcomes and action
- feedback-points within the organisation are identified
- there is a clear articulation of limitations of policy and specific initiatives.

Go public
You need to ensure that you go public with what you are doing. The existence of an integrated communications strategy, where the implications and outcomes of the authorities initiatives are communicated to all appropriate audiences, will ensure that this happens as a matter of course.

Measure performance
You need corporate and personal performance measures for public involvement.
You will do this if you have:

- public involvement benchmarks built into strategic documentation
- performance in public involvement built into personal performance assessment criteria
- processes in place to amend policy / reward performance.

Peer review in public involvement, Oxfordshire Health Authority 1996
There is potential for public involvement at all levels of primary care from formulating primary care policy to addressing health inequalities, and a range of methods can be used. Involvement can, and should, happen at all levels of the functions of the trust:

- providing support to general practice in delivering integrated primary services;
- formulating primary care policy and directing future development of services;
- working with others to develop Health Improvement Programmes, to implement local health strategies, through LHCCs, and to deliver their Trust Implementation Plan;
- developing integrated care pathways between primary and secondary care;
- stimulating improvements in quality and standards of clinical care;
- addressing health inequalities; and
- developing teamwork within primary care.

Local health care co-ops will have the objectives of:

- providing services to patients;
- developing plans which reflect clinical priorities for the area, taking account of specific health needs;
- supporting health improvement;
- improving the quality and standards of care; and
- supporting the development of extended primary care teams.

This section addresses the range of ways in which public involvement can take place in these areas. The examples given illustrate the processes and methods by which involvement can be developed in primary care. Much of the work takes place with organisations like LHCs, patient and carer groups and community organisations that have already established links with primary care providers and health boards.

Finally, primary care providers themselves have a role to play in developing public and patient involvement. Techniques about which there is already considerable knowledge include patient participation groups, patient surveys, and health panels. In addition, the use of volunteers as a vehicle for public involvement is being explored. Advocacy is an important means to facilitate the involvement of people who would otherwise find it difficult to participate.

It is hoped that the exchange of good practice can be facilitated through an interactive web page linked to this document on the internet.
Working in Partnership with others to develop Health Improvement Programmes, and to deliver their Trust Implementation Plan

Oxfordshire Health Authority has a well developed public involvement strategy which is integrated with its communications strategy. A wide range of methods are used across all of the activities of the authority as can be seen from their public involvement portfolio on the opposite page. The use of a range of approaches to involvement can be seen, with focus groups and questionnaires and the use of community organisations featuring clearly. The health authority has also developed a large citizens’ panel, sharing this with the city council and Thames Valley Police.

A collaborative approach to involvement can be seen throughout the work of the health authority. Those charged with making decisions about the development of health services in Oxfordshire find that involving the community gives greater public confidence in their decisions and a greater understanding of the views, concerns and priorities of the population they serve. The profile of public involvement is increasing both within the authority and outside. Oxfordshire Health Authority is developing a culture which is responsive to the public (see Box 8).

Another interesting example of strategy development is West Sussex Health Authority’s “A Partnership with the Public, Patients and Carers–Building a Collaborative Strategy”.

Formulating primary care policy and directing the future development of services

There are many examples of needs assessments at community, locality and health board level. These range in method from postal questionnaires, user panels, and rapid appraisal, to combinations of methods. The key issues for PCTs, and LHCCs in needs assessment are:

- how patients, carers and local people can be involved in assessing the health needs of their communities;
- how professionals can work together with local people as well as LHCCs and voluntary sector organisations to take a holistic approach to health needs;
- how to identify gaps in existing services, in particular for groups whose needs may not yet be recognised.

Contact
Caroline Vass
Public Involvement Manager
Oxfordshire Health Authority
01865 226520

SNAP
Needs Assessment in Primary Care: a rough guide, Edinburgh 1998
**Box 8: Oxfordshire Health Authority Public Involvement Portfolio**

<table>
<thead>
<tr>
<th>Health Strategy and Purchasing Plan Consultation</th>
<th>Formal consultation on local health needs and plans with interest groups and the general public. Detailed analysis of responses publicised and circulated widely.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children’s Services Strategy</td>
<td>The Health authority working with other organisations will develop 3 youth panels across Oxfordshire to gain the views of young people on the planning and development of children’s services. The youth panels will integrate with the work of Health Promotion and Health of the Young Nation, and feed into discussions with the Trusts.</td>
</tr>
<tr>
<td>Physical Disabilities</td>
<td>Following consultation on the physical disability strategy, further carer and user involvement will be required. Conferences to be arranged to feed back responses to the consultation process and agree next steps.</td>
</tr>
<tr>
<td>Local Voices—GP fundholding and Public Involvement</td>
<td>The Authority will work with 6-10 primary health care teams providing advice and facilitation on involving patients/clients in service planning.</td>
</tr>
<tr>
<td>Coronary Heart Disease</td>
<td>A Care Programme Approach to coronary heart disease services is being implemented in Oxfordshire. Public involvement is concentrating on rehabilitation services and information. Focus groups and questionnaires will be used.</td>
</tr>
<tr>
<td>Learning Disabilities</td>
<td>Initially exploring ways of involving users.</td>
</tr>
<tr>
<td>Mental Health</td>
<td>Initially exploring ways of involving users.</td>
</tr>
<tr>
<td>Provider Networks</td>
<td>Links with Trusts will be fostered. Oxford Radcliffe, Mental Healthcare, Learning Disabilities, NOC. Radcliffe Infirmary, Horton Community Trust and Primary Care.</td>
</tr>
<tr>
<td>Ethnic Minorities</td>
<td>Consultation through established community groups for example Oxford Multicultural Action Group. Explore expanding this area by working with other groups including the Rural Racism Forum.</td>
</tr>
<tr>
<td>Training Carers</td>
<td>The specific needs of carers will be addressed through a training programme for users and carers recruited via the Carers Centres/Forum. The programme will develop the skills of carers in planning and evaluating health and social care needs and services. Links with Trusts will be fostered.</td>
</tr>
<tr>
<td>Talkback</td>
<td>Panel of 1000 drawn from Oxford City have been recruited for consulting on services provided by Oxfordshire Health Authority, Oxford City Council, Thames Valley Police.</td>
</tr>
<tr>
<td>Priorities Forum</td>
<td>Workshop organised to explore ways of involving the public in priority setting for Oxfordshire Health Authority.</td>
</tr>
<tr>
<td>Peer Review</td>
<td>Evaluate the Public Involvement Programme through peer review using the performance indicators for successful public involvement.</td>
</tr>
<tr>
<td>Maternity Services and Women’s Health Forum</td>
<td>Study day in January to share good practice. Work to be picked up on women’s perceptions of maternity services and feed into Womens Health Forum.</td>
</tr>
<tr>
<td>Cancer Services</td>
<td>This work will be long term in response to Calman on Cancer. Initially working on breast cancer services. Focus Group discussions for users and providers of services.</td>
</tr>
<tr>
<td>Cancer Information in Primary Care</td>
<td>Mapping cancer information in Oxfordshire and assessing how patients understand the key messages.</td>
</tr>
</tbody>
</table>
Strathkelvin Health Needs Appraisal and Strategy Project
This project was funded from 1994-97 with the aim of improving the health of the patients of the seven practices which participated. The total population involved was 43,710. A local strategy based on the needs identified has been produced and will be incorporated into the planning process in co-operation with other agencies.

Needs were assessed using three methods:

- a locality health profile was produced using socio-economic, demographic and epidemiological data;
- a professional perspective of need was gathered from interviews with health social and allied professionals as well as key informants from special groups;
- a service user perspective of needs was developed through interviews with 91 respondents drawn randomly from all seven practices.

Many corresponding needs were identified by both professionals and users such as transport, access to services, lack of alcohol services and the need for targeted services for those most in need.

Local community workers and those with a particular knowledge of the area and its problems were visited and interviewed, and a small randomly selected sample of the local population was interviewed. The benefits to the practice have been a greater understanding of local needs, improved communication with other professionals and improved knowledge of other services. The benefits to patients are service planning that is more responsive to local needs and improved communication between the community and local professionals.

Kyle Pilot Rapid Appraisal Project
A primary care led needs assessment using rapid appraisal was developed. The project was carried out in Kyle of Lochalsh. A multi-disciplinary team was formed consisting of the local health visitor, the area team leader for social work and the area health promotion adviser. A research assistant was co-opted onto the team for the information gathering phase.

A semi-structured interview schedule was developed and key informants were identified. They included people with professional knowledge about the community and people with

Contact
Dr Ann Doubal
18 Union St
Kirkintilloch

Contact
Janet Shaw
Health Visitor
Skye and Lochalsh Division
Highland Communities NHS Trust
local knowledge. Residents were selected to represent various age groups and two group interviews were also carried out, with teenagers and over 65’s. A list of outcomes from the group and individual interviews was sent to informants from which they prioritised themes and problems.

A range of improvements to services have either been implemented or are under discussion, including the setting up of a mental health ‘drop in’ facility in the village hall, the appointment of a community education worker, a drugs roadshow and the appointment of a school nurse.

**Other interesting reports:** Local Voices–Local Lives: the story of the Kendoon Community Health Profile This report of a community based questionnaire survey is of interest for the description of the process of involvement and the extra outcomes of the work in terms of the development of broader community action. It has a video which accompanies the report.

**Developing plans reflecting clinical priorities and specific health needs**

There are many examples of the involvement of service users and carers in service planning and development, particularly in areas like mental health services and maternity services. People with long term medical conditions are a particularly important source of input into the planning of services, and the Patients Influencing Purchasers Project in England involved the Long-term Medical Conditions Alliance working with health authorities in six areas to develop an effective partnership between service providers.

Highland Health Board has an “Involving People” Group whose objectives are to include lay involvement in needs assessment, service evaluation and service design. The aim of this project is to refine and implement a model of partnership between the health board and people with long-term medical conditions, working together to commission quality health care services which meet the needs of patients using them. The objectives are:

- to identify common problems experienced by patients in four areas of long term medical conditions;
- to use the feedback from the patients to improve the quality of services commissioned;
- to determine the effectiveness of this technique for use in Highland.
The four medical conditions under consideration are breast cancer, epilepsy, acquired brain damage, and multiple sclerosis.

The exploration of patients' experiences will be through focus groups supplemented if necessary with depth interviews with parents and carers. The topics covered include the range and quality of service and what patients need from the health service.

**Care of the elderly and mental health services**

This was a Scottish Office funded project looking at involving users/carers in a locality group of GPs. The project was carried out by Highland Community Care Forum.

Highland Community Care Forum was asked to evaluate the pilot co-operative's impact on care of elderly and mental health services. This work included various methods from rapid appraisal to population surveys.

Direct user/carer involvement in the executive-level decision making of the pilot local health care co-operative was achieved. Public awareness of the LHCC and primary care developments was raised, as well as greater GP awareness of community organisations.

LHCCs hold the potential as an effective forum for change in the community. This potential depends on co-operatives having sufficient staff time and resources to allow GPs to develop their links to patients, community groups, develop plans for change and consult the community on them. In this particular case, it was found to be easier to effect change in primary care and dialogue with GPs once they had formed a collective body.

In Fife, innovative work with panels of frail elderly people has demonstrated how the views of an otherwise excluded group of service users can be obtained. Panels have discussed primary health care issues, and the local healthcare trust has found the panels to be a useful source of feedback.

**Contact**

Susan von Reusner/
Sheena Munro
Highland Community Care Forum
01463 718817

**Contact**

Age Concern Scotland
152 High Street
Kirkcaldy
01592 204 273
Providing services to patients

Taking public involvement to its extreme, it is possible to develop services that involve lay people in their delivery.

Peer support in Breastfeeding

This Breast-feeding Initiative has taken on 40 volunteer breast-feeding counsellors across three localities in Glasgow to provide peer support for breast-feeding mothers. Funded via the locality planning scheme in the three areas the aim of the initiative is to increase rates of breastfeeding to six weeks and over in each locality. The project uses the model of the Easterhouse Breastfeeding Promotion Project of training local women to act as advisors and supporters to their peers, allied to good networking and communication across all parties working in the area.

Stimulating improvements in quality and standards of clinical care

There is work going on in various areas to promote improvements in quality. Professional organisations including the Royal College of General Practitioners (RCGP) are helping their members to address issues like clinical governance, and are developing quality assurance mechanisms. Public and patient involvement in audit, clinical guideline development, research and clinical outcomes work should be encouraged and promoted.

There are examples of user involvement in SIGN guidelines including Alzheimer’s Scotland - Action on Dementia and the British Diabetic Association’s contribution to clinical guidelines for GPs.

Feedback from patients in primary care

A range of qualitative and quantitative research methods can be used. A simple and cheap tool is “Ask the Patient - an action pack for GPs to get feedback from patients”. This was designed from the patient’s perspective and can be used by non professionals.
Local Health Councils and monitoring
Local health councils are involved in surveys and research into patients’ experiences of service provision in all health board areas, using a wide range of methods.

For further information contact your local health council, or refer to the SAHC publication.

Patient Participation Groups
A number of Scottish GPs and their practices have established these groups. They can be a simple, relatively cheap and an encouragingly effective way to involve broad groups of practice populations. Royal Colleges, including the RCGP Scottish Council, are also working towards a national Patient Participation Group.

Communication and information provision
The new PCTs have a responsibility for informing the public about the way services are provided and what the implications are for patients. This communication should be part of an active dialogue between the trust, service providers, the public and patients.

Communication covers a range of areas and many health boards and authorities already have broad based communication strategies that include involvement as key values (see Oxfordshire example on p 30).

Good shared communication is an important foundation for effective public involvement in primary care. It is a developing field in the NHS, but much of the work that has gone under this title in the past has in fact been more about information management than shared dialogue. Designed to Care has given a real opportunity to build strong communication into the new primary care trusts’ practices and systems. This will take time to implement in the NHS and will require support and training at all levels.
**Community Development**

*Community Development is:*

...directed in particular at people who feel excluded from society. It consists of a set of methods which can broaden vision and capacity for social change, and approaches, including consultation, advocacy and relationships with local groups.

It is a way of working which is informed by certain principles which seek to encourage communities – people who live in the same area or who have something else in common – to tackle for themselves the problems they face and identify to be important, and which aim to empower them to change things developing their own skills, knowledge and experience and also by working in partnership with other groups and with statutory agencies. The way in which such change is achieved is crucial and so both the task and the process are important.

*Monitoring and evaluation of community development in Northern Ireland 1996 p29*

**Tackling Inequalities**

**Community Development and involvement in health**

Participation and involvement can improve communication, lead to better targeted and more appropriate services, and can help communities to tackle health inequalities from the bottom up. The use of community development as a means of supporting a broad range of involvement is an important ingredient in the menu of approaches and methods that foster public involvement.

In areas of inequality in health, the range of social and community support found is often much poorer than in more affluent areas. This can give problems to health workers who are attempting to build public involvement into their activities as the framework for the involvement is not there. Primary care trusts may need to invest in broadly based work in poor communities to provide a foundation for developments. Work on social inclusion and equity will probably focus in the early stages on issues that are health promoting in the broadest sense, such as stress reduction, housing action, traffic calming, and accident reduction, and the trust and its workers need to develop it through alliances with the local authority, other agencies and the community.

One of the successful ways in which action on health in communities can be developed is through the support and development of community health projects. Recent health service guidelines have stressed the importance of community development and participation in tackling inequalities, building on the lessons that have been learned by community health initiatives. Action to further develop this type of work is already taking place.
Community Health Action Resource Team (CHART)
The CHART project is a two year initiative funded by the Scottish Office and based in Lothian Health Promotion. CHART is concerned with promoting the use of a community development approach to health within primary care.

The benefits to primary care include a wider range of knowledge and skills, and greater motivation to respond to local need, to improve team work and to increase the public health role of health visitors.

CHART aims to:

• help primary care teams find ways to tackle inequalities in health;
• develop models of alliance working that can be replicated in areas of social and economic deprivation in Scotland;
• explore the development of a public health model of nursing for Lothian health visitors;
• set up ‘training for trainers’ courses for a range of workers for example health promotion facilitators, community development health visitors, community health project workers and GP trainers to enable the training to eventually ‘cascade’ throughout Lothian.

It hopes to foster empowered communities, able to voice needs and be actively involved in addressing them, leading to the creation of a regenerated community able to support and help itself. It may also reduce inappropriate demand for primary care services (especially GP).

Primary care teams will be helped to develop a more community oriented approach using their skills and knowledge to identify and address public health needs in partnership with the local community.

Contact
Yvonne Dalziel
CHART
Lothian Health Promotion
Deaconess House
148 Pleasance
Edinburgh
EH8 9RS
0131 536 9448
Stockport Community Health Workers (Public Health Health Visitors)

This community health project is of interest because it was developed by the Director of Public Health and is fully funded and managed by the Health Authority as part of their empowerment strategies in deprived areas. The project recognises the importance of social support and networks to health. It aims to reduce inequalities in health by working in partnership with local residents, by empowering groups which experience discrimination and by collaborating with groups and workers in the area.

Based in local communities and health centres, community health workers work in partnership with the local community on needs identified by them. These range from structural concerns, eg money / loan sharks, childrens’ accidents through to information, education and training. Work done has included the development of a workers’ co-op providing creche care, a subsidised safety equipment scheme, food co-op, cook and taste groups and a credit union as well as a number of other groups.

There are also a wide range of community health projects funded mainly from either health boards or local authority tackling community identified issues at a local level these can range from small local concerns around a community (for example the Concrete Action project in Drumchapel) up to concern about city wide issues on women's health and the development of new services to address these needs (for example Glasgow Healthy City Partnership Women’s Health Working Group).

Drumming Up Health in Drumchapel trains local people as community health volunteers and supports them in their development of activities. This has led to the provision of various services and networks such as stress reduction, men’s health project, health forums and support groups. The project is based in a health centre and receives regular referrals from primary care.
Most community health projects are generalist, providing a range of services from a community base. The majority of users of these projects are women. Some projects however, such as WomanZone, an Edinburgh community health project, are specifically for women. Looking at the service provided by the Craigmillar Health Project will give a clearer picture of the type of project. It provides this:

- Drop in: support, information and company three days a week.
- Groups: men’s group, menopause group, cardiac support group, confidence building group, parent/toddler playgroup, dementia group, breast feeding support group.
- Counselling: individual sessions, person centred approach (12 sessions a week)
- Complementary therapies: for stress, pain etc: aromatherapy, massage, acupuncture, reflexology, Bach flower remedies, Reiki Healing.

The provision of non NHS personal health support within poorer communities is often mediated through community health projects. As can be seen from the description of the work of projects like Drumming Up Health or of the Craigmillar Health Project, personal support and development is central to the work that they do. Some of these approaches such as taking health information to the community using trained local people have been taken up by local and health authorities.
The **Camden Lay Health Workers Project** building on the experience of the Camden Healthy City Project has trained local people as lay health workers and they now provide a service in King’s Cross. This project is jointly financed through the local regeneration budget and managed by a local neighbourhood association. A similar approach to developing the idea of having local people with their knowledge and experience work in an area has been utilised in the community health projects managed by the **Glasgow Healthy City Partnership**. Local people receive training to develop them as lay health workers in the Urban Aid funded community projects in five sites around the city. These projects have gone on to develop a range of innovative local activities.

The strengthening of local community infrastructure and the development of action across services at the local level has a positive effect on communities’ ability to see an active role in developing responsive local services. The involvement of local people in primary care is facilitated by the personal development and support that individuals gain through working with local projects. The ‘knock on’ effect to the local community of this group of people and the activities they engender mean that it becomes much easier and more productive to develop involvement work. The support of ‘health aware’ residents and community networks leads to active participation and development of a range of activities.

**Box 9** shows the range of community based work tackling issues which communities identify as important.
Box 9: Opportunities for community based organisations in health and well-being

Well Being

Prevention of Illness

Healthy behaviours and lifestyle Preventative medicine

Health and Social Care Responsive and appropriate health and welfare services

Health Awareness Knowledge and understanding of health

Mental Survival Community and self-esteem

Physical Survival Food, shelter, warmth and safety

Immunisation and screening, Smoking cessation groups, Exercise prescriptions.

Healthy eating and Get Cooking projects.

Community led Health Needs assessment, Improving access to responsive services.

Education in school and community, Lay health workers.

Counselling, self-help and support, Assertiveness training and confidence building.

Developing local economic solutions such as credit unions, Campaigning for employment, improved benefits and uptake.

Housing and environmental action, Improving access to food via food coops and retail outlets.

Advice and information, Community-based health workers.

Participation in local democracy and decision making.

Laughlin and Black 1995
The following table compares different methods of exploring community views and beliefs. More information can be obtained from the publications listed in the bibliography.

### Appendix 1: Overview of techniques for involving people in health care decisions

<table>
<thead>
<tr>
<th>PURPOSE</th>
<th>POSSIBLE TECHNIQUES</th>
<th>LIKELY FINANCIAL COSTS</th>
<th>LIKELY TIME INVESTMENT</th>
<th>STRENGTHS</th>
<th>WEAKNESSES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Involvement of local community decisions about health service planning and priorities.</td>
<td>• Citizen’s juries.</td>
<td>High - £17,000 plus. Requires external consultation.</td>
<td>Considerable – eg. up to 70 hours planning time. Overall process 4-6 months.</td>
<td>Complements representative processes; uses sample of electoral register. Informed involvement can raise public awareness of issues.</td>
<td>Expensive and time consuming.</td>
</tr>
<tr>
<td></td>
<td>• Quantitative surveys.</td>
<td>High - £10,000 plus.</td>
<td>Considerable time required for preparation and planning.</td>
<td>Statistically valid so taken seriously.</td>
<td>Difficult to get views of minority groups. Only answer pre-set questions.</td>
</tr>
<tr>
<td></td>
<td>• Public meetings.</td>
<td>Low/moderate – hall hire, adverts, catering, equipment, etc.</td>
<td>Considerable time for planning and presentation.</td>
<td>Danger of 'professional capture'; may not reflect all views. Public relations value in openness.</td>
<td>Can be confrontational; attendance can be low; 'same faces' syndrome; not representative feedback.</td>
</tr>
<tr>
<td></td>
<td>• Citizen’s panel.</td>
<td>Moderate – set up and maintenance costs.</td>
<td>Moderate, long term.</td>
<td>Representative if large enough.</td>
<td>Time consuming; skill required to produce support materials.</td>
</tr>
<tr>
<td></td>
<td>• Open days/road shows.</td>
<td>Low/moderate – venues, publicity, presentational material.</td>
<td>Considerable time for planning and presentation.</td>
<td>Danger of 'professional capture'; may not reflect all views. Ad hoc feedback from individuals.</td>
<td>Cannot provide representative feedback.</td>
</tr>
<tr>
<td>Involvement of a community of user/carers to inform major service configuration, eg. mental health community.</td>
<td>• Deliberative opinion polls.</td>
<td>Moderate. Recruitment of 250-600 participants. Briefing and small group work.</td>
<td>Considerable time for preparation and planning.</td>
<td>Measured informed opinion; representative.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Consultation with representative organisations.</td>
<td>Low.</td>
<td>Moderate – fit with their meetings but could be one-off.</td>
<td>Independent qualitative feedback; allows contact with hard-to-reach groups.</td>
<td>Not quantitative feedback; sometimes biased views.</td>
</tr>
<tr>
<td></td>
<td>• User representation on committee groups.</td>
<td>Low.</td>
<td>Moderate (for the users).</td>
<td>Formal process for direct feedback; users can influence decision-making.</td>
<td>Must have more than one user, but even then not representative; tokenism; professional capture.</td>
</tr>
<tr>
<td>PURPOSE</td>
<td>POSSIBLE TECHNIQUES</td>
<td>LIKELY FINANCIAL COSTS</td>
<td>LIKELY TIME INVESTMENT</td>
<td>STRENGTHS</td>
<td>WEAKNESSES</td>
</tr>
<tr>
<td>---------</td>
<td>---------------------</td>
<td>------------------------</td>
<td>------------------------</td>
<td>-----------</td>
<td>------------</td>
</tr>
<tr>
<td>• Regular meeting with support groups.</td>
<td>Low.</td>
<td>Moderate.</td>
<td>Informal; knowledgable users/carers; useful for sounding out.</td>
<td>Potential for bias; many not reflect range of views.</td>
<td></td>
</tr>
<tr>
<td>• Outreach work.</td>
<td>High – employing worker or paying user groups to network/draw people in or survey.</td>
<td>Considerable – 12 to 18 months.</td>
<td>Involves wider range of people, including hard-to-reach users; allows interviews and meetings.</td>
<td>Long term and costly; difficult to sustain.</td>
<td></td>
</tr>
<tr>
<td>• Focus groups.</td>
<td>High – if professionally moderated and depending on number of meetings.</td>
<td>Considerable – depending on number of meetings.</td>
<td>Interaction of participants allows sparking of ideas; issues can be explored in depth; membership criteria can be specified to ensure mix of users.</td>
<td>Interpretation of data needs to take account of group dynamics and conflicting views.</td>
<td></td>
</tr>
<tr>
<td>• Rapid appraisal.</td>
<td>Moderate.</td>
<td>Moderate – planning; identify key respondents; interview.</td>
<td>Involves local community; can be carried out quickly; builds support for action.</td>
<td>Needs time and commitment; not useful with large populations.</td>
<td></td>
</tr>
<tr>
<td>• Exit questionnaires/patient opinion surveys.</td>
<td>Moderate to high.</td>
<td>Low – if conducted professionally.</td>
<td>Provides normally reliable quantitative feedback.</td>
<td>Results not always reliable or systematically used; relies on good questionnaire design.</td>
<td></td>
</tr>
<tr>
<td>• User panels/patient councils.</td>
<td>Low to moderate.</td>
<td>Moderate though long term.</td>
<td>Regular and rapid feedback; continuous dialogue with users; sounding board.</td>
<td>Danger of ‘professional capture’ may not reflect all views.</td>
<td></td>
</tr>
<tr>
<td>• Patient participation groups.</td>
<td>Low to moderate.</td>
<td>Moderate but long term.</td>
<td>Develops dialogue; regular feedback.</td>
<td>Depends on staff commitment; may not be representative.</td>
<td></td>
</tr>
<tr>
<td>• Complaints monitoring.</td>
<td>Moderate – requires staff time and information systems.</td>
<td>Considerable staff time.</td>
<td>Identifies recurring problems; both quantitative and qualitative information.</td>
<td>Some professionals reluctant to act in response to complaints; can be reactive process and not used to improve services.</td>
<td></td>
</tr>
<tr>
<td>• Telephone helpline.</td>
<td>Moderate – requires staff time and information systems.</td>
<td>Considerable staff time.</td>
<td>Provides immediate feedback, and useful for people who don’t want long term involvement.</td>
<td>Limited opportunity for showing improvements have been made.</td>
<td></td>
</tr>
</tbody>
</table>

Involvement of individual patients/users to get feedback to help improve the quality of services.
Anglia and Oxford Public Involvement Network, Peer Review in Public Involvement: guidelines for Health Authorities, Oxfordshire Health Authority, 1996.


M Barnes, J Cormie, M Crichton, Seeking representative views from frail older people, Age Concern Scotland, Edinburgh, 1994.


A Carver and V Entwistle, Patient Involvement in SIGN Guideline Development Groups, SIGN/SAHC, 1999


R Freeman et al, Community Development and Involvement in Primary Care A guide to involving the public in COPC, Kings Fund, London 1997.


R Labonte, A community development approach to health promotion, HEBS 1998.


NHS Executive, NHS Confederation, Institute of Health Service Management, In the Public Interest: Developing a strategy for Public Participation in the NHS, NHS Executive / the NHS Confederation / IHSM, 1998

North Derbyshire Health Authority: Department of research and information, Listening and responding to local people, North Derbyshire Health Authority, Chesterfield, 1994.


Plain English Campaign, How to write reports in plain english, Plain English Campaign, Stockport, 1995.

Scottish Association of Health Councils, The Clinical Effectiveness Agenda: informing and involving the public, SAHC, 1997


Scottish Needs Assessment Programme, Needs Assessment in Primary Care; a rough guide, SNAP, Edinburgh 1998.


J Smithies, Community Participation in Health Purchasing: A review of examples of interesting practice, Sheffield Health / Labyrinth Training and Consultancy, 1996


The National Association for Patient Participation  
PO Box 999  
Nuneaton  
Warwickshire  
CV11 5ZD  
Telephone and fax: 0151 630 5786  
Enquiries will be directed to a regional office near you.

Scottish Association of Health Councils  
24 Palmerston Place  
Edinburgh  
EH12 5AL  
Telephone: 0131 220 4101 Fax: 0131 220 4108

Scottish Community Care Forum  
17/19 Claremont Crescent  
Edinburgh  
EH7 4QD  
Telephone: 0131 557 2711

Scottish Consumer Council  
Royal Exchange House  
100 Queen Street  
Glasgow  
G1 3DN  
Telephone: 0141 226 5261 Fax: 0141 221 0731  
Minicom: 0141 226 8459  
Web site: www.scotconsumer.org.uk

Community Health Network Project  
Scottish Community Development Centre  
Suite 329  
Baltic Chambers  
Glasgow  
G2 6HJ  
Telephone: 0141 248 1924

The Public Involvement Project  
Institute for Public Policy Research  
30-32 Southampton Street  
London  
WC2E 7RA  
Web site: www.pip.org.uk

Volunteer Development Scotland  
72 Murray Place  
Stirling  
FK8 2BX  
Telephone: 01786 479 593  
Promoting volunteering in the NHS in Scotland, and developing a  
strategy for volunteering in the NHS. VDS has run an action  
research project on volunteering in primary care.