

Contents

Introduction	3
Guidance on approaches	7
Involvement approaches (in alphabetical order)	19
1. Action Planning	20
2. Advocacy	22
3. Art Work, Photography and other creative means	25
4. Choices	28
5. Citizens' Juries And Civic Commissions	30
6. Citizens' Panels, District Circles And Users Panels	35
7. Comments and Complaints Cards	42
8. Community Indicators	44
9. Community Profiling / Community Appraisal	46
10. Deliberative Opinion Polls And Referenda	50
11. Design Game	53
12. E-consultation	55
13. Exhibitions, Campaigns and Presentations	56
14. Focus Groups	58
15. Future Search	63
16. In-depth Interviews	65
17. Internet	67
18. Leaflets and Other Written Information	69
19. Local Sustainability Model	73
20. Nominal Group Technique	74
21. Open Space Technology	77
22. Opinionmeter	79
23. Parish Maps	81
24. Participatory Appraisal	83
25. Patient/Lay Representatives	85
26. Patient Participation Groups	88
27. Person Centred Planning	91
28. Planning For Real	96
29. Priority Search	99
30. Public Meetings	102
31. Round Table Workshops	109
32. Social Auditing	112
33. Story Dialogue	115
34. Surveys (Questionnaire Based)	118
35. Think Tanks	122
36. Volunteering in Health	124
37. Other approaches worth looking at	125
Integrating Patient Focus and Public Involvement into Clinical Governance	127
Further reading and websites	131

Introduction

Involving people in the NHS - one definition

Involving: meaningfully engaging with people at all levels - in any aspect of health care planning, delivery or monitoring.

People: anyone - individuals, groups or communities or populations - who has an interest in the National Health Service - patients, service users, potential users, staff.

In 'Our National Health: A plan for action, a plan for change', particularly in Section 5 'Involving People', it states that a patient-centred NHS must not just be a slogan: it must become a way of life (p50). NHSScotland undertook to ensure that listening, understanding and acting on the views of patients and carers, local communities or groups, is given the same priority as clinical standards and financial performance. A short section on involving people in Clinical Governance is included in this paper.

Building Strong Foundations: Involving People in the NHS, forms part of the commitment within 'Patient Focus and Public Involvement' published in December 2001 by the Scottish Executive Health Department, to publish a 'toolkit' of approaches to facilitate involving people in the NHS.

In the Patient Focus and Public Involvement document it states that the NHS is trying to achieve:

- A service where people are respected, treated as individuals and involved in their own care;
- A service where individuals, groups and communities are involved in improving the quality of care, in influencing priorities and in planning services; and
- A service designed for and involving users of the NHS.

There is no doubt that NHSScotland is committed to involving people in all aspects of planning, delivery and monitoring of health services. NHS professionals and members of the public, including patients and their carers, have asked for a summary of the different ways that they can engage with each other. This document provides a summary of some of the ways in which this can happen, though not all.

The Scottish Executive Involving People Team compiled this document from two main sources (see below), using examples from around Scotland, as well as learning from the work of Designed to Involve, Public Involvement in Primary Care, which was funded by the Executive from October 1999 - October 2001. Around 80 projects were funded, a summary of which, with the learning from the work, will be published separately to form part of this 'toolkit'.

4

This publication has been produced with the very much appreciated co-operation of the Central Research Unit of the Scottish Executive, NHS Grampian, Grampian Local Health Council and the New Economics Foundation, who agreed to allow us to base much of this publication on their respective documents.

Contacts

There are people in the NHS and people and organisations in the community who have the skills to carry out these approaches and others. We hope that through the mapping exercise planned for 2002 and publicised through the Involving People Network will be helpful soon. In the main we have avoided giving you specific phone numbers or names of Consultants or organisations in this document. Local information on who has tried which methodology, and with what results, will be of special interest to the readers of this document and this information will be published on an Involving People website and through correspondence. This will help in further updates of this toolkit, providing more case studies and examples.

Other Support

Many NHS staff and members of the public have expressed an interest in providing independent facilitation in different areas

from their own. This concept is currently being explored. A series of training seminars is planned during 2002, that will offer some more of the skills and competencies to carry out some of these approaches. A national Involving People Network of NHS professionals and members of the public and patients will facilitate shared learning and help create a pool of people with particular skills to ensure that the NHS and its users and potential users work and speak to each other constructively.

The Scottish Executive Involving People Team exists to provide strategic direction and advice to the NHS, and to the Executive itself, in developing patient focus and public involvement. We will work with a network of experienced professionals and the public, within the NHS, Public Sector and Voluntary Organisations, to create new opportunities and to share the learning across Scotland.

Long term development of participation and involvement will need to include the direct engagement and support of these knowledgeable and committed participants. Thanks go to the patients, NHS staff, carers and members of the community who have provided their time, knowledge and skills to create this 'toolkit'. Building Strong Foundations is what this document is about in order to achieve an NHS that listens and respects the evidence of the people it serves.

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Guidance on approaches

An Involving People Health Warning

Choose your approaches carefully and make sure the right people are involved and always ask WHY you are doing this before you start

Someone will take the initiative or the first steps to involve individuals, groups, communities or populations in some aspect of planning, delivery or monitoring of their particular area within the NHS. This can be an NHS professional or a member of the community or patient. Each will have a different perspective and set of skills to bring to the work. Read the first part of this toolkit to see more detail on this important aspect of involving people.

As in research, it is important to be clear about what question or issue you are working with, before selecting an appropriate methodology and 'sample'. In order for the work to have valid results, and learning that is valued, those who have an interest or stake in the issue need to be convinced that the resources, efforts and time will be used to change and improve things.

Some professionals say that the public is apathetic or not interested - until they are affected in some way by proposed changes. This is not shown to be true in the participation work going on in other fields like urban regeneration, environmental science or new economics. Examples throughout the NHS in Scotland in the past 2 years, particularly within Primary Care, have shown that it is important to remember that even the most 'unlikely' people will get involved if they believe that we are serious about listening to them and taking account of what they say they need. It is also important to agree what platform or by what means we communicate.

A special note about 'representatives'

Having a 'patient representative' on a committee is not the only answer (see more notes below) to this. In order to be a representative, that person has to have a network or constituency of their own and be supported to gather and synthesise that information to 're-present.' The NHS should be aware that this method of involving people can be very tokenistic and that this method has implications for the way that NHS Committees traditionally work.

Choosing a method

There are many examples of particular groups being 'consulted' time and time again to seemingly no effect. There are also many examples of so called participatory approaches that exclude large sections of the community. This only underpins the importance of being clear about:

- WHY people are being involved; and
- WHAT is going to happen to the information gathered; before
- Deciding on the HOW - a particular methodology.

It is also important to use a range of initiatives so that people have every chance to participate and perhaps even use a range of approaches at different stages of the same project.

8

Each method has strengths and weaknesses, depending on why the work is being carried out. Remember that carrying out individual approaches or projects does not constitute the main reason for all of this: an ongoing dialogue and improved working relationship with the people who use or potentially use the NHS.

Talk to all relevant stakeholders (see Section 1) to decide around 6 or 7 criteria. For example, "The method should...

1. hear the views of people who would not attend a public meeting
2. capture people's own ideas and issues
3. hear people who are hard to reach
4. be easily recorded, analysed and fed back to the participants
5. identify issues that can be acted on
6. will facilitate an ongoing dialogue with people we have not participated with before."

Approach (see more complete list in following pages)	Does it meet our criteria? (tick if yes)						
	1	2	3	4	5	6	TOTAL
Nominal Group							
Participatory Appraisal							
Citizen's jury							
Imagine!							
Community Appraisals							
Action Planning							
Focus Group							
Etc							

With thanks to New Economic Foundation for inspiring this approach www.neweconomics.org

What are your responsibilities as organisers?

- Ensure that stakeholders have the chance to organise or say how an event will run.
- Listen to people without blame or judgement, respecting where they are as individuals or groups.
- Resource involvement adequately.
- Put systems in place that will ensure that members of the public/patients are not out of pocket. Develop financial systems that mean that expenses are met on the day.

Expense payments should cover all travel, childcare, carers' costs, interpreters, signers for deaf and deafblind people and personal assistants, if required by people. In rural areas this is likely to cost more. Expenses should never be as a voucher, though this is a positive gesture to recognise people's good will and time in taking part. Around £10/15 is normal at the time of writing.

There may be some issues in different areas in Scotland around the review of people's benefits or liability for tax if they receive high or regular payments. There should not be a problem when actual expenses are reimbursed, but please check this out in your own area.

- Ensure the safety and comfort of all participants. Have adequate breaks (as agreed by the group) and ensure that the venue and proceedings are accessible to people with mobility or sensory impairments. A signer for people with hearing impairments usually costs £40 per hour and you will need two if the meeting is more than 2 hours or so. Ensure that microphones are used at all meetings where people may have a hearing impairment. People speaking loudly does not usually help and an induction loop can be hired that will ensure that people can hear as long as microphones are used.
- Feedback to ALL participants as routine, even if it is to say why something has not happened. Written information should be in Arial Font, size 14, according to RNIB guidelines. Check out Scottish Accessibility Forum Standards for more information. Copies from Scottish Consumer Council, 110 Queen St, Glasgow or www.scotsconsumer.org.uk or www.connections.gcal.ac.uk/saif/standrds/index.html
- Ensure that action (who, what, by when) takes place - do not waste people's time and commitment. They will be reluctant to get involved in the future.
- Use plain language at all meetings and events and consultations. Do not use management or clinical jargon without explanation.
- Don't be afraid to suggest what can be done to engage people - there is no one right answer to any of this. How else will we start to shift how the NHS and patients or communities relate and talk to each other?
- If in doubt about the details of the practicalities, ask the people who will be attending. Below you will see one version of what you can ask on application forms for meetings or conferences. Please feel free to use or develop as required.

Please tell us if you will require any support on the day and detail as clearly as possible what this will be. (Please tick the boxes)

- Wheelchair Access
- Hearing Loop System
- Signer
- Braille
- Large Print (please specify point size in the box)
- Special Diet (Please specify) _____

Any other requirements _____

replace with A£

replace with A£

'Involvement Ready' and Excluded People

Often there are already strong networks or groups of people in our local area who have the language, the knowledge and the skills to engage with the NHS on certain issues. They may also provide challenges which can bring a healthy dimension to the discussion around the committee or other table. Community Health Projects bring together a wide range of people with a common interest in health related issues (See reference to CHEx 0141 248 1990 below or www.scdc.org.uk). Other groups, like Health Councils, are already providing representatives on Trust and Board committees. Family networks, self-help networks and mental health survivors' groups have often become independent of the NHS and can provide a perspective that will complement other involvement work. Long term development of participation and involvement will need to include the direct engagement and support of these knowledgeable and committed participants.

There are also many individuals and groups of people who are called 'difficult to find' or even 'difficult to engage'. Many NHS managers have expressed this as a real problem when making the effort to get 'a truly representative sample of the population'. Here are 4 main points to consider:

- It is not always necessary to have a 'truly representative sample'. Involving people means involving individuals in their own care, as much as it means engaging with the whole Board or Trust population.
- It will take a combination of different approaches to engage with different groups or communities. Some are 'involvement ready' as described above, where others, quite legitimately, have no desire to be involved at committee or organisational level.
- Many patients, service users or others do not identify with any particular group or label. Some people have no wish to 'belong' to organised community groups or take part in organised events. The NHS should make efforts to ensure that their voices are still heard and taken into account at all levels.

- Members of the community or users of a particular service are likely to have more knowledge of where people are who have a stake in what is being considered. The NHS should support them to find and gather the views and aspirations of the people they know.

Please note that carrying out any, or even all, of the approaches described below does not necessarily constitute full patient focus and public involvement. They can only contribute one part of what must be a different relationship between NHSScotland and the people it serves. The people who really know that the NHS is involving people are those who use or who will use the NHS. Their perspective must be an integral part of any evaluation framework for patient focus and public involvement.

Involving People is as much about empathy and useful and significant dialogue with individual patients or service users, as it is about large scale consultative exercises. Please therefore, use this section on approaches appropriately, acknowledging the limited contribution they can make to significantly involving people at every stage and in every area of the NHS.

In involving people in the NHS, good communication skills are valued as much - if not more - than carrying out any of these techniques.

Involvement and consultation approaches

This section provides some details on a limited range of approaches that are often used to inform, consult with and involve people. This is not a comprehensive examination of all the possible approaches. We have concentrated on providing as much information as possible about approaches that are being widely used at present or which are likely to be used in the near future. As stated before, there is no one answer. At the time of writing the NHS and the people it serves are exploring the possibilities together. Though there are still many questions and issues to be explored, the opportunity is welcomed widely throughout the country. It will take time to continue building on the skills, competencies and attitudes that it needs to ensure the commitments of Our National Health, but many are meeting the challenge and beginning to share the learning.

The approaches are listed to help you see a wide spectrum of possible systematic ways of involving people in the planning, delivery or monitoring of NHS services and more broadly in health related issues. Different approaches will appeal to different people and no one methodology is the answer. Often a combination of approaches are used in one specific initiative, using the strengths of a range of ways of engaging with people.

Involvement strategies must include going out to people in communities. There are already many good examples of NHS organisations going out to local clubs, pubs, bingo halls and shopping centres and other examples of community organisations inviting the NHS in to see how they work. There is also an example from Midross at the end of Opening Up (Part One of the Building Strong Foundations toolkit). The advantages are clear: people are more willing to express themselves in their own surroundings and feel more confident to be constructive, as well as critical. This also gets round the problems of finding accessible venues. The Scottish Executive will publish a list of endorsed meeting places which meets criteria set by disabled people and this will be available later in 2002.

Main Documents used in this Section of Building Strong Foundations

Assessment of Innovative Approaches to Testing Community Opinion

Central Research Unit of the Scottish Executive.

The information gathered in this report represents the collective wisdom of a great many users, commissioners of, and participants in, public sector consultation in Scotland. The research focuses on the use of innovative approaches to consultation by a range of agencies and in a range of policy contexts within Scotland. It should, however, be noted that views on 'innovation' differ between organisations - what is innovative or new to one agency may be commonplace to another. It is important for the NHS in Scotland to be informed of consultations by other public sector organisations - to learn from each other, to ensure that the public are not going to be over consulted and to make best use of resources. This may not affect particular NHS services who are consulting and involving users or patients, but is particularly important for NHS Boards who are operating at citizen level.
www.scotland.gov.uk/cru/innovative.pdf

18

Participation Works: 21 Techniques of community participation for the 21st Century

Published by New Economics Foundation, London.

The rhetoric says that Participation Works! But what does participation really mean and what makes it really happen? Participation Works! contains twenty-one proven techniques from around the world. It shows how to choose between them, how to use them properly and where to go for more information.
www.neweconomics.org/uploadstore/pubs/doc_1910200062310_PWA4.doc

Public Involvement Toolkit. 2002

NHS Grampian and Grampian Health Council

The Grampian Toolkit is the most recent toolkit published at NHS Board level. There are several others which are cited in the references. It aims to give some guidance when the NHS is considering involving patient and the public. It includes a 'Public Involvement Checklist' when any involvement initiative is being planned. Highland Primary Care Trust have also developed a similar one. The Grampian version which was available on writing is appended after the references at the end of this document.

Involvement approaches

The information presented here includes:

- an overview or description of the approach
- some key issues to consider when thinking of using the approach
- resourcing issues and
- examples where available in Scotland.

NHS organisations should consider ways of developing these approaches and employing them in an innovative way to meet their particular requirements. See some information on this in 'Involving People Health Warning' earlier in this document. The skills required are often already in the area and the NHS has an opportunity to learn from the community.

With adequate thought, planning and resources, it is possible to build a strong participative element into most approaches to consultation and to develop more evidence-based approaches to more effectively involve people in any aspect of the NHS and in their health. Whose evidence are we looking for when we involve people? This is key to which method is chosen.

The following list is not a full description of the approaches, but is mainly for giving ideas to people in the NHS and members of the community, on how they can start a meaningful dialogue and bring balance and a range of evidence in NHS planning, delivery and monitoring.

The views expressed are those who provide or who have used the approaches. Examples and lessons from the main sources (cited below) are included.

1. Action Planning

Overview

Action Planning, if used appropriately, is suited to projects looking at planning and development issues within the community and urban regeneration for example. Events are usually run by a partnership of interested bodies (from different backgrounds) and everyone in the community is invited along to give their opinion. Members of the community work, in conjunction with specialists, assist in advising on matters such as planning or urban design issues. The events can last anything from 1 to 5 days depending on the subject matter.

- Action Planning can be a good way of involving community members in deciding what they want and need in their community and making plans on how they can achieve it.
- Community involvement is a key feature where people are given the opportunity to voice their opinions.
- It is a good opportunity to inform members of the community about any proposed plans.
- It provides an opportunity for communities to raise new and innovative ideas that the specialists may not have considered themselves.

Targeting

Action Planning is similar to many other approaches in that it is not always guaranteed that you will reach the people whose views you seek. However, a carefully planned advertising campaign can increase the community's awareness of the event.

Issues to Consider

- Careful consideration of the venue and location where the event will be held is important; it must be in an accessible location where members of the community are likely to attend.
- Encouraging participants to prioritise community needs may help minimise disagreement.

Resources

The cost of conducting an event can vary drastically and is dependent on factors such as the topic for discussion, the length of time across which the event is taking place and the specialists that are involved in the event. Action Planning events can cost approximately £15,000-20,000 (although this does not include professional organisers).

Typically, Action Planning events involve 150 to 300 people, although it has been known for up to 1000 people to be involved.

2. Advocacy

Advocacy is about standing up for and sticking with a person or a group, taking their side, helping them to get their point across. Advocacy adds weight to people's views, concerns, rights and aspirations. It should be an integral or included way of ensuring that everyone's voice is heard, people being supported to express their views where needed.

Independent advocacy groups should be constitutionally and psychologically independent of government and of the statutory and voluntary service system.

(Independent Advocacy - A Guide for Commissioners, 2001)

Independent Professional Advocacy

Independent Professional Advocacy uses paid advocates. Advocates working in these projects usually support people in dealing with a specific issue or problem and work with them until that issue is resolved. (Key Ideas On Independent Advocacy, 2000) Professional advocacy organisations will also often use volunteer advocates.

Citizen Advocacy

The objective of Citizen Advocacy is to encourage ordinary citizens to become more involved with the welfare of those who might need this in their communities. Citizen Advocacy schemes aim to develop communities whose members are more able, competent and willing to speak on behalf of another person and to protect their interests. Citizen Advocacy brings an individual together with an advocate on a long term, personal, one to one basis. The advocate stands with their partner to defend their rights and to support them to pursue their interests, and the project is structured in such a way to ensure that their loyalty is to their advocacy partner not to the project. Citizen advocates are usually partnered with only one person, and they are not paid. (Key Ideas On Independent Advocacy, 2000)

Collective Advocacy

Collective advocacy is where a group of people with similar experiences meet together to put forward shared views. It offers a shared voice rather than singling out individuals. It can however present a range of views.

Collective advocacy builds personal skills and confidence and supports individuals to represent issues of common concern. Members of a collective advocacy group set their own agenda. Groups campaign for change and seek to lead and influence the change process.

Collective advocacy groups organise around a distinct identity or issue but need effective links to wider networks.

Background reading

Advocacy 2000: A map of Independent Advocacy across Scotland
Published by Advocacy 2000, Edinburgh

Advocacy 2000: From patchwork to blanket - the lessons learned from independent advocacy
Published by Advocacy 2000, Edinburgh

Advocacy 2000: Key Ideas on Independent Advocacy
Published by Advocacy 2000, Edinburgh

Advocacy 2000: On Solid Ground (2002)
Published by Advocacy 2000, Edinburgh

Advocacy 2000: Principles and Standards in Independent Advocacy Organisations and Groups
Published by Advocacy 2000, Edinburgh

Scottish Executive: Independent Advocacy: A Guide for Commissioners (2000)
Published by Scottish Executive, Edinburgh

Websites

Advocacy 2000

www.advocacy2000.org

On the Links and Resources page you will also find links to other websites which are sources of information about advocacy, links to the sites of advocacy projects, and links to information that may be useful to those involved with Independent Advocacy.

Scottish Health on the Web

www.show.scot.nhs.uk/advocacy

At the time of writing this site was not live but was scheduled to come online by the end of April or beginning of May 2002.

Scottish Human Services Trust

www.shstrust.org.uk

This site has details of projects relating to advocacy development. It also has details of useful events and publications.

3. Art Work, Photography and other creative means

Overview

People express their views, feelings and perspectives in different ways. Discussion is not always the best method for everyone, particularly those who are not used to articulating what is important to them in words. Using visual stimuli, or asking people to create visual images, is one way of engaging them at a different level. You can use these and other creative approaches, including play, video, poetry, drama and sculpture to elicit thoughts, feelings and views on most aspects of the NHS.

Giving people a cheap, single use camera or a cheap taping device allows people to input their thoughts and views in their own time and in their own location. This is particularly useful if you are considering a person-centred planning approach (see below).

Targeting

What is it you want to know? With whom do you wish to consult, involve or engage? Children and young people particularly enjoy this kind of work, but give other groups of people the option to work like this if they wish.

Issues to Consider

- People usually enjoy this more than they think they will. Don't not consider it on the basis that you think you would hate it yourself!
- Groups of people who know each other well will probably be particularly keen to try something new.
- Drama presentations at Public Meetings have a unique impact.
- People who are suffering from 'consultation fatigue' or who feel that their views have not been acted on may feel that this is a better way to get their message across.
- Sometimes this is the only way that people can communicate what is important to them.
- Photographing significant issues related to health can add another dimension that the professionals had no idea about.

Resources

Community Drama Workers are less expensive than many other professional facilitators. Often several sessions with a group of people are necessary before a 'polished' performance can be shown. The worker will use techniques to elicit key questions and issues of the group and then facilitate the expression of these. Cameras and tapes can be purchased cheaply and have profound impact. You may wish to supply relevant staff with cameras also in order to have a session to compare priorities for health or within a service.

Examples in Scotland

NHS Glasgow Health Promotion Department worked with young people to elicit their health issues. The young people used photography and artwork which have been used for postcards and posters. The significance of certain issues, like overcrowded housing, was highlighted as well as mental health issues.

26

In Kirkcaldy Local Health Care Cooperative, young parents took part in a Forum Theatre workshop to explore health issues. Forum Theatre comes with a script that participants can change to highlight certain issues.

In Midlothian Local Health Care Cooperative, young people made a video of an improvisation about the problems around getting sexual health information, 'Follow the Fish'.

FPAScotland worked with young people over a weekend around the topic of sexual health. The finished piece was shown to participants of a national conference on Sexual Health Education. The young people entered their role in the play to answer questions from the floor which had great impact.

An example of ongoing work in this area (outwith Scotland) is Gateshead Arts In Health. This projects acts as a springboard to getting arts projects into Healthy Living Centre bids. They are also leading on a 2-year evaluation study of community-based arts in health involving five projects in a consortium - Gateshead, the West End Health Resource Centre in Newcastle, the South Tyneside Art Studio for mental health referrals, the Bromley by Bow Centre, and Pioneer Projects' groundbreaking 'Looking Well' initiative in rural Bentham, North Yorkshire.

The study will document the processes of arts in health projects from several perspectives, accumulate testimony through ethnographic research, and look for intermediate qualitative indicators of health gain. The King's Fund is the core funder of this initiative.

Websites

Arts and Health http://194.66.253.138/eGrants/html/arts_and_health.html

CAHHM - Centre for Arts & Humanities in health & medicine - University of Durham <http://www.dur.ac.uk/cahham/>

MAiLOUT - developing pARTicipation in the arts <http://www.e-mailout.org/>

The mailout journal is a good source to explore for a range of participatory approaches re the arts.

National Network for the Arts in Health <http://www.nnah.org.uk/>

4. Choices

Overview

The Choices technique involves large numbers of people in developing a vision for their community. It is an elaborate process requiring a long lead-time and the support of local media and volunteers.

The exercise is divided into four stages:

- Meetings Throughout the Community - people generate ideas to improve future quality of life.
- Consolidation of Goals - ideas are presented to meetings or vision workshops led by facilitators and are then consolidated into goals or 'vision statements' by interested parties.
- Vision Fair - people vote on the goals which matter most to them and which they would most like to attain, following which the goals and visions are published.
- Action Groups - these are formed to implement the chosen ideas.

The strengths of the approach are as follows:

- Choices is conducted in such a way that the community feels inspired to act upon the vision.
- People can conduct the discussions in familiar surroundings with friends and neighbours, thus facilitating participation.
- As much of the population as possible is involved in the exercise.
- Highly successful outcomes are achieved.

Targeting

All sectors of the community can be involved in this process.

Issues to Consider

The following issues should be taken into account:

- Choices is a lengthy and complicated process
- Many different groups are involved in the exercise

Resources

As stated above, Choices is a lengthy process.

In the event that a Discussion Guide is not produced for local groups, many facilitators will be required at this stage - for example, the planning phase of ReVision 2000 included the training of 150 volunteers in facilitation. Facilitators are definitely required for meetings that involve the whole neighbourhood. Venues can range in size from small public meeting places to large facilities for meetings involving the entire neighbourhood. Budgets depend on the scale of the project and can expand with the success of the programme. Bristol allocated a budget of around £35,000 for the whole city, in addition to £50,000 to cover volunteers' time and expenses.

Examples of Use

Some aspects of the approach are apparent in the use of consultation documents by Scottish organisations for example Vision for Edinburgh and Imagine Aberdeen by their respective city councils.

5. Citizens' Juries and Civic Commissions

Overview

Citizens' juries were developed over the last 20 years in both Germany and the USA, and are now being used in the UK. They usually contain between 10 and 25 participants who have been selected to generate a representative cross-section of the wider population in terms of gender, ethnic mix, age and other factors. As such, they represent the general public rather than particular sectors or interest groups. Citizen Juries are not a consultation method to be used on their own. They can be used with other approaches described here, perhaps using the Jury to consult on the recommendations that have been highlighted by other approaches.

Civic commissions are similar to citizens' juries. However, the difference between them relates to the way in which the output and recommendations are achieved, with the commission asked to examine the evidence and make recommendations. This issue was alluded to in a recent paper for the Market Research Society which discussed the pressure on 'juries' to reach either a unanimous verdict or consensus view. Commissions are regarded by some as a way of avoiding the perceived pressure towards uniformity and allow a wider range of issues to be considered and commented upon in the output.

Juries meet to deliberate upon specific issues and have the opportunity to cross-examine witnesses, while facilitation is carried out by a trained moderator. The entire process generally takes between three and five days. Despite the above comments, there is no requirement for unanimity amongst the jurors and their conclusions may take the form of guidelines rather than recommendations. A range of different subjects has been covered in juries conducted in Scotland to date, especially within Social Inclusion Projects.

The strengths of the approach are as follows:

- It can be used to develop, guide or implement policy proposals and to resolve complex issues which have no immediate or straightforward solution.
- Jurors/individuals can spend a period of several days in consideration of one particular project, thus providing a well-reasoned and viable solution.

- People are given the opportunity to play an active role in decision-making and to participate more fully in the citizenship process.

A recent review of juries concluded that the jury approach was effective where:

- The output is suggestion/recommendation based, not an understanding of behaviour or views.
- Quantitative data on the strength of views is not sought.
- There is full transparency of the process.
- Recommendations will have an influence.
- More than one jury is run. Given the resources required to establish a jury, this could be a significant limiting factor.

Citizens' juries and commissions tend to be stand-alone exercises although the information obtained and resulting recommendations will often input into thinking for a number of years.

Targeting

The process encourages a culture of citizenship and allows a complex issue to be explored in-depth by the people who are affected by it. As detailed above, it can cover topics as diverse as employment opportunities, transport choice, vandalism and services for the elderly, and is most appropriate when the Council is undecided about an issue.

However, there is a risk that the selection process might not deliver a representative sample, either because reliable results may not be obtained from a limited number of participants, or because of the unrepresentative nature of a self-selecting sample. In addition, citizens with below average literacy skills or non-English speakers could be excluded by this type of consultation exercise. Please note that 'representativeness' is important for this methodology but is not required for all of the approaches and depends on the nature and scope of your 'consultation' exercise.

Issues to Consider

The following issues should be taken into account:

- Citizens' juries and commissions seek to be representative of the general public and allow deliberation of complex issues and unbiased decision making. There is doubt, however, about whether a small group of jurors can be truly representative of all views.
- Information for the jury/commission should be presented in a clear and concise manner.
- The moderator should not direct or manipulate those taking part; the role of the moderator is facilitation not interpretation.
- The jury's/commission's findings must be made clear in the final report.
- The decisions or recommendations of the jury/commission are not binding on the organisation although there will be an agreement that the organisation will take full account of the recommendations.
- Juries and commissions are expensive and time-consuming.
- The output is qualitative.
- A training or briefing element is necessary, to inform jurors how the process will work.
- Time must be built in at the end of the exercise to allow jurors to approve the report.

Resources

Citizens' Juries can be an expensive method of consultation, costing between £5,000 and £25,000 to run. In addition, jurors are normally paid to participate, covering their loss of earnings, carer costs and transport costs. Special provision such as crèche facilities may facilitate participation by lone parents, while special arrangements may need to be made to compensate those jurors who are in receipt of benefits in order to ensure that they do not suffer any adverse financial effects. Estimated costs of a citizens' commission were higher than those of a jury.

Juries/commissions are usually recruited and facilitated by external consultants who work with them to prepare their recommendations and to ensure that the organisation is not seen to be manipulating the outcome. The jury/commission also hears presentations from a range of experts or those with a particular interest in the subject matter.

The planning and implementation of a citizens' jury or commission can be a time-consuming process, both in terms of internal and external input. In exceptional cases, several months' preparation may be required to recruit the representative sample and obtain the services of the expert witnesses and moderator, while the exercise itself is conducted over a period of three to five days (sometimes split over two weeks).

Potential Pitfalls

Concern has been expressed about the ability of one jury to provide the full picture. In addition, they can involve substantial direct and indirect costs such as the provision of pre-jury background material and staff time and in terms of opportunity cost this may appear to be poor value for money.

It should also be noted that juries and commissions are not considered to be an effective method of consultation when dealing with emotive subjects or in cases where views have become entrenched over time.

Examples of Use in Scotland

- As part of the Good Neighbourhood Initiative, South Lanarkshire Council carried out Scotland's first citizens' jury - "Focus on Hillhouse" - in March 1997 to debate, and formulate solutions to, the problems of vandalism and graffiti in the Hillhouse area of Hamilton. Subsequently, the Council conducted two further juries - "Services for the Elderly in Rural Areas" and "Access to Leisure/Entertainment for Young People in East Kilbride" - in November 1997 and April 1998 respectively.
- In March 1997, Fife Council also held a citizens' jury to address the following topic - "What can public agencies and local communities do to create employment opportunities in Levenmouth?" This resulted in 50 recommendations.

- Grampian Primary Care Trust used a Citizen Jury to look at the use of services for drug users.

In the Central Research Unit research (see below), of 126 organisations interviewed, 20 stated that they would consider using citizens' juries for the first time in the future. Those that expressed most interest in using citizens' juries were SIPs, Health Boards and local authorities. Few significant changes to the format of the juries were cited. The main change that had been implemented was in a phasing of the jury, splitting it over a two-week period and giving Jurors more time to deliberate.

In addition, early experience indicates the need to have witnesses drawn from senior positions within an organisation so that jurors can debate with them the feasibility of certain courses of action. Jurors also need to have some say in the mix of witnesses they see. Phasing of the jury allows this flexibility.

Recommendations should be acted upon quickly and the consultation should not be undermined by other action that is ongoing and which relates to the subject under discussion.

Background Reading

Barnes, M.: *Building a Deliberative Democracy: an evaluation of two citizens' juries* (1999). Published by IPPR, London

Buckinghamshire Health Authority: *Should Buckinghamshire Health Authority fund treatment for osteopaths and chiropractors for people with back pain?* Buckinghamshire Citizens' Jury Report (1997). Published by King's Fund, London

Coote, A. and J. Lenaghan: *Citizens' Juries: theory into practice* (1997). Published by Institute for Public Policy Research, London

Davies, S. and S. Elizabeth et al: *Ordinary Wisdom: reflections on an experiment in citizenship and health* (1998). Published by King's Fund, London

London Borough of Lewisham: *People take drugs: what can we do to reduce harm to the community and individuals.* Lewisham Citizen's Jury Report. (1996). Published by IPPR, London

McIver, S.: *Healthy Debate? An Independent evaluation of citizen's juries in health settings* (1998). Published by King's Fund, London

6. Citizens' Panels, District Circles and Users Panels

Overview

A citizens' panel is a group of people who have agreed to be consulted periodically for their views. It is intended that the panel should be as representative of the population as possible, although this cannot be guaranteed.

The number of people on the panel can vary from 750 to 2,000. A larger number allows sub-groups such as young people, the elderly or those living in a specific geographical location to be identified. The membership of the panel is changed regularly and systematically - i.e. one third replaced each year - to allow people to "drop out" and to enhance its representativeness. This is probably a good idea to consider for all members of any Committee or formal group within the NHS. Once recruited, an organisation can use the panel for large-scale surveys. Alternatively, individuals can be selected to participate in smaller group discussions, focus groups or other consultation exercises. Users' panels are similar to citizens' panels with the exception of the fact that they focus on individuals with certain characteristics rather than the whole population. For example, a users' panel may be comprised of a particular group of people with long term medical condition, those who use a specific service, those who visit a certain hospital or those using the occupational therapy service. One way of using a user panel is to operate it as a district-wide customer panel, in partnership with other organisations, using postal questionnaires and consulting a few times per year. District Circles can be rapidly established and easily maintained, even with limited resources. Please find out if your Local Authority, Local Health Council, Local Health Care Cooperative or NHS Board has established a user panel before setting one up.

Panels can be used in a wide range of ways - for surveys, as a source of delegates at conferences or workshops or for other forms of participatory and qualitative work. Panel consultation can be stand-alone exercises or used jointly with other approaches. However, there is a risk that, because of this very flexibility, they may be over-used to the point where participants suffer from "respondent fatigue".

The strengths of the approach are as follows:

- Panels allow co-ordination within and between agencies, enhancing partnership working.
- As panel members are recruited on a voluntary basis, they are more likely to be committed to responding to questionnaires, thus producing more reliable results than non-panel postal surveys.
- Panels usually involve contact with a large number of people and offer the opportunity to consult members of the population who have traditionally been hard to consult - such as members of ethnic minority groups - by conducting door-to-door recruitment.
- Panels can allow changes in the composition of an area to be tracked by obtaining regular and updated information about the resident population.
- Panels allow individuals to develop a relatively high degree of collective knowledge of an organisation's responsibilities and services.
- Once established panels are a quick and inexpensive method of gathering information.
- Providing that adequate feedback is given, participants generally feel valued.

Targeting

A key aspect in the establishment of the panel is ensuring that it is as representative as possible. Panels established in Scotland generally have adequate representation of ethnic minority and disabled people, but this must be ensured by careful targeting at the outset. There is a risk however that certain groups, such as those with limited spoken English, could be excluded.

The larger the number of people on the panel, the greater the potential for sub-groups to be identified e.g. young people, older people, those in different geographical locations. Some methods of recruitment involve self-selection but it is possible to ensure that the panel is not entirely self-selecting.

Issues to Consider

In establishing a Citizens' Panel (sometimes called a Health Panel in the NHS), the following issues should be taken into account:

- The panel is a means of developing an understanding amongst a group of people with a sense of involvement in an organisation's activities, and of acting as a sounding board for issues and proposed developments.
- It has a very flexible format which can be adapted for use in a variety of areas, or issues.
- Panel recruitment reaches a large number of people either through postal distribution or door-to-door contact.
- Experience has shown that, once recruited, panels can elicit high response rates and expressions of interest from the community.
- Scientific and robust methods of recruitment, questionnaire design and analysis must be used to recruit and survey panel members, both to ensure that the members are representative of the population as a whole and to ensure that minimal bias is achieved. Use other approaches to check out detailed opinions of the panel.
- Panels allow surveys or other research to be undertaken at short notice.
- Considerable staff support is required to establish and maintain the panel.
- As panel members become increasingly experienced and knowledgeable, they may also become less representative of the population as a whole, thus necessitating regular replacement of the membership.
- The panel reflects the agenda of the organisation, rather than that of the community.
- Specific skills are required to analyse the data.
- A considerable degree of commitment is required from participants who may be asked to contribute to regular questionnaire or telephone surveys for example, or to attend various events. Please ensure that effective support mechanisms are in place for this, for example, expenses on the day, debriefing, adequate breaks and access support.

Resources

The set-up and recruitment costs are likely to be expensive, requiring significant resources in terms of staff time, skills and money. However, sharing costs (both set-up and maintenance) with other partners can be cost-effective and should ultimately prove to be cheaper than conducting regular, one-off surveys. Panels allow regular, large-scale surveys to be carried out at a lower cost than if done separately and response rates tend to be very high. For example, a postal survey of panel members might be expected to achieve a response rate of 60-75%, compared with response rates of c20-25% for non-panel audiences.

Recruitment of potential participants can be undertaken by postal distribution, followed by a door-to-door “top-up” exercise to target those participants who might otherwise be excluded (i.e. disabled people, the young or those from ethnic minority groups). Recruitment costs will vary according to the method of recruitment used. As guidance, one of the cheaper options is to recruit using a self-completion approach, but with some personal targeting of more difficult groups. A panel of 1,000 recruited by this means would cost £10,000-£18,000. The annual revenue cost of the South Lanarkshire Citizens’ Panel is estimated at £20,000. This sum provides for the maintenance of the panel database, rotation of panel members, stationery, feedback and the annual Quality of Life survey of the full panel.

As mentioned above, a high level of staff support is required both to establish and maintain the panel, and to analyse the data.

A number of panels in Scotland are jointly managed. The advantages in jointly managing a panel with other key service providers are as follows:

- The ability to share resources and avoid duplication of effort
- Improved communication and information-exchange
- The promotion of joint objective-setting and performance monitoring
- Access to a valuable tool for community planning.

Providing feedback on survey results or the outcome of consultation can minimise the dropout rate of panel members. However, regular and systematic renewal of panel members is required to ensure that they are still representative of the population.

Potential Pitfalls

There is a risk that organisations can become over reliant on their panels. This is one of the problems faced by Scottish Local Authorities, as individual service departments become increasingly aware of the potential value of this resource. However, the panel may not contain sub groups of interest to make it an effective consultation channel for such purposes, and it may be more appropriate to develop user panels or user surveys for example. Strategies need to be put in place, particularly in the case of shared panels, to ensure that participants are representative of all groups in the community and that self-selection and attrition do not bias the sample.

Much of the literature on citizens' panels highlights the potential problems of panel staleness and wear-out, discussing the need to refresh panels as well as replace panel leavers or no-participants. Over an 18-month period response rates declined from 70+% to 50-55% for two panels in Scotland. These panels are now being refreshed and consideration being given by one panel manager as to how to better incentivise panel members. As part of their panel maintenance, local authorities in Scotland actively ask panel members to opt to continue their panel membership on each occasion they approach them for information. This is seen as more cost effective than trying to contact those who have decided not to participate.

Panels are not ideally suited to the collection of tracking data and monitoring of change in performance standards as panel members may become more aware and informed of services or issues and may provide atypical results. There is a belief that panels do not need to be refreshed if care is taken about the range and mix of issues on which they are consulted. It is argued that as long as panel members are not continually consulted on the same issue, and if no attempt is made to use panels to measure change over time such as in service delivery standards,

then a panel could be run for years before being 'retired' and entirely replaced.

Examples of Use in Scotland

Following discussions with local public service providers in spring 1998, South Lanarkshire Council established the first Scottish citizens' panel of 1,600 members in conjunction with Greater Glasgow Health Board, Lanarkshire Health Board, Scottish Homes and Lanarkshire Development Agency. City of Edinburgh Council established the second panel in Scotland.

As well as having a citywide panel of 2,000 individuals, there are two booster panels, one in the West Edinburgh Community Planning Area and one in the South Edinburgh SIP.

Numerous other panels now exist in Scotland.

Borders

The Health Council Consultation panel was started 2 to 3 years ago and the reason for this was to expand the number of people responding to questionnaires or attending focus groups. The purpose was to create a group of people who could be asked to attend meetings, focus groups or respond to questionnaires so that it was not always the same people responding and is a way to gain views quickly. The Health Council is currently expanding this group and developing it so as to represent members' interests. For more information or, if you live in the Borders area, to join this group please contact Borders Local Health Council on 01896 753 601.

Forth Valley

The 'Forth Valley 500' is a group which has been set up by the Local Health Council to participate in Surveys, questionnaires and focus groups amongst other things to develop the health service in their area. A database has been set up of members detailing who they are and what they are interested in. Already members of this group have participated in a postal survey on GP & Dental Services with a second one on Pharmacy Services about to be distributed as well as a Focus Group on Cancer Services. As an incentive the people who have joined have their names put into a hat and the one whose name is drawn can have £25 donated

to charity in their name. For more information or, if you live in the Forth Valley area, to join this group please contact Forth Valley Local Health Council by emailing admin@forth-hb.scot.nhs.uk

Background Reading

Argyll and Clyde Health Council: Health Panels in Consulting the Public: The Role of Health Panels in Argyll and Clyde (1999).
Published by Argyll and Clyde Health Council, Paisley

Local Government Information Unit: Citizens' Panels - a new approach to community consultation (1997). Published by Local Government Information Unit, London

7. Comments and Complaints Cards

Overview

Customer comments cards or complaints cards are a simple concept by which cards are displayed in an accessible place for members of the public or users of a service to record any comments they have to make about the service. This is a cheap and effective way of monitoring service provision; it can highlight recurring problems and also provide feedback. The approach can be extended to allow comments or complaints to be registered by other means - by telephone or through IT-based systems.

- This is a very cheap way of monitoring users' views of a particular service.
- Due to the anonymous nature of the approach, users are more likely to be honest in their comments.
- The approach attaches equal significance to both small and large issues that are raised by users as no attempt is made to gather information on numbers affected or strength of feeling.
- The cards provide a channel to collect accurate and current perceptions of the service delivered as their use is tied to consumption of the service.

Targeting

The respondents are generally self-selecting and there is no opportunity for targeting specific groups. Certain groups will be excluded due to time pressure and access issues. Cards may also only attract comments from those at the extreme ends of the spectrum - the very satisfied or very dissatisfied. However, the cards are more likely to be completed if they are attractive and eye-catching. Midlothian Local Health Care Cooperative have found the best response rates are when Suggestions Boxes are used around a particular issue rather than something which is operating all the time.

Issues to Consider

- The wording on the comments cards / complaints cards should be carefully considered as any ambiguity could be very misleading

- Quite a low level of response should be expected as the target population relates solely to the number of service users who are motivated to take part.
- Use Suggestion or Comments boxes for specific issues/ ideas rather than a continuous initiative.

Resources

As the resources are often already in place within the organisation, the use of comments cards / complaints cards can be a very cost-effective method of consultation.

Potential Pitfalls

People are more likely to complain about a bad experience than applaud a good one. This may result in the pattern of responses being skewed.

Future Use/Approach

Due to their cost effectiveness, future use is likely to continue to be widespread. If possible, acknowledgement should be made of the views expressed on the cards, and subsequent actions taken, in order to encourage others to use them.

8. Community Indicators

Overview

Community indicators are being developed in communities throughout the UK to measure local trends that are important in these communities. These tools allow essential information to be simplified, measured and communicated and can be a mechanism through which local people can make their opinions heard. The results increase awareness of problems and opportunities and help to establish agreement about future action. They contrast with performance indicators, established using a top down approach and seek to provide a uniform basis for comparing communities on standard measures.

The process involves six distinct steps:

- Start-up
- Identification of issues through questionnaires, interviews and workshops
- Selection of indicators for each issue
- Gathering of information
- Communicating progress to the community through the relevant media
- Action and progress review.

The strengths of the approach are as follows:

- Communities of all varieties and sizes can be involved
- Local people have the opportunity to effect changes in their communities
- The operational costs are relatively low.

Targeting

All sectors of the community are involved in this process.

Resources

An internal or external facilitator, in addition to local experts, may aid the process.

Participants should have access to a quiet area where they can work in small groups.

Information display boards may also be helpful. Operational costs are low, unless a report or display is prepared.

Examples of Use

At present, there are many community indicator initiatives in the UK, which aim to involve the whole community. Work planned by SIPs in Scotland will also follow this model in identifying a range of indicators appropriate to each SIPs target groups.

Background Reading

Burton, P. and L. Harrison: Identifying Local Health Needs: New Community Based Approaches (1996)
Published by Policy Press, Bristol

New Economics Foundation: Communities Count! A step by step Guide to Community Indicators Tel: 0207 407 6473

9. Community Profiling / Community Appraisal

Overview

Use of the Community Profiling or Community Appraisal approaches involves a group of individuals from a community working together. Numbers involved can vary, with up to a few hundred taking part. The group, by establishing priorities, builds an all-encompassing description of an area. The description takes into account factors that will shape the development of the area such as social, environmental and economic issues. This is then used to inform decision-making and explore changes that need to be made in the community.

The process is totally focused on the community i.e. it is a survey of the community, by the community, for the community and produces an action plan or list of recommendations for the future of the community.

46

The typical stages of a good Community Appraisal are as follows:

- A few enthusiasts seek to establish a sound basis of local support for the appraisal.
- A widely drawn steering group is established to decide the "what" and the "how".
- A questionnaire is drafted and a household survey planned.
- Individual questionnaires are distributed to every household for later collection.
- The responses are coded and analysed.
- An appraisal report, recommendations and action plan are drafted.
- The recommendations are prioritised and linked to the most appropriate group/agency.
- Organisations are persuaded to adopt the recommendations as official policy.
- The report is publicised via the press, local magazine or notice boards.

- The document is distributed locally and to outside agencies at no, or only a small, cost.
- The document is discussed by the community and consensus on priorities/action sought.
- Task forces are established to take forward action points within an agreed timescale.
- Progress is monitored and reported.
- Community Profiling/Appraisal gives community members the opportunity to discuss issues which they feel are important within their area.
- Community members are encouraged to contribute towards identifying ways in which the issues could be approached and resolved.
- All parts of the community can be involved and everyone who attends has an equal opportunity of having their views considered for action.
- Priority issues are identified through discussion.
- Response and participation rates can be high; e.g. 60% return on self-completion questionnaires was recorded in one area and turnout at meetings can be in excess of 100.

Targeting

Not everyone in the community can take part in the community profiling exercise. Care should be taken in assembling the initial steering group to ensure that a good mix of individuals from different backgrounds is obtained. It is vital that those who form the group will have the support of the community whose views they represent. In particular, minority viewpoints should be represented.

Issues to Consider

- The group should be structured in a way that gives all participants equal opportunity to contribute.

- As discussion of community issues can provoke much heated debate, a way of reaching a consensus about priorities needs to be found.
- The process can last as long as 2 years.

Resources

Community Profiling can benefit from outside expertise to facilitate the process and ensure that priorities emerge. This adds significantly to the cost. Suggested budgets range from £500-£5,000, mainly to cover report costs. A computer analysis package may be required.

Potential Pitfalls

The prioritisation approach can often leave members of the group feeling that their points of view are not being heard because others within the group are more assertive or outspoken, and care must be taken to avoid this. This is an interactive process and some of the steps below are continuous. Later steps in the process will need to be considered at an early stage.

The ten steps (identified by the School for Advanced Urban Studies) are as follows:

- Step One: Assembling a Group
- Step Two: Initial Prioritising
- Step Three Initial Planning and Timescale
- Step Four: Mobilising Resources
- Step Five: Gathering Data (survey based)
- Step Six: Analysing Data and Identifying Needs
- Step Seven: Presenting Results
- Step Eight: Taking it Forward - discussion with the community and consensus
- Step Nine: Working with Others
- Step Ten: Monitoring and Evaluation.

Other sources of information add an initial stage of establishing support for the issue within the community at the outset.

Examples of Use in Scotland

The approach is mainly used in rural areas, but is not widely used in Scotland. We are aware of only one SIP in Scotland that is considering the option in order to identify problems and issues within various sub areas of the SIP.

Background Reading

Burton, P: Community Profiling - A guide to Identifying Local Needs (1993)

Published by School for Advanced Urban Studies

Hawtin, M. and G. Hughes: Community Profiling: Auditing Social Needs (1994)

Published by Oxford University Press, Buckingham

10. Deliberative Opinion Polls and Referenda

Overview

To conduct a deliberative opinion poll, a representative sample of the target population is selected. The chosen respondents then learn more about the topic - through information sessions, asking questions or participating in a meeting or discussion group. At the end of the discussion, a poll of their views is taken.

On occasions, other polls can be carried out during the process - sometimes at the outset - so that the way in which views have altered can be measured.

This method enables participants to develop some knowledge of the issue prior to giving their views. As such, it can be a better reflection of what views will be following the education and debating process that surrounds a variety of general interest issues.

50

Referenda are similar to deliberative polling techniques in that people are asked to vote either for or against one option or a limited number of options. Referenda are wider in their coverage, often attempting to poll all those likely to be affected by an issue.

A variety of different approaches such as postal ballots and personal voting can be used to conduct referenda, while information technology is presenting new possibilities. In addition to electronic systems that allow groups of people to vote for particular options, telephone and Internet voting from home can be used. Remember to consider the characteristics of the people who are most likely to have access to the internet.

The strengths of the approaches are as follows:

- Respondents have time to consider relevant information before stating their views
- A quantitative measure of “informed” views is provided
- The public’s likely response to a proposed campaign can be tested.

Targeting

Although all sectors of the population can be included in deliberative opinion polls, care must be taken to identify respondents within the target group. As with other techniques, there is a risk that non-English speakers could be excluded.

Issues to Consider

The following issues should be taken into account:

- Deliberative polling and referenda are only suitable for certain types of issue on which people can effectively be asked to vote after being given some preliminary information.
- A pilot study is recommended.
- The issues discussed should be of significant interest to the users.
- A decision has to be made regarding the type and quantity of information which is to be given to respondents and this has to be presented in an appropriate manner.
- Questions must be phrased in a way that allows a clear choice between options.
- The meetings, information sessions and/or discussion groups must be well planned and structured.
- Results can be swayed by the amount and quality of information provided by the supporters of each option.
- The use of IT-based methods of polling or voting may improve participation levels, but these techniques may pose issues of confidentiality and misuse.
- Deliberative polls are generally seen as part of a continuous or wider process.

Resources

Deliberative polling and referenda can be very expensive methods of consultation. Participants often receive a small fee if taking part in a deliberative opinion poll. The approach differs from the jury approach in that a count of opinion or quantitative response will be taken.

The approach can vary in length depending on the amount of information provided. Participants at deliberative opinion poll events should have the opportunity to debate the issues, hear from supporters of all the different options and make a considered choice. Participants generally number between 100 and 300. The format of the meeting has to be carefully planned, including speakers, equipment, room layout and group leaders. Referenda require mass publicity and a substantial input of resources.

Potential Pitfalls

The main problems identified by organisations that have conducted deliberative opinion polls were poor attendance and a low response rate. One organisation stated that the information they had obtained was skewed and unrepresentative as insufficient people had voted and an interest group had managed to sway the result. Another claimed that the exercise had been too time-consuming. As both approaches only produce top line information, they may need support from other approaches in order to demonstrate how certain views have developed.

Examples of Use in Scotland

The approach was used by a small number of Pathfinders, local authorities, SIPs and Education Departments in the since 1999. Only one Health Board claimed to have used the approach. National referenda are fairly rare although they have been carried out at local levels - for example, the former Strathclyde Regional Council carried out a referendum amongst residents in the area on the proposed change in responsibility for the water and sewerage service. Western Isles Council carried out two referenda on the proposed quarry development at Lingerbay, in Harris.

11. Design Game

Overview

The Design Game is a modelling technique. It is based on a scale plan of a site mounted on card and has moveable pieces that can be used by a group to create their own design.

This consultation method is relevant when the following circumstances apply:

- The site is not excessively large and can be easily defined.
- Members of the group are well acquainted with the pertinent issues and problems.
- The project has received confirmation.

The exercise is divided into several distinct stages:

- A survey of the site and its problems is implemented
- The group participates in site visits and examines relevant material
- Following a brainstorming session, specific elements are drawn to scale
- The pieces are moved around the board (main game)
- The results are drawn up by a landscape architect
- A detailed scheme is put together for implementation by a contractor or the group, working independently or as a partnership.

The strengths of the approach are as follows:

- Participants are empowered to manage the exercise.
- Responsibility for management decisions is disseminated outwards.
- Many people can be involved in the process.

Targeting

As mentioned above, this technique is accessible to a large number of people. The visual display is acceptable to those with poor literacy skills and appeals to all ages.

Resources

There is no finite number of participants. The services of a landscape architect and contractor are required. The venue should be sufficiently large to allow people access to the model.

12. E-consultation

Overview

In Grampian a two year project is funded to explore the potential and implications of a new on line consultation tool devised by British Telecom. The software has three modules:

- Questionnaires or surveys (census)
- Collection of Feedback from documents (comment)
- Open Discussion (collect).

The software can ask both quantitative and qualitative questions. BT can host consultations on their dedicated servers to enable controlled secure access to them across the Internet. One of the strengths being evaluated is that it can elicit people's 'immediate' currently held views. It should also elicit the views that people arrive at if they have had an opportunity to learn about and deliberate on issues on which they are consulted.

Issues to Consider

- Not much is yet known about how e-technology can be used in the NHS to facilitate public involvement.
- Methods of sampling needs to be explored.
- Respondents may not be representative of general population.
- People may have concerns about security and confidentiality of their personal details.
- Suitability of topic for e-consultation.
- Computer literacy and access to computers of the people you want to involve.

Resources

The costs and benefits, as well as the pitfalls, will be evaluated by the funded project in Grampian.

Examples of Use in Scotland

This methodology is being piloted and evaluated in Grampian Health Council from 2001. The current contact at the time of writing is Cathy Dorrian. Her email address is catherine.dorrian@glhc.grampian.scot.nhs.uk.

13. Exhibitions, Campaigns and Presentations

Overview

In many ways the use of presentations, campaigns and exhibitions is similar to that of public meetings, albeit that the audience may be more targeted. The overall aim of these approaches is to convey information to the general public or to a specified group. The community themselves can also instigate, design and present to the NHS. An aim may be to notify users of a service that it is about to change, inform the public of an organisation's plans, or fulfil an educational function. Often these approaches are run over a period of time - this increases audience penetration. Campaigns, presentations and exhibitions are often used in conjunction with other work being conducted by an organisation.

This approach:

56

- Involves the community affected by raising their awareness and usually giving them the opportunity to contact someone if they wish to discuss the topic further.
- Provides wide access to a range of individuals through a variety of means / materials e.g., illustrations or interactive technology.

Targeting

The range of success in terms of reaching target groups who are normally excluded can vary with these approaches. One way to overcome this is to ensure that the promotional campaign is widespread or targeted effectively to the group of interest. There needs to be a clear understanding of the identity of the target group.

Issues to Consider

- The materials being used to convey the information must be in plain language (without jargon) and, where appropriate, in translated form or other accessible formats.
- A creative approach should be adopted.

- It can be difficult to measure effectiveness in reaching different groups or in communicating with individuals, especially if there is no feedback or update mechanism in place.
- The approach may not reach a large number of people or all target groups.
- It can be very expensive to produce materials and run these, both in terms of staff time and in terms of value for money if a low turnout results.

Resources

The cost of implementing these approaches - both financially and in terms of time - can vary greatly. It is important to get advice from people or professionals who are trained in effective communication initiatives. Leaflet writing and poster design is a skill, as is writing in plain language.

Potential Pitfalls

Ineffective promotion may mean that the population is not targeted effectively. Due to the random nature of those reached by this approach, the information generated cannot be considered as representative of all views.

Examples of Use in Scotland

All Health Boards say they have used campaigns, presentations or exhibitions, while most LECs and local authorities have also used this method.

Many Local Health Care Cooperatives have held 'Open Days' in the past two years or so. The success, as judged by the Local Health Care Cooperatives, has been varied. In one area in Glasgow one 'patient' and 22 staff attended. In Lothian (Leith), several hundred people attended with many activities happening before and after the event itself. Some Local Health Care Cooperatives have carried this out with an integral theme, for example, in Kirkcaldy young parents came and took part in Forum Theatre, a Health Promotion needs assessment, information seeking and alternative therapies. A creche was provided. Several of the attendees have gone on to become much more involved in the work of the Local Health Care Cooperative.

14. Focus Groups

Overview

Focus groups usually involve 8 to 10 people in each group who discuss a particular topic or a range of issues, in depth. It is normal for more than one group to be convened on an issue and for participants with similar characteristics to be included within the same group.

Focus groups are a useful way of targeting specific groups whose views may not normally be heard. Generally a focus group will last for 1 to 1½ hours. However, as it is a very flexible approach, it can be extended to last for a 2-3 hour period, or may have reduced numbers (i.e. a mini group of 3-4 individuals where attendees are likely to be very articulate about the issue under debate). A wide range of stimulus materials can be used. Some semi-quantitative data can be obtained during the recruitment process for larger programmes of groups using this technique, for example, if a number of individuals are recruited to the group, quantitative information can be obtained for all contacts, regardless of their attendance at the group.

- Focus groups and depth interviews can provide participants with an opportunity to illuminate ideas and views that are not always accessible through other means of consultation.
- By targeted recruitment, they provide the advantage of exploring the views of groups that are traditionally excluded from consultation.
- Flexibility - focus groups and depth interviews enable participants to raise and discuss issues other than those identified in the topic guide/by the researcher.
- Participants are more likely to get involved and feel their views are valued when they have been invited to participate.
- Careful recruitment is essential.

Focus groups and depth interviews tend to be conducted as one element of a project and will often take place within wider consultation approaches. Focus groups are often used with workshop sessions or to help develop questionnaires.

With other more quantitative approaches, focus groups can be used at the end of the information gathering, to obtain more information about points that have been raised by the quantitative research or to inform future quantitative research, most often in terms of questionnaire design. Depth interviews (see below) are often used in association with focus groups.

Targeting

Focus groups provide a way of speaking to groups that would normally be excluded from other consultation approaches, where control is exerted over the recruitment process. To ensure that all individuals feel at ease with one another and to reduce any feelings of unease, people from similar backgrounds are often recruited to attend a group together as this enhances the group dynamics and promotes discussion. You can find groups of people with similar characteristics through local community groups, for example, the local youth groups, bowling club, bingo hall or pub.

For sensitive subjects or when dealing with young people, groups can be recruited using friendship pairs i.e. recruiting one person who meets the requirement and asking them to bring someone else with them who will also fit the group profile. In the Scottish Borders, male partners of the women at the Mother and Toddler Group were invited in the evening and encouraged by some embibing incentives!

Issues to Consider

- If the general tone of a focus group is one of conventionality this can sometimes prevent others from raising points that they feel are salient, but not part of the norm.
- Use of a fully trained moderator is essential to ensure that any dominant individuals within the focus group do not influence others, and to ensure that everyone has the opportunity to state what they think and that the data is analysed properly.
- It is often preferable to conduct a number of focus groups on one topic as this ensures that a wide range of views is covered and not those based purely on what may be a particularly opinionated group.

- There is a need to ensure that those recruited are representative - or for the organisers to be explicit about the particular perspective of the group.
- To ensure that a full interpretation can be made, discussions should be recorded in full, where possible. Analysing this type of information is a skilled process involving reference to written, verbal, observed and unarticulated data. Particular skill is required to identify patterns in the data and interpret it.
- A topic guide should be used to guide the discussion although participants should be able to raise other issues. Development of a clear interview structure is needed to ensure that the information gathered from the interview is relevant and of interest.

There should also be a generous time allowed to set up the groups, as potential participants may not be available to take part at the required time.

60

Resources

- Time and costs of facilitator
- Venue and catering
- Supporting participants - carer or child costs, travel expenses (to be met on the day). Cash or vouchers for their time (around £15 is the norm currently).

It is hoped the National Exchange Trading Scheme will allow NHS staff and members of the community to trade trained time and facilitation.

Potential Pitfalls

Recruitment for focus groups can be time consuming, as it is sometimes difficult to find a target group that meets the very precise characteristics of the target group. Extra time should be allowed to ensure that appropriate recruitment is conducted. Self-selecting groups should be avoided. Nor is it possible to regard one group as representative of all views. A wider programme of groups is often needed.

As some target groups are difficult to access, numerous recruitment approaches should be considered. Also, as the location of the focus group will have an impact on attendance, it is important to ensure that it is accessible and informal (depending on the target group) and that provision is made to help those with children or access problems to attend, for example.

Additionally, it can often be difficult to remain interested and to formulate an overview if only one person is conducting all of the focus groups on a subject, especially when there is a large number to be completed.

Examples of Use in Scotland

Greater Glasgow Health Board ran a programme of focus groups to look at health issues in part of Glasgow. The groups made use of video diary stimulus materials to prompt discussion.

The Scottish Executive funded the Scottish Consumer Council to carry out 40 focus groups around Access to Primary Care in Scotland. The groups were a range of people, reflecting social class, rural or urban and community of interest, for example, lesbian women. A report is available from the Scottish Executive, Primary Care Division.

Sandyford Initiative (Sexual Health) in Glasgow carried out Focus Groups with disabled people to assess how accessible their services were. The young disabled people (part of a Disability Forum) had no idea that they were allowed to seek sexual health advice of their own accord.

Background Reading

Haines, M.: Patient Focus Groups and Dynamic Improvements: a practical approach to achieving excellence in health care management (1995)

Published by Royal Brompton NHS Trust, London

Kreuger, R. A.: Focus Groups as Qualitative Research (1988)

Published by SAGE Publications, London

Morgan, D.: Successful Focus Groups (1993)
Published by Sage Publications, London

Morgan, D. L.: Focus Groups (1988)
Published by Sage Publications, London

Preston, C. et al: All you ever need to know about running focus groups but were afraid to ask (1995)
Published by Audit Trends

15. Future Search

Overview

A Future Search conference enables a community or organisation to create a shared vision for its future. Stakeholders are selected on the basis of prior knowledge of the topic or as they are likely to be affected by the outcomes. The main stages of the process are as follows:

- Review of the past
- Exploration of the present
- Creation of ideal future scenarios
- Identification of a shared vision
- Formulation of action plans.

Participants may feel empowered as they are regarded as experts in their own lives, there is an emphasis on self-management in small group work and all contributions are displayed.

63

Targeting

Future Search commonly involves 64 participants forming 8 tables of 8 stakeholder groups.

Resources

A minimum of one facilitator is required, together with a committed partnership group. The venue must be large enough to incorporate 64 people in tables of eight, presentation space and display areas. This highly structured process generally costs between £5,000 and £10,000, although the cost of some of the first Future Searches in the UK ranged from £2,500-£40,000.

Issues to Consider

A Future Search conference is considered appropriate when the following factors apply:

- There are influential people in strong support of the approach in the sponsoring body.
- All sectors of the community are represented by the steering group.
- Sufficient time is available to recruit participants and prepare for the event.

Examples of Use

Approximately 20 Future Search conferences have been held since the first UK training was organised in 1995, including one in Moray. Most conferences have taken place in local communities, with some specifically targeted towards health. Aspects of the approach have been used in various conferences organised in Scotland e.g. Wester Hailes Youth Conference.

Background Information

Future Search Video of an event in Hucknall
Published by Nottinghamshire County Council on 0115 977 3067

16. In-depth Interviews

Overview

In-depth interviews are similar to focus groups in the skills required, set up and type of information that can be obtained. As they are usually conducted on a one-to-one basis and allow exploration of a particular topic or feature relevant to the participant, this does restrict the extent to which the views expressed may be challenged and subject to debate.

In-depth interviews give the interviewer the opportunity to build a relationship with the participant, gain their confidence and as a result gather very detailed or sensitive information. In-depth interviews can also be conducted as paired interviews (2 people) or triads (3 people). When an interview of a sensitive nature or, for example, is being conducted with young people, it is often a good idea to use a pairing approach. In the instance of interviewing a young person, they could bring a friend along - this approach may make them more relaxed and thus improve the quality and content of the interview. In-depth interviews are also useful where it is not possible to group respondents - i.e. busy Chief Executives of organisations whose diaries will not dovetail or patients widely dispersed across an area.

Targeting

An interviewer who has been trained to conduct in-depth interviewing and who has independence from the service or organisation can target relevant people. People who live in the community or who have established trust in the community may provide links to people who will agree to be interviewed.

Resources

The cost of conducting in-depth interviews can vary greatly depending on the numbers being interviewed, the travel needs and the number of interviews being completed.

Examples of use

Depth interviews are useful when interviewing members of traditionally excluded groups, or on a very sensitive subject. In one area the referrers to the Podiatry Service were interviewed rather than invite them to a Focus Group.

The use of depth interviews is especially widespread amongst LECs and local authorities. Borders Health Board interviewed elderly patients (in depth) who had been in hospital, to assess the way the health service had worked for them and how it could be improved.

In Tayside, people receiving palliative care were interviewed carefully and in depth about their views of the service.

The Medical Research Council Sociology Unit, based at University of Glasgow, carried out 1500 in depth interviews as part of a large scale research project "2007 Project". Three cohorts (15, 35 and 55 year olds) are being followed over 20 years, from 1987 till 2007, examining in depth the factors that influence inequalities in health.

17. Internet

Overview

The Internet provides an electronic means of communicating with individuals or organisations across the world. Its main strengths are:

- It is immediate.
- Distance is no barrier
- You can set up discussion groups or chat rooms.
- You can reach audiences that are not already in contact or are not known.
- It is one means of two-way communication.

Targeting

Only around 15% of people have access to the internet at the current time but this is growing all the time. Most people who have access are either younger, professionals or have higher income. If you want to target people who are not in these bands, then consider using other ways of involving them.

Potential Pitfalls

As above, the range of people who have access is limited and respondents are not likely to be representative of the general population. It is dependent on the reliability of hardware and software and the response rate may be low. The respondents are not anonymous which may affect response. The same guidelines for written information (above) apply to the written text on a website, including text size, reading age and format.

Examples of Use in Scotland

The use of the internet is widespread within the NHS, though particular groups of staff do not have easy access.

- SHOW (Scottish Health on the Web) is well known within the NHS but the public are not so well informed.
www.show.scot.nhs.uk
- www.designedtoinvolve.org.uk was the website to support the public involvement in primary care in Scotland initiative. It is currently being developed as the

Involving People website to include the content of Designed to Involve and other work related to the 'Patient Focus and Public involvement' document published by the Scottish Executive in December 2001. The website meets the standards of the Scottish Accessibility Information Forum and is 'Bobby Approved' which means that people with visual impairments can access the information. Ref: www.saifscotland.org.uk

- Many NHS Trusts and Local Health Care Cooperatives have their own websites, as do Local Authorities which are an excellent source to find out community networks and organisations.
- There are many e-groups and chat rooms around specific health issues on the internet. Chat rooms and bulleting boards are easily built on to websites. One example can be seen on the Designed to Involve website. The problem is trying to keep it up to date!

18. Leaflets and Other Written Information

Overview

Information is a basic human right and is extremely important to most people. For individuals, patients, carers, friends and family, information on diagnosis, prognosis and clinical treatment, is crucial. All efforts should be made to ensure that when the NHS conveys information that it is accurate, timely, relevant and appropriate to the people who receive or who are with people who receive NHS services. Giving information is not a substitute for involving people in wider and more in depth NHS issues.

Remember also that patients and members of the public may wish to use written information to communicate with the NHS. Written complaints follow a formal process, but people may wish to feedback ideas, thoughts or suggestions in writing.

Information can help people to contribute more effectively to discussions about their care or about services. Traditionally it is the NHS professional who decides what is contained in information to patients and potential service users. It is important to recognise that people who have experience of illness and disease or our service have a valid view on what has happened to them and that this perspective is gathered and they are included in the development of information.

It is also important to be aware of how information is presented. Young people know what appeals to them and we should ask them to help us to help develop the content and the presentation of that information. This also applies to other groups of people. They know the routes that people use to get information, and this may not be racks in the surgery or clinic.

Targeting

Noticeboards and leaflets are generally not the best source of information for the 88,000 people in Scotland who have a visual impairment or the many thousands who do not read English. The average reading age of people in Scotland is around 11 years. One of the most popular newspapers has a reading age of 9.5 years. It is still possible to use medical terminology as long as it is well defined.

Issues to Consider

- What is the best format to reach your target group? Leaflets, noticeboards, websites, verbal information, large print, audio tape?
- It is very expensive to get all information translated into many different languages and in many different formats. Consider who you are targeting and why and ask them what is the best way to have this information conveyed and understood.
- Written information, even if it meets reading age requirements, will not necessarily meet all of your target population.
- People who have special communication problems should be considered when you are planning information. There are various ways of conveying information that does not depend on written English, for example, graphical languages for people with learning difficulties.
- The minimum font that should be used is Arial 14. Avoid the use of passive expressions, for example, 'You will be treated..' or 'a catheter will be inserted'. Instead use active verbs like 'a nurse will give you a ...' or 'the physiotherapist will ask you to...' As well as being more explicit, this lowers the reading age of written materials.
- When designing information, use questions gathered from those who have experience of the service or the illness or condition, as prompts for the information. Perhaps design it in a way that people can skim for basic information and then go back to the same leaflet and read underneath that for more details.

Resources

Printing can be expensive so it is important to target information where it is needed and in the format that will reach the people it is meant to inform. Printed information will never be a substitute for good verbal communication and is only a back up for this. People need different kinds or levels of information at different times and written information can never be as flexible, so consider using your limited printing budget in a very targeted way.

Potential Pitfalls

Written information can very quickly become out of date. It is tempting to write the information without consulting patients and users of the service. Do not assume that you know what people need or want to know.

Examples of Use in Scotland

In 1998 West Glasgow Hospitals Trust (as it was then) trained over 100 staff in the Plain English Campaign writing course. These staff formed a network within the Trust to edit and advise on the development of all Trust information. Information which met set standards and had gone through the process was given a 'Striving for Good Communication' award. All Trust written information was audited yearly. Ninewells Hospital in Dundee and Grampian University Hospitals Trust have developed a similar scheme which is still current (in 2002)

Background Reading

How to provide information well to Bangladeshi, Chinese, Indian and Pakistani People: a good practice guide (1998)
Published by National Information Forum

Royal National Institute for the Blind: See it Right! (2001)
Published by the Royal National Institute for the Blind, London

Scottish Accessible Information Forum: Standards for Disability Information and Advice Provision in Scotland (1999)
Published by Scottish Consumer Council, Glasgow

Websites

Aberdeen University Health Service Research Unit
www.abdn.ac.uk/public_health/hsru

The national remit of the Health Services Research Unit (HSRU) is to research the best ways to provide health care, and to train those working in the health services in research methods. They are producing three, evidence-based patient information leaflets.

Cabinet Office - Service First
www.cabinet-office.gov.uk/servicefirst/

"This site brings together two important aspects at the heart of public services - meeting user needs and helping to improve the effectiveness of Departments, agencies and the wider public sector."

Centre for Health Information Quality

www.hfht.org/chiq/index.htm

This site is dedicated to ensuring that all patient information is clear and evidence based.

DISCERN

www.discern.org.uk

The DISCERN website is an experimental site consisting of an online version of the DISCERN instrument and handbook. The handbook is designed to help you understand and use DISCERN effectively.

Joseph Rowntree Foundation

www.jrf.org.uk

The Foundation is the largest social policy research and development charity in the UK and places great emphasis on disseminating the findings of its work and engaging with policy-makers and practitioners to develop better policies and practices. The site has many documents relating to the involvement of people from many walks of life.

Scottish Accessible Information Forum

www.saifscotland.org.uk

SAIF aims to make information more accessible to everyone who needs it. SAIF supports the rights of disabled people and carers in having access to timely and accurate information about a wide range of services.

Scottish Connections Disability

www.connections.gcal.ac.uk

Offers a variety of services such as website design and auditing of your existing website. Also has a discussion forum for disability issues.

19. Local Sustainability Model

Overview

The Local Sustainability Model is a technique by which a community can assess its present position and test the likely effects of projects. The Model consists of a three by three matrix. The columns represent the three components of sustainability while the rows represent the condition of these components. The current state of affairs is defined and projects are assessed through their effects on the Model. Using a quantitative approach, teams of no more than seven people assign scores to each column, discuss the results and agree a common assessment.

The strengths of the approach are as follows:

- Local people can assess the impact which projects will have on their community.
- Discussion and co-operative working are encouraged.

Targeting

There is no finite number of participants, although it is preferable for the discussion groups to have no more than seven members.

Resources

A facilitator is required in the initial stages. The size of the venue will depend on the numbers involved, while the budget should be sufficient to cover facilitation and training.

Examples of Use

To date, the Local Sustainability Model has been utilised to train the personnel responsible for Local Agenda 21 in several UK councils and by Highland Perthshire Community Partnership in Scotland. The approach involved representatives of 19 local and diverse voluntary organisations working together on economic, environmental and community development with the aim of addressing rural disadvantage. The Model was used to identify a common view of the current local area and assess the likely impact of proposed projects.

20. Nominal Group Technique

Overview

The Nominal Group Technique is similar to Priority Searching. Beginning with a specific and clear question, the participants can identify issues and prioritise them. The same question or topic can be used with different groups of people, for example, staff, patients, carers, and the issues and priorities compared. One session usually lasts about 3 hours

The Nominal Group Technique can be split into five main stages:

1. Idea - for five to ten minutes delegates write down ideas based on the question/s posed.
2. "Round Robin" stage - each delegate reads out one of their ideas with their best one first and these are jotted down onto a larger piece of paper, blackboard or flipchart.
3. Clarification - At this stage each idea is discussed more widely and clarified; duplicate ideas are brought together and the individual ideas are numbered.
4. Voting - from the ideas which are numbered the delegates prioritise them based on an agreed voting system.
5. Action - the group discuss their plan of action and, based on the outcome of the vote, with the intent of reaching agreement on how they will deal with the original question.

What are the advantages?

- Many ideas are generated - obviously the more ideas that are generated the wider range of options the group will have to decide upon.
- Technique is useful for identifying problems, exploring solutions and establishing priorities - the Nominal Group Technique can be used as a total assessment tool in that it can be used to identify the problem, generate solutions and implement them.

- Encourages everyone to contribute and prevents people from dominating the discussion - this allows everyone's opinions to be heard and judged equally.
- Participants are equal members of the group.
- It is a way of involving the "grassroots" in the decision-making process.
- Participants may be of mixed backgrounds - a variety of different people suggest a variety of different perspectives and priorities.
- The written generation of ideas encourages the commitment of the participants in taking part in the planned action.
- Requires only one skilled facilitator.
- Nominal Group Technique produces an answer with few resources.
- Decisions are made at the close of the meeting.

What, if any, are the disadvantages?

- People have to be able to read and write - this is something, which should not be taken for granted and such assumptions can prove dangerous and threatening to the outcome of the activity. However, it can be done verbally with some experience.
- Group members have to make themselves available for the required time - this can prove difficult but must be attempted.
- The ideas may be ill informed or impractical - it must be explained that the process being carried out is not being done so in a hypothetical sense but is a realistic problem requiring realistic solutions.
- For the Nominal Group Technique to be a success those in authority must accept their conclusions or they must participate in the activity themselves.
- The Nominal Group Technique is a good stand-alone technique for simple issues but must be combined with other approaches where the issue is more complicated or affects people outside the sphere of influence within the group.

Targeting

The participants of a Nominal Group (maximum 8 - 10 people) can either be sampled from the population or invited from particular patient or service user groups. This will depend on the question and the priorities the organisation wishes to be identified.

Resources

An external facilitator is recommended to avoid bias. A member of staff can address the results at the end, saying what will happen with this information. For example 'This one begins on Monday (!), this one needs to go back to the committee, this one is part of the overall plan for the organisation and will take up to a year to happen' Venue costs, expenses, carer and child care, along with a gift voucher or similar is usual.

Examples of Use

Cumbernauld and Kilsyth Local Health Care Cooperative asked a representative group of patients 'how can the Local Health Care Cooperative make a difference to health in this area?' Several areas of work were identified and acted on. The General Manager went through the list at the end of the session and said what he would do with the information. Several working sub-groups were set up to work on specific area, for example, written information for patients, development of a community health map.

Dunfermline Local Health Care Cooperative used Nominal Groups with complainants, Podiatrists and GPs and other referrers, asking them 'what makes an excellent Podiatry Service?' An action plan was devised from the results and participants have ongoing feedback.

21. Open Space Technology

Overview

Open Space events involve from 20 - 500 people in identifying important issues, discussing these, prioritising them and deciding on action. It moves away from an outmoded command and control structure to modern participation based on voluntary cooperation. It involves all stakeholders and is therefore a 'whole system' approach.

- The sponsor sets the theme and invites the participants, setting diversity.
- The participants create their own agenda within the theme and 1-2 hour workshop sessions identify the key issues.
- Participants self organise by signing up to those topics important to them.
- Groups move on to prioritising and identifying action.
- Management has the option to respond on the day.

Targeting

All stakeholders should be invited. You will have to think about how you ensure a good turn out on the day. Again, remember those who cannot come to such events for whatever reason - young people, children, homeless people, people from other excluded groups, for example, those who live in poverty, people who feel they cannot contribute to such a big official thing, people with learning difficulties, people from other harder to reach groups like LGBT (lesbian, gay, bisexual, transgender) groups, women from ethnic minorities, ill people etc.

Resources

Depends on the size of the event, accessible venue, carer and child care costs, catering. An external facilitator can cost up to £1000 per event.

Potential Pitfalls

Bad organisation with not enough breakout areas. The official version of Open Space says that all participants should get written summaries on the day which means organising a bank of typists and a large capacity photocopier. Some areas have found difficulty in getting large turnouts of the public.

Examples in Scotland

NHS Argyll and Clyde used an open Space Event to consult with stakeholders on their Public Involvement Strategy.

Glasgow Primary Care Trust used the methodology to inform the strategy for Primary Care in Glasgow. A video of the event was circulated to all participants as well as feedback on the day.

Background Reading

Harrison, O.: Open Space Technology: A User's Guide (1997)
Published by Berrett-Koehler Publishers Inc, San Fransisco

Websites

Open Futures

www.openfutures.com

Since March 1997, Open Futures has facilitated 51 events involving over 3000 people. They have lists of the events they have facilitated demonstrating the wide use of the methods used by a variety of different organisations.

22. Opinionmeter

Overview

The Opinionmeter is a free-standing unit that consists of a keypad terminal and screen with the capacity to hold a number of questions in questionnaire format. Members of the public can complete a series of questions by using the keypad to indicate their response. The Opinionmeter is usually located in a convenient place that is relevant to the research and accessible to the target group. It has been used in supermarkets and libraries as well as at particular events. It is suitable for issues where you would like to ask about 10 closed questions.

Opinionmeter is quick and easy to use - the results can be analysed at any time over the fieldwork period. This type of instant feedback can help to detect whether particular questions are being misunderstood or if any interesting issues are emerging.

Targeting

One of the advantages of Opinionmeter is that it can be used in exact locations where the target group may be present - for example, in a clinic if the views of clinic users are sought. The unit can also be brought to other locations where socially excluded groups may be more likely to be found.

However, the unit does rely on people volunteering to give their views. Some organisations help ensure that the unit is widely used by having a staff member in attendance to persuade people to take part. This also allows some guidance about the way in which the system will work and ensures that usage problems are resolved.

Issues to Consider

- Questions used in conjunction with Opinionmeter are very rigid. Participants can only choose from yes/no or multiple choice responses, which may result in some important issues being overlooked. The results are quantitative, not qualitative.
- Some members of the public may feel apprehensive about using Opinionmeter and thus the respondents may be self-selecting. To overcome this, it may be useful to have a member of staff on hand to encourage and assist everyone.

- Questions should be short and clear, so that everyone can understand. It must be possible to anticipate and incorporate all potential responses in the options given to respondents.
- It can provide instant feedback with good graphics.

Resources

Once an Opinionmeter has been purchased, the only subsequent costs relate to the time taken to write and input questions and any staff support that is deemed necessary.

The number of people consulted using Opinionmeter depends on a number of factors; the topic covered in the questions, the location of the Opinionmeter and the length of time that the Opinionmeter is accessible, amongst others.

Potential Pitfalls

- The information which appears on the screen is limited and this can make it difficult to understand and answer
- Samples are self selecting and likely to be more IT literate.

Examples of Use in Scotland

In Braemar Surgery, a survey on views on introducing an appointments system was undertaken. The Opinionmeter was sited in the surgery and 94 patients completed the questions. 77% stated that they were happy with an open surgery and did not want an appointments system introduced. A Needs Assessment was carried out in Newmachar, Grampian. The Opinionmeter was sited in the local shop and 108 people completed the questions. Many respondents stated they experienced difficulties with transport and appointment times when accessing primary care services. These issues are currently being looked at. An evaluation of the use of the Opinionmeter is available from Grampian Health Council.

Info@glhc.grmpian.scot.nhs.uk

23. Parish Maps

Overview

This approach encourages people to examine and assess what is important to them in their local environment and to contribute to its development. The most effective Parish Maps are established by local people, although local authorities have also produced good examples. The Map expresses the views and experiences of the 'mappers', and can be produced in many formats e.g. woven, printed, painted, filmed, animated, performed and written. The project is undertaken by groups of varying sizes that establish their own methods and rules of working and set their own timescales. Individuals can participate by gathering information or contributing to the production of the Map. Mapping can be part of Participatory Appraisal (see above)

The strengths of the approach are as follows:

- All sectors of the community can be involved.
- Each participant is allowed to act as an 'expert'.
- Individuals can work at their own pace and with a high degree of flexibility.
- Levels of community spirit, co-operation and awareness are increased.
- Many new initiatives are encouraged.

Targeting

As stated above, any members of the local community can participate in this activity. The group is encouraged to be adaptable and flexible in order to attract new participants.

Resources

Numbers of people involved can vary from a core group of less than 10 to a large group of many hundreds. Although facilitators are not an essential requirement, some groups have used the services of an arts or environment worker, and professionals such as archaeologists or planners may provide assistance. Venues are required for meetings and for permanently displaying the Map. Budgets range from a minimal cost to several hundred pounds.

Examples of Use

This approach has been widely used in the UK. Over 2,000 Maps had been produced by 1989, whilst a series of nationwide exhibitions in 1996 resulted in many hundreds more.

Websites

Common Ground

<http://www.commonground.org.uk/>

Championing local distinctiveness

24. Participatory Appraisal

Overview

In general, this is a practical technique that places particular emphasis on the people who are usually excluded from decision-making.

Participatory Appraisal emerged as Participatory Rural Appraisal (PRA) and Participatory Learning and Action (PLA) in the Southern Hemisphere in the mid-1980s. It is now spreading rapidly to the industrialised countries and has already accounted for more than fifty events in Scotland alone.

PRA can be described as a group of approaches, methods and behaviours that enable people to express and analyse the realities of their lives and conditions, plan what action to take and monitor and evaluate the results. It emphasises processes that empower local people.

The approach aims to create a cycle of gathering data, reflection and learning which leads on to action. Each group of participants examines their perceptions of the current situation, identifies barriers or gaps and proposes solutions or areas for change. It is a methodology that encourages learning and interaction and frequently employs visual techniques. As an overall approach it is extremely flexible and can encompass elements of other approaches such as the more visual assessments of a Planning for Real exercise for example, and the participatory and consensus building of a community appraisal exercise.

In many instances the process will be facilitated by an independent agency working closely with the community and outcomes and actions will be agreed with participants. Participatory Appraisal can be used both with small groups or whole communities. It does not depend on attendance at meetings and can be utilised wherever people are to be found. In general, sessions are undertaken by groups of peers with people having the freedom to choose their own level of participation.

The strengths of the approach are as follows:

- Flexibility
- A highly visual content which counteracts potential literacy problems and stimulates people's memory.
- The ability to simplify complex issues.
- The capacity to be modified and extended.

Targeting

The purpose of Participatory Appraisal is to involve individuals from all sectors of the community, particularly those who are frequently excluded from decision-making.

Resources

It is essential that the sessions are moderated by facilitators experienced in Participatory Appraisal, although they may be either independent or from the community concerned.

84

The costs will depend on the length of the process and the numbers of participants involved.

Examples of Use in Scotland

East End Health Action Project in Glasgow used the approach with people from one part of the city to develop an action plan to deal with previously identified health issues. A voluntary organisation used the approach to look at the management of forests in rural Scotland as a means of generating local livelihoods.

Websites

The Resource Centres for Participatory Learning and Action Network <http://www.rcpla.org/>

Participation in development Home Page <http://www.ids.ac.uk/ids/particip/index.html>

25. Patient/Lay Representatives

Overview

This is one of the main ways in which the NHS in Scotland has sought to involve people in the recent past. People, not employed by the NHS, are invited to be part of a new or existing committee to 'represent' the views of 'the public' or 'patients'. People organising this say they find it difficult to 'find a patient who can truly represent the views of the public'. It is unlikely that such an individual actually exists, in the same way that no one NHS professional can represent the views of all the people who make up that profession.

Who are they and whose views do the re-present? There are so many sub-groups and individuals within our communities that it would be impossible for any one or two people to be 'truly representative'. It is slightly easier to find people who represent a particular group of patients, for example people with diabetes or people who use a particular service.

It is important to remember why we are seeking 'patient or lay' representatives. Is it because we want the views and needs of the public - or a particular group of service users or patients - to inform the work of the NHS? If so, then it may be that a combination of the other approaches explained here will be more suitable.

Several individuals may be identified or identify themselves as the involvement work grows, and these people may be the ones who are most suited, with training and support, to act as representatives. RE-presenting information or perspectives means that you must have been able to gather that information or perspectives in the first place. The NHS should find ways to ensure that individuals being representative have the support they need to gather that information in the first place and the community should be aware of how they can contact the representative and be clear of the role of the representative.

The strengths of the approach are as follows:

- The voice of the public or particular groups of patients/ service users is heard at a high level within the NHS.

- The representative can act as a reality check - if they feel supported to do that. Many representatives feel as though they are often the only dissenting voice and quickly become less vocal.

Targeting

In the first instance you should look to 'involvement ready' groups for representatives - or delegates. It is good practice to have at least 2 people who can provide support to each other. Target the whole committee in terms of making clear their own role and the role of the lay representatives. As involvement work progresses, look out for individuals or invite groups to consider who can represent the views of the public or particular group and who could have a clear mandate from their group.

Issues to Consider

The following issues should be taken into account:

86

- Does your representative have access to a network or constituency whose view they can REpresent?
- Do they have access to training, perhaps in Committee skills or NHS matters?
- Are they supported properly, their expenses or other access needs being met on the day of the meeting?
- It is not fair to ask patients or members of the public, who are unpaid, to sit through long meetings without adequate breaks.
- Representatives are more likely to come from older, professional, white groups who are articulate and well dressed. How are you going to harness the views of younger people, very old people, ill people, people living in dire poverty etc?

Resources

- Travel, carer, child care, food expenses if required, should be met on the day of the meeting.
- Safety should be paramount.

- Administrative support should be offered to representatives, as well as other members of the committee.
- Time of someone familiar with the work of the committee should be allocated to brief and de-brief the representative.
- Representatives should be offered training in committee skills and information on how the NHS works. The Involving People Network will provide training in these aspects.

Examples of Use

Individuals, often called 'patient representatives' are found throughout the NHS at all levels. Often they are members of the Local Health Council or other key group in the community. Groups of service users, often called Patients Councils or Forums, are also prevalent in the NHS. The main weakness seems to be lack of clarity of role or level of influence, with NHS professionals unsure of the agenda and who should set that agenda.

Paisley LHCC have supported and trained 'patient representatives'. These people were recruited through advertising and selected by interview. They have been liaising and listening to community groups and feeding this information to the LHCC Committee. They are aware of the issues for others in their position and have organised a Board wide meeting to discuss and make recommendations.

Scottish Human Services Trust, who managed the Partners in Change project, has published a set of Meetings Checklists which will also be very useful if you wish to involve representatives on committees. www.shstrust.org.uk

Background Reading

Partners in Change: Checklists for Meetings (2001)
Published by Partners in Change, Edinburgh

Scottish Consumer Council: Stronger Voice - an educational pack (1999)
Published by Scottish Consumer Council, Glasgow

26. Patient Participation Groups

Overview

There are several Patient Participation Groups based in General Practices in Scotland. Many of these are affiliated to the National Association of Patient Participation Groups. (www.napp.org.uk)

Much of the learning around the role of lay representatives applies to Patient participation Groups: It is important to have a clear role for the group and all the members must be sure of their remit. The organisation too should be clear of why the group is being set up and agree the role and remit with the members.

There follows some information on the main, kindly supplied by NAPP.

Aims and objectives of a Patient Participation Group

88

- To give doctors and patients the opportunity to discuss topics of mutual interest in the Practice
- To provide the means for patients to make positive suggestions about the practice and their own health care
- To encourage health education activities within the Practice
- To develop self-help projects to meet the needs of fellow patients
- To act as a representative group to influence the local provision of health and social care.

The first step: a member of the Primary Care Team can:

Call an Open Meeting of the Patients.

Approach selected individuals.

Approach Surgery User Groups (e.g. Mums and Toddlers, Elderly Screening Clinics, Well Women/Man Clinics).

Involve the Primary Health Care Team.

Contact the National Association for Patient Participation

Read the literature already available about PPGs.

Contact FHSAs.

A patient can:

Approach a member of the Primary Care Team at the surgery

Follow steps 2 - 7 above.

Canvas the level of interest in Patients.

A member of the Local Healthcare Cooperative (LHCC) can:

Contact N.A.P.P. for information

Encourage the LHCC to support the development of Patient Participation as part of the Public Involvement strategy.

Discover if any practice within the LHCC has a Patient Participation Group. Enlist their help in sharing their expertise.

Identify one or more practices that could act as pilots.

Approach the Primary care team at the surgery.

Once it has been established that there is a mutual interest in a Patient Participation Group, then the Primary Care Team and Patients need to initiate joint discussions. One way to do this is an inaugural Open Meeting. Advertise on the Surgery Notice Board, at Surgery User Groups, by word of mouth, leaflets/handouts at Reception, leaflets in Repeat Prescriptions, Practice Newsletters.

Contact Local Groups

Groups such as the Red Cross, Women's Institutes, Rotary, Round Table etc., can be asked to send a representative, who is also a Patient of your Surgery.

What then?

- Agree the proposed aims and objectives of the Group.
- Establish channels of communication between the LHCC and the Group.
- Call another meeting where the Election of Officers (usually Chairman, Secretary and Treasurer), and the drafting of a Constitution can take place.

- See notes called Guidelines For Committees (included in the N.A.P.P. Starter Pack or see Partners in Change Checklists for meetings, Ref below).
- Contact other Practices in the Area and tell them of your proposals.

Getting help

Contact the Regional Officer of the National Association for Patient Participation for your area, who will give advice and practical support. A problem that is new to you may have been solved by another group.

The network of groups affiliated to N.A.P.P. support one another by sharing information and ideas. Your regional officer can put you in touch.

NOTE: The major content of these notes were provided by NAPP. Please read them in conjunction with other parts of the Building Strong Foundations and speak to other Scottish groups before setting one up.

Examples in Scotland

It is not known how many Patient Participation Groups there are in Scotland. Through Designed to involve work, there were common difficulties highlighted which ranged from NHS staff and members not being sure of the role of the group, who should be a member, how to get representative patients (see 25. above), unsure about the level of influence of the group (deciding or informing decisions). Please let the Involving People team know if you know of a well-functioning group - share the learning.

Background Reading

Salford Community Health Council: Developing Patient Participation Groups in Primary Care: A Brief Guide (1998)
Published by Salford Community Health Council, Salford

27. Person Centred Planning

Overview

Person-centred planning is a way of organising around one person to help them define and create a better future for themselves. This way of working has evolved over the last twenty years, mainly in North America and the UK. Person-centred planning grew out of a commitment to inclusion as a social goal and was consciously designed as an inclusive process. The way that person centred planning takes place illustrates this.

Typically in person-centred planning the person invites people who know and like them to come to a meeting. One or two facilitators guide and record the discussions and decisions. After the meeting, the people who came along to the meeting help the person who called the meeting do what's been agreed.

The questions explored during the meeting and the way the meeting is organised often means that new possibilities emerge, new understandings develop, new alliances are formed and people's lives take a definite turn for the better.

What do we mean when we talk about person centred planning?

There are 3 commonly used but distinct planning tools, which have strengths in particular situations.

The first two, Map and Path (developed by Jack Pearpoint, Marsha Forest, John O'Brien, Mary Falvey and Richard Rosenberg), are meetings where the person is surrounded by the people they have invited and the facilitators guide the group through a series of questions. The process happens live, in the room, and is recorded graphically on a large sheet of paper.

- Map - the questions in Map help the person reflect on their own story so far, take stock of who they are, think about what their aspirations and anxieties for the future are and come up for a plan to help them avoid their nightmare future and achieve their dream.

- Path - the questions in Path focus not only on connecting with your dreams for the future but on articulating them in detail, coming up with a strategic plan to achieve them and recruiting a team to help you do this.

The third widely used planning tool is Essential Lifestyle Planning (developed by Susie Burke Harrison and Michael Smull). The process is a combination of individual interviews and group meetings. Whilst the final ELP product may be a booklet or folder, the real product is the change in the way people around the person support them and help them plan for the future.

- Essential Lifestyle Planning asks lots of questions to help the author of the plan produce a rich picture of who a person is and discern what is essential and important to them. The plan also contains detailed directions for how best to support this person (personal assistance, communication support and medical/ health care) to live the lifestyle they want to live.

What's different about person centred planning?

- It is concerned with what happens in a person's life, rather than with their role as a patient or user of a range of services. The locus for the work of the plan is the real world - not the span covered by services - although the information contained in the plan may be of use to service providers. The defining question in person centred planning is 'what kind of life do you want?' not 'what services do you need?'
- It is an event in the person's life, not a procedure of the service system. As much as possible, it takes place in the person's world, with the service system seen as part of the environment. So for example 'here' means the person's house, 'there' means the hospital or the day centre.
- It is concerned with what this person wants, not with what people like this person usually need - it is about seeing the person, rather the diagnosis or category.

- As a process, it values capacity and contribution more than needs and deficiencies. The starting point is the person and their likes, dislikes, aspirations and contribution. Having an illness or disability is part of who the person is, but not the main part.
- The process is action orientated - it is about recruiting a team of people around you to help you make changes in your life. The people who take part, including people who are staff in the health service or other organisations, must be willing - and allowed by the system - to fulfil the roles and tasks they have agreed.

There are usually two independent facilitators for any plan - a graphic facilitator (particularly for Map and Path) who keeps a record of everything that happens and a process facilitator. It is important that the facilitators are independent and do not exercise any control over the person's life. The person has to really explore what they want rather than be inhibited by other people's conscious or unconscious views about what they think they can have.

Why use graphics?

The use of a graphic record in Map and Path is a central part of the process. The graphic recording process facilitates creativity, as people see their ideas become reality on the wall. The live public record is accountable to the group, who can correct and amend it through out the process. It makes it easier for people to connect previously unconnected patterns and ideas in their life and make new sense of them. It is also a truly memorable and evocative record of the planning session, capturing the emotions and energy of the meeting as well as the content.

Resources

The main resources needed are for the facilitators' time. This will come to between £600-£1,000 for each plan, involving trained facilitators experienced in the process. This fee should cover pre-planning for the meeting, facilitation of the meeting and (with ELP) production of the full Essential Lifestyle Plan document.

Networks of people who are learning and applying person-centred facilitation are emerging in Scotland.

Examples of use in Scotland

Person-centred planning has mostly been used in work with people who are at risk of social exclusion - older people, people with labels of disability, people who have mental health problems, children in care, people who are homeless, people with the label of learning difficulties.

Some care providers - especially in the voluntary sector - have been developing the application of these approaches for several years.

As well as being relevant for individuals, both Map and Path can be used in organisational consultancy as a method for helping groups and organisations think about their own stories and their future development.

94

The principles and ideas behind person-centred planning mean that it can be used in many situations where someone wants to make changes to their life that will involve practical help from other people. Some people are now beginning to look at how the approach can be used in helping other people who are living with long-term or serious health problems and perhaps considering complex treatment - such as people who have diabetes, or cancer, or coronary heart disease.

Background Information

Getting a life: a short introductory video on person centred planning; SHS

Background Reading

Sanderson, H. et al: People, Plans & Possibilities - Exploring person centred planning
Published by SHS Trust, Edinburgh

Williams, B. and G. Grant: Defining 'people-centredness': making the implicit explicit (1998)
Published by Health and Social Care in the Community
Vol 6 Issue 2 Pages 84 - 94

Websites

Innovations

<http://www.ibv.org.uk/personcentredplanning.html>

This website is for a project funded by the Department of Health. The aim of the project is to find and publicise outstanding examples of innovative practice in supporting people with learning disabilities across the UK. Contains links to articles, research and background information on Person Centred Planning along with individuals stories.

North West Training and Development Team

<http://www.nwtdt.com/pcp/pcp.htm>

This website is for a project working towards better futures for people with learning disabilities in Cheshire, Greater Manchester, Lancashire, Merseyside and South Cumbria. Contains articles and information on Person Centred Planning Tools as well as individual's stories and experiences of using the tools to plan their futures.

Paradigm

<http://www.paradigm-uk.org/>

This website is for a UK based training organisation that provides Person Centred Planning. The site contains articles on Person Centred Planning plus links to Joseph Rowntree Foundation research about Person Centred Planning in a UK context.

Scottish Human Services Trust

<http://www.shstrust.org.uk>

Person Centred Planning and the values it reflects underpin all aspects of SHS's activities. This website has details of events, publications, training and research around the values of inclusion and their application.

28. Planning For Real

Overview

The first stage of Planning for Real involves the construction of a large 'model' of a neighbourhood. Both large-scale maps and 3-dimensional models may be used. The approach is used by the local community to demonstrate its needs and show the improvements which require to be made in the environment. These are often shown by having participants write on or attach to the model, their comments - for example, any known problems in the area or improvements needed. As such the community is fully charged with identifying issues.

The second stage involves group meetings with the community to prioritise their suggestions and draw up a profile of community needs. In its entirety, Planning for Real is a complete process of community involvement, which can be applied both to small local projects, and the development of strategic planning.

96

The strengths of the approach are as follows:

- The approaches is non-confrontational
- All sectors of the community have a chance to be involved
- Discussion of a large number of topics is permitted
- Flexibility in terms of timings and venues
- Simplicity and ease of understanding.

Targeting

It is possible for all sectors and members of a local community to be included in the process, as detailed below:

- Meetings can be held in appropriate venues - for example, "women only" environments for female members of the Muslim community or young people's environments such as schools.
- Suggestion cards and publicity materials can be presented in a variety of different languages.
- The visual display is acceptable to those with poor literacy skills.

- The approach is reported as appealing to all ages due to its ease of use.
- Everyone within a neighbourhood can be invited by use of a targeted campaign to all households in the area.
- There is no finite number of participants and all sectors of the community can be involved.

Resources

In order to obtain maximum benefit from the exercise, a facilitator experienced in Planning for Real should be involved. 'Experts' from the statutory authorities may also be invited to attend Planning for Real events, but solely in an advisory capacity.

The venue should be sufficiently large to allow people access to the model/maps. The size of the model varies according to the size of the area being represented and the scale, but is typically sixteen feet by eight feet.

A budget of between £500 and £15,000 should be allocated to cover the cost of materials and venue and the services of a fully trained facilitator for several months prior to the event, during the exercise and at the follow-up prioritising meetings.

Examples of Use in Scotland

Planning for Real has been extensively used within the UK. It has also proved successful within Europe and worldwide. Clackmannanshire Council has conducted a Planning for Real exercise in Scotland as have Perth and Kinross.

Planning for Real recently formed the focus of an initiative in Clackmannanshire to provide input to the Development Plan. Large scale models were used with residents being asked to identify local problems by attaching 'fix it notes' - with written details of the problems - to the maps in the areas where problems had occurred.

Further Details

Information on Planning for Real can be found in Participation Works!46 . Further details can be obtained from the website www.neweconomics.org

The Neighbourhood Initiatives Foundation runs a regular two-day course on Planning for Real. Organisations wishing to get involved in Planning for Real events should contact the Foundation to discuss the ways in which they can obtain optimum benefit from the approach and obtain permission for use of the trademark.

Website

Neighbourhood Initiatives Foundation
www.nifonline.org.uk

The Neighbourhood Initiatives Foundation is a charity, specialising in community participation, training and development and work with local authorities, housing associations, voluntary agencies and community groups. Contains information on Planning for real - a whole process of community consultation.

29. Priority Search

Overview

Priority Search is a computer-aided survey process that combines qualitative and quantitative techniques. Its aim is to improve the performance and effectiveness of an organisation by giving the people surveyed the power to identify their needs and wants, and state their priorities. These ideas are then arranged into a priority ranking for appropriate action.

- Project Planning - the issue is identified and focus groups established to discuss it.
- Focus Group - the groups respond to the main issue being explored and outline all the issues of relevance to a constructive debate and consideration of the issue.
- Survey - the ideas generated by the focus group are converted into a questionnaire containing paired statements which are distributed to everyone being consulted.
- Participants are asked to indicate on the questionnaire the extent to which they would prioritise one element within each pairing over another.
- Results - following rapid analysis of the questionnaires, results are produced showing all the statements in ranked order of priority.
- A specific question(s) is developed prior to a meeting.
- The group is then divided arbitrarily into smaller groups of six to eight people, each with a leader, at which point they are shown the question.
- The participants work individually or in pairs for ten to fifteen minutes to answer the questions and these are presented to all those attending.
- Once the results are read out, all group members vote for their top five answers.
- An overall summary chart is compiled.
- The moderator decides whether the groups are ready to vote for their top five overall preferences or whether further work is required.

- The session is closed with a summary and agreement relating to the next stage.

The strengths of the approach are as follows:

- A wide variety of issues can be addressed
- Key priorities emerge
- One issue can be explored in detail
- The analysis facility allows instant results to be provided, allowing a conference or large group meeting to discuss the findings immediately and obtain feedback
- Results can be prepared in a variety of formats including a priority list, bar charts, scatter plots and individual results
- Significant differences in attitudes between different stakeholder groups can be identified as the software can produce this type of analysis.
- Flexibility and speed.

Targeting

The approaches should reflect a genuine cross-section of respondents, or be explicit about the range of perspectives, and should include the full range of sub-groups within the population. Recruitment can be carried out in a variety of ways - for example, by using a market research company, the electoral register or housing records.

Issues to Consider

The following issues should be taken into account:

- Priority Search requires input from external consultants or an initial investment in training and software
- Some respondents at the groups may wish to offload complaints rather than engage in constructive discussion
- The quantitative nature of the results may make solutions appear too simple and straightforward
- Analysis of qualitative information may be superficial
- Care must be taken to ensure that the focus groups which will generate possible answers is representative of the larger population.

Resources

Three groups of people are involved in the approaches:

- Management - to commission the survey and act on its findings
- Survey Team - to organise, facilitate and advise
- Target Group - to give the ideas, opinions and priorities.

Priority Search also requires investment in training and software, thus increasing the operational costs. In addition, participants may be offered incentives to cover childcare, travel and attendance costs. The questionnaire can be issued to the group and/or taken out to a wider population (up to a maximum of 450) for completion.

Examples of Use in Scotland

The approaches can be used to tackle a wide range of issues in any organisation, at both macro and micro level - for example, customers' wants and needs, work priorities, use of resources and training needs.

The Priority Search software has been purchased by a number of Councils and organisations throughout Scotland, and is in the process of being tested by others. It has been used by many of the case study organisations including Inverclyde Regeneration Partnership and South Lanarkshire Council.

30. Public Meetings

Overview

The aim of Public Meetings is to create a platform upon which members of the public can be given the opportunity to discuss, and give their views on, a particular topic. Whilst very much a traditional approach, the effectiveness of the meeting can be enhanced by the use of targeted methods of ensuring attendance (i.e. inviting individuals to attend specifically) or through the use of new technology to enhance the way in which information is presented.

The public can also organise public meetings to raise or highlight issues or talk about their concerns.

Public meetings can be arranged so that they are much more participative.

102

It might be helpful to discuss the following questions before a public meeting is planned. The possible answers were provided by a group of primary care professionals who took part in a one day course on Participative Public Meetings organised by Designed to Involve in 2001.

What is the purpose of a public meeting?

- Engender ownership
- Representation of the public

The training group decided that public meetings, as they know them, would not allow either of these. A large NO was printed on the flip chart.

What do you NOT want to happen at a public meeting?

- Only axe-grinders to get heard
- Pressure groups taking over
- One or two people taking over the agenda with their own issues
- Loudest voices only are heard

- Public shouting out together
- The police to be called
- Biased representation of the public
- Heckling
- People to get really angry
- Break down of structure of the meeting

Bad preparation

- Speaker does not to turn up
- Misjudge attendance
- No one turns up
- A 'greetin' meetin'
- Apathy
- Put people off being involved e.g. by being boring and not achieving anything
- Give out the wrong messages

Outcome of meeting

- People to leave feeling it was worthless
- People to feel disenfranchised
- To be worse off at the end than when we started
- The issue/purpose gets ignored

What DO you want the meeting to be like?

- Active involvement
- Enjoyable
- Keeps to time
- Organised
- Interesting
- Genuine, open/friendly discussion

- Participative
- People to know that their views count
- Everyone feels their voice has been heard
- A frank exchange of views
- Good representation of stakeholders
- Range of people to attend e.g. young, elderly, disabled
- Both sides to accept and acknowledge each other's point of view
- REAL options open for discussion
- Both parties to feel it was worthwhile
- Everybody feels included
- Constructive discussion
- Generate ideas
- To not leave me with too much work
- To have an outcome
- All REAL issues are raised and discussed
- Change to happen as a result
- Meeting has action/next steps specified
- Supportive, allowing people to express themselves
- As many different views as possible to be heard
- Dialogue
- Informed discussion/debate

What do you want to get out of the meeting? What do you want to happen next?

- Information
- Understanding of the community view and commitment to feedback
- Good, fair, feedback in as short a time as possible
- To know how to hear better the views of the public
- Greater understanding of local need
- A feeling for the views of participants

- The issues are moved forward with good representation of stakeholder views
- Enthusiasm of interested community
- Build working relationships
- Support for needs
- Contacts maintained - partnerships
- Open up channels for communication, input and participation
- Support from the public
- Closer ties with the participants
- A developing relationship which can be built on in future
- Backing for the next stages
- New networks to result
- Continue momentum
- Find a way to allow public to be decision-makers
- Direction
- Plan of action/next steps
- Use responses from this and other approaches to form a response to planning issues
- Agreement on the way forward
- Ownership and Action
- Develop clinical priorities
- Options to progress
- Information that can be used in development of services
- Public involvement in planning
- Go to the pub!
- Positive action
- Positive change

There could be an element of exchange in Public Meetings with talks given to introduce the subject and set the context within which views are sought. Those attending could then be divided into smaller groups and asked to provide their considered views before wider discussion takes place.

- They provide an opportunity to establish a relationship between service users and providers - creating a feeling of community involvement / participation. This is enhanced where a programme of meetings takes place in rural areas, as this can be seen as recognition of the importance of the views of smaller communities.
- If promoted correctly, Public Meetings can achieve a high profile and reach a wide audience while innovative approaches, such as 'Planning for Real', can increase attendance.

Public Meetings are often used to supplement public consultation projects. It is important that feedback is provided to the attendees at the Public Meeting as this indicates that all views raised have been recorded and will be used where appropriate.

Public Meetings are also used on a stand-alone basis - particularly if an organisation wishes to gauge public opinion on their proposed plans.

106

Targeting

Public Meetings are not particularly effective in incorporating the views of excluded groups, as the individuals who usually attend them are self-selecting. As such, these individuals are more likely to have strong views and opinions and thus may not be representative of the community.

Some organisations have broadened the reach of Public Meetings by inviting certain individuals or groups to attend. This type of targeted personal invitation can be more effective than a general invitation.

Issues to Consider

There are a number of issues to consider when using Public Meetings:

- As Public Meetings are traditionally subject to poor attendance, it is very important to consider the target group and arrange the meeting time and venue accordingly - for example, an afternoon event held at a local community centre for a target group of retired people.

- The use of an independent facilitator is recommended.
- The issue being discussed will have a significant impact on attendance, as people are more likely to attend if the subject is of relevance or interest to them.
- The structure of the Public Meeting should be planned in order to avoid backtracking and ensure a flow of comment takes place.
- It may be possible to break up into smaller discussion groups at some point during the Public Meeting in order to increase participation from those attending.
- It is important to be explicit about what the organisation is going to do with the information gathered at a public meeting. How will it be fed into the decision making process?
- Be clear to attendees about the purpose of the meeting. Is it to inform change or provide information?

Resources

The typical cost of holding a Public Meeting is likely to be around £3,500, although this can vary greatly depending on the innovative nature of the approach. The cost includes advertising materials, venue hire, refreshments and the cost of facilitating the meeting. Effective advertising will ensure that a wide range of groups is aware of the Public Meeting. This could involve using methods such as newspapers, flyers and mail drops.

The Community Training Development Unit (www.ctdu.org.uk) in Forth Valley use a wide range of approaches to engage people. Notes from a workshop they ran for Designed to Involve will be published on the Involving People website.

Potential Pitfalls

There is a chance that specific topics can dominate or that some points of view may not be heard. Attendance may be much higher or lower than you expect.

Examples in Scotland

In one Board area so many people attended a public meeting that the Police had to be called when traffic came to a stand still.

In another area 32 public meetings were arranged around the Acute Services Review. There was variable numbers and mixed responses.

Both areas have now reconsidered how public meetings are organised and use a much wider range of ways of involving the public.

31. Round Table Workshops

Overview

The Workshop method enables participants to make a full contribution to discussions on local issues of shared concern and to brainstorm ideas for action. A short-term vision and strategy may be generated as part of a longer-term outlook.

Each Workshop can have a single theme or several themes as part of a strategy. A Workshop may last for only half a day, but ideally will run for a longer period, with the outcomes of one feeding into the next.

The strengths of the approach are as follows:

- Relationships can be built between different groups and sectors by targeting participants widely.
- Every effort should be made to ensure that the people with influence and authority in local networks and organisations participate in the workshops.
- Participants - who may have been briefed in advance - are seated in a single room at individual round tables of seven to ten people, thus avoiding hierarchies.
- By ensuring "maximum mix" of participants to discuss a specific topic, individuals have the opportunity to widen their circle of contacts and cross boundaries.
- It is a good method of providing a wide range of opinions.

The broad stages of the process are as follows:

- A brief introduction is given setting the context and aims of the event.
- Specialist presentations, lasting a maximum of one hour, provide technical information and case studies in order to generate new ideas and approaches.
- Round Table (brainstorming) discussions, lasting one and a half hours, produce ideas which are recorded on paper or tape.

- An opportunity for questions and answers may precede the hour-long concluding session during which the groups report their findings.
- A draft of the outcomes is produced for comment.

Targeting

As stated above, participants are targeted from different groups and sectors including all communities of interest.

Resources

Participants can number from 30 to 100 for each Workshop, while a series of sessions allows as many as 500 people to participate. The venue should be on neutral ground with sufficient space between tables to allow uninterrupted discussion.

Consultants are usually responsible for carrying out the initial organisation and briefing, while the individual events may be chaired by people of influence. In addition, each table may have a convenor and reporter from other bodies. Specialist contributors bring visual and verbal examples of similar exercises for the purpose of stimulating creative thinking. Costs can range from £3,000-£5,000 per event to £10,000-£20,000 for a series of events.

Potential Pitfalls

The main problems identified by those who had used the approaches in the past were poor attendance and a possibility of domination by single issues. However, there was a view expressed that some of the Workshops conducted had too wide a remit, as a result of which a more defined approach would be used in the future. Adequate planning time at the outset is required.

Examples of Use in Scotland

The Scottish Council Foundation and Cairn Housing Association used a similar method to work with three communities around Scotland. Representatives who comprised known community activists and members of the usually 'silent majority' came from areas that represented 'Excluded Scotland', 'Insecure Scotland' and 'Settled Scotland'. A report is available through their website www.scottishpolicynet.org or from the Scottish Council Foundation in Edinburgh.

Websites

Scottish Council Foundation

www.scottishpolicynet.org.uk

Contains information on publications and provides an online forum for discussion on a variety of issues relating to social, economic and governance issues. Reports on participative events.

The Aspen Institute

www.aspenroundtable.org

The Roundtable on Comprehensive Community Initiatives is a forum in which people engaged in the field of comprehensive community initiatives (CCIs) can meet to discuss the lessons that are being learned by initiatives across the country.

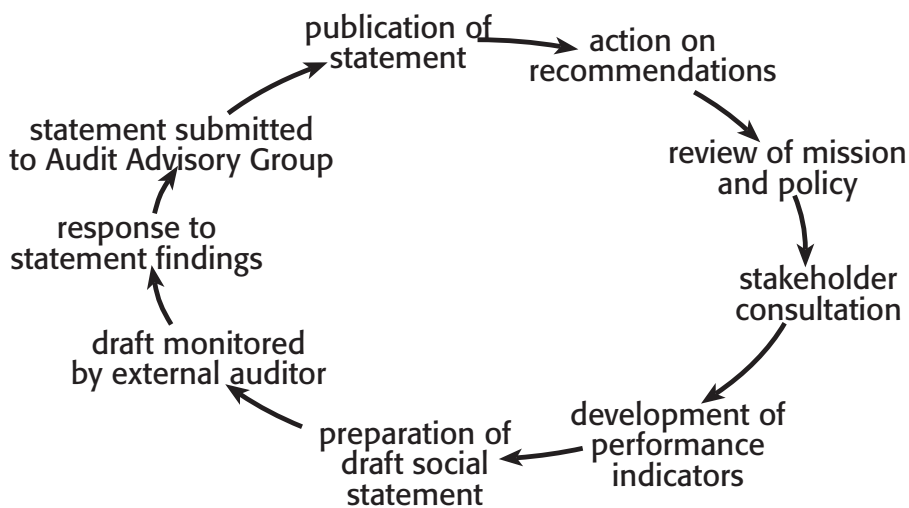
32. Social Auditing

Overview

Social Auditing is a way of measuring, understanding, reporting and ultimately improving an organisation's social and ethical performance.

Social Auditing is used by organisations which realise that they will only continue to prosper if they satisfy the aspirations of their stakeholders. These include employees and volunteers, governments, funders, suppliers, customers, investors, local communities, environment and public interest groups. They are increasingly recognising the need to measure, track and report on their social and ethical performance.

The Audit Cycle



New Economics (46:1998)

The social audit process is not a 'one-off' exercise but a regular cyclical process. This identifies whether the organisation's performance has improved over time in relation to its own objectives, the objectives of its stakeholder and broader social norms.

There are four 'building blocks' used in the social audit method:

1. Stakeholder Dialogue

Stakeholders are those individuals and organisations who can affect and are affected by an organisation's activities. The dialogue draws together the values, issues and indicators relevant to stakeholders in a language that is meaningful, consistent and useful for decision-making. This is done through focus groups, interviews and questionnaires.

2. Indicators and Benchmarks

Indicators (both quantitative and qualitative) of performance are generated. They should where possible be benchmarked against comparable organisations, compared with previous years, against relevant social norms and against procedures and policies.

3. External Verification

External verification ensures legitimacy by ensuring that the views of the stakeholders are secured within the accounting process.

4. Communication

The results need to be published in an accessible form.

Targeting

All stakeholders.

Issues to Consider

The Social Auditing Method is an ongoing process which has to be done at regular intervals in order to gain an insight into the workings of the organisation in terms of its performance. Failure to do so could lead to an apparent high performance increase where there isn't one.

Resources

People: It is vital to have commitment at a senior level within the organisation. A full social audit requires an external verifier as well as significant time inputs from an internal social audit person or team.

Budget: Varies with the scope of the audit and the level of verification.

Potential Pitfalls

This is an organisational performance indicator, not an individual one, but people may create a link between the two and fear it could affect them at work, especially if they are on performance related pay. The Audit Cycle itself, as in the diagram above, has many linked steps, none of which can be overlooked or bypassed but there is always the possibility that this could happen.

Background Reading

Mayo, E.: Social Auditing for the Voluntary Sector (1997)
Published by VOLPROF City University Business School

Pearce, J., P. Raymond and S. Zadek: Social Auditing for Small Organisations: a workbook for trainers and practitioners (1995)
Published by New Economics Foundation, London

33. Story Dialogue

Overview

In many sectors - especially in those of health and research, individual stories are often dismissed as being merely 'anecdotal evidence'. With increasing interest in narrative-based medicine and narrative therapy on the one hand and giving individuals and communities a voice to influence community planning on the other, there is a need to explore new, accessible research tools that can enhance community participation and understanding across sectors. Story-dialogue is one such tool.

This is an extremely versatile and creative method that can be applied in a variety of settings for a range of purposes such as seminars and conferences, research and evaluation, community consultation and planning, supervision and peer review.

The purpose of the story dialogue method is to illicit the views, skills and experience of all those present to have an opportunity to influence and shape any development. This is a method for evaluation and knowledge development. This approach involves practitioners in reflective analysis and synthesis of their own experiences. The rationale for using the approach is based on the current emphasis on learning organisation cultures and that the approach is consistent with the values of inclusion, empowerment and social justice.

Targeting

Anyone interested in new tools for enhancing public involvement in health, adding value to the consultation and community planning process or making research and evaluation more creative, accessible and inclusive. In the Health Sector this would include:

- People involved in partnerships and participation for health in various ways including Social Inclusion Partnerships
- Community Health Projects
- Healthy Living Centres
- Health demonstration projects

- Local Health Care Co-ops
- Acute, Primary Care and other NHS staff
- Voluntary organisations
- 'Lay'/community representatives, researchers and relevant local authority staff.

Issues to Consider

- Value must be ascribed to qualitative approaches as well as quantitative

Resources

Three or four key story tellers to be identified before the start of the day (depends on the size of the group). Enough room to be able to introduce the subject to the whole group and then allow them to split into smaller groups. Expenses for venue, catering, and participants. Facilitator fee.

116

Potential Pitfalls

- As with any involvement methodology, feedback and action are key to the success.

Examples in Scotland

The technique was used to extract the learning from Local Exchange Trading Schemes in relation to health. Community Health Exchange (CHEx) and Health Education Board for Scotland (HEBS) supported. A report is due around April 2002 from CHEx.

The method was used with the NHS Public Involvement Officers and staff from around Scotland. The generative theme was:

"Your views on your role as a public/patient involvement worker or someone who has public/patient involvement as a key feature of your job. How your role has begun to change the culture within the NHS locally/nationally and how this role works towards sustaining public/patient involvement within the NHS."

The workshops were asked to consider 4 key questions in relation to the story they heard. The questions were:

- What? - What did you hear in the story?
- Why/How? - Why/How was it like that?
- So what? - What does this tell us?
- Now what? - What needs to happen now?

A report is available from jane.davies@scotland.gsi.gov.uk

Background Reading

The key resource is the 'Handbook on Using Stories in Health Promotion' by Labonte and Feather, 1996, Health Canada, ISBN: 0-662-24665-7

34. Surveys (Questionnaire Based)

Overview

Questionnaire based surveys are an effective way of contacting a large number of people and gathering their views and comments. Questionnaire surveys are generally used to achieve representative findings and results that are statistically robust. Surveys using this approach can be conducted through face-to-face interviewing, postal/self-completion approaches or by telephone interviewing.

Computer aided interviewing approaches are now available and widely used, both for personal and telephone based surveys. Internet and e-mail questionnaires can also be used to collect information quickly from dispersed groups at a relatively low cost.

- Questionnaire surveys are a useful way of collating the views of a large number of people.
- They can gather views on a range of issues while the results can be made available relatively quickly.
- The same approach can be used again in the future, to track any changes that may have occurred.
- Completing the questionnaire face to face or by telephone provides the added benefit of interviewers being able to explain complex points or probe for full information.
- Questionnaire surveys that are based on sound sampling approaches will provide results that are statistically reliable.

118

Questionnaire surveys are often part of wider research projects, although they can be used on a stand-alone basis also. They can often be conducted and analysed over a relatively short space of time, thus allowing a quick turn around on urgent projects.

Targeting

An appropriate sampling approach to reach the target group is key to ensuring that the information obtained is valid and representative of the views of those you wish to consult. For this reason, when considering the use of self-completion

approaches it is important to think about the likely response rate and whether another approach may give a more representative spread of views.

To ensure that everyone is included in questionnaire surveys, it is important to consider the range of features, such as question wording, which may be a cause of exclusion. While it is vital to keep questions simple and clear, it may also be necessary to have questionnaires translated or in Braille format. In other instances, interviewers may need to provide extra help to people who have difficulty in reading and writing.

Issues to Consider

- Response rates to postal questionnaires are rarely high - in the region of 10-25% is likely, while 60% is outstanding.
- Due to the structured nature of questionnaire surveys, respondents are not always given the opportunity to explore or discuss issues which they feel are important.
- Use a technique like Focus Groups to highlight what people believe are the key points that should be asked about in a questionnaire. Work together with the community or service users to design the questionnaire.
- Questions should be kept to a minimum as respondents are less likely to complete a form or take part in a survey that will take thirty minutes to complete.
- As a poorly worded questionnaire can result in unclear findings, the aim of the questionnaire should be carefully considered and reflected in the questions.
- The questionnaire should be tested prior to use (and not just on colleagues); a pilot should be conducted amongst those who will actually be expected to take part in the survey; ideally a professional interviewer should be used for this purpose as they can provide insight into questions/words which might be unclear and can suggest how the interview might be improved (i.e. use of prompts etc).
- The use of a telephone approach will automatically bias the sample by excluding those without telephones.

- Unless telephone numbers for the target group are available it can be more expensive to use a telephone approach for interviewing rather than face to face (bearing in mind the need to find an appropriate sample, higher refusal rates and the cost of calls). One exception is for more dispersed populations in rural areas.
- Even excellently designed questionnaires often only provide quantitative information (how many people think or have....?). But there are opportunities to involve people in a qualitative method (what do they think about...?).
- Consider small scale surveys to compliment other involving people work. They can cover qualitative as well as quantitative issues and can be used alongside in-depth interviews.

Resources

The cost of questionnaire surveys depends on a number of factors including the number of questions asked, the sample size, and the way in which the questionnaire will be completed (self-completion, face-to-face or telephone). As an example:

- 1,000 face to face interviews of around 30 minutes' duration could cost c£25,000 - £40,000 through an external agency.
- 500 short, 5-minute, face to face interviews could cost c£3,000-£5,000 through an external agency.
- Analysis of 20,000 short, self completion questionnaires through an external agency, where there is limited coding and no reporting, would cost £3,000- £5,000.
- Analysis of 2,000 complex, self-completion questionnaires, producing tables and reporting on the results, could cost £8,000 -£13,000.

Potential Pitfalls

The aim of conducting a quantitative survey is to get representative results. An appropriate sampling approach is paramount. Skills in questionnaire design are important, as is an ability to deal with the data generated. It is easy for respondents

to form jaundiced views about the consultation if it is an issue that has already been debated publicly. It is important to ensure that the questionnaire gives everyone the opportunity to express his or her views. Questions should not be leading, multiple or include jargon.

Consultations based around questionnaire approaches can appear quite distant. Respondents should be offered the opportunity of feedback and efforts should be made to publicise the outcome.

Examples of Use in Scotland

A report on the use of surveys (prepared by Scottish Consumer Council) will be published in the first part of 2002. This will be made widely available.

Lanarkshire Health Council and Cumbernauld and Kilsyth Local Health Care Cooperative used a questionnaire to ask about the potential role of the Local Health Care Cooperative. Respondents were able to elect to have further involvement and 20 people attended a Nominal Group exercise (See 1.16) to prioritise 'What is the best way for the Local Health Care Cooperative to make a difference to health in this area?'

A General Practice in Edinburgh asked patients "What is the one thing we could have done better for you today?" They say they will never do a long questionnaire ever again!

Websites

Picker Institute Europe
www.pickereurope.org

Information about measuring people's experiences of health care and using this information to improve the provision of health care. Contains Guidance on Conducting Surveys and also the research undertaken.

35. Think Tanks

Overview

Think Tanks are a commonly used technique designed to promote original and creative thinking. Its purpose is to generate a number of ideas from a group of people - ranging from two to a large number of participants - within a short period of time. A particular topic is raised for discussion, and participants are asked to call out any thoughts or ideas that the topic may bring to mind. As ideas are generated, they are recorded for all participants to see in order to stimulate further thoughts. These additional thoughts are then added to the list until such time as no further thoughts are forthcoming from participants.

The approach is often used as part of, or in conjunction with, other exercises as the ideas will need refinement, discussion or prioritisation. As such, this is very much a starting point for an exercise rather than a complete approach.

122

Targeting

Think Tank sessions are reasonably easy to set up and conduct and can be used with groups of various sizes. As participants are not required to stand up and speak in public and are thus not the focus of attention, this is an effective method of encouraging contribution from a large number of people. However, as is the case with other consultation approaches, there is a risk that certain groups such as non English-language speakers or those with literacy or hearing difficulties might be excluded.

Issues to Consider

The following factors should be taken into account when managing a 'quickthink' session:

- All ideas presented are of equal importance and validity.
- Thoughts can be as unstructured and wide-ranging as necessary, although linkages between ideas should be encouraged.
- Quantity, rather than quality, of ideas is the prime consideration.

- Ideas should not be discussed or rejected.
- Facilitators should be aware of common trends and potential solutions.

Resources

The technique does not require great input in terms of time or expense.

Examples of Use in Scotland

The approach is widely used in all facets of life and types of organisation. For example, it is intrinsic to many of the consultation exercises conducted by South Lanarkshire Council and is identified in their guide as a useful initial stage.

Websites

New Economics Foundation (34)

www.neweconomics.org

The New Economics Foundation is bringing together the ideas, people, resources and influence to challenge business-as-usual.

New Economics also published "Participation Works: 21 Techniques of Community Participation for the 21st Century"

36. Volunteering in Health

Overview

Volunteers complement and add to the services provided by paid staff but are never a substitute for them. There are documented health benefits for volunteers. Some doctors in Scotland even prescribe volunteering as a therapy!

Volunteers are involved in activities, support and services ranging from: advocacy, befriending, cafes, delivering prescriptions, entertainment, listening, mentoring, nutrition, outings, peer support, shopping, transport, user groups, visiting, welcoming and many other activities.

Volunteers can contribute much to implementing the changes recommended or advised through other approaches.

Websites

Volunteer Development Scotland

www.vds.org.uk/volunteeringinhealth

The VDS site contains a wealth of information about Volunteering, Volunteering Events and Volunteer Initiatives.

37. Other Approaches worth looking at

1. ACE (Act, Create, Experience) Youth and Agenda 21
See www.envirovision.org for examples

2. Developing a mixture of approaches to suit the situation and the people, for example:

The Board, NHS Trust and local authority were developing a mental health strategy, which included proposals to replace an old long-stay hospital. There had already been a lot of discussion about whether this was the right thing to do, and there was support from the public, including people who used mental health services. Before the strategy was finished, it was agreed to spend longer talking to the people who were at the hospital, some of whom had been there for many years.

The strategy manager, manager for the services and the worker from the advocacy project met to plan how do these discussions. The points they thought were most important here were:

- giving people enough time to think about what was being suggested
- giving people opportunities to see that some of the alternative provision could be like, so they were not just thinking about losing what was familiar to them
- opportunities for people to talk about what was important for them
- keeping the discussions separate (as far as possible) from the staff who were part of the current service.

What was done included;

- an external facilitator and the advocacy worker had a series of discussion over 2 months with people at the hospital
- the advocacy worker and some of the people who were at the hospital went on 'fact finding' visits to see new services in other places: they fed back to other people, including staff at the hospital

- the advocacy project provided additional volunteers and some time for a worked in another project, to give people individual access to advocacy if they wanted this
- the Trust and the Trades Unions set up a series on meetings for staff at the hospital.

At the end of this process - which took about 4 months - the facilitator and some people from the hospital put together a report on the things that people at the hospital wanted to happen: this included the types of houses people wanted to live in, the kinds of things they wanted help with when they lived in the community, and what they thought should happen for all people living in the local community (such as better libraries and a campaign on ending stigma around mental health problems). This report was made to the Mental Health Strategy Group and became part of the strategy.

PLEASE REMEMBER TO SHARE THE LEARNING IF YOU TRY ANY OF THESE APPROACHES, INCLUDING MIXING AND MATCHING. ONLY IN THIS WAY WILL WE BUILD UP THE 'EVIDENCE' OF WHAT WORKS, WHAT ARE THE BENEFITS AND WHAT ARE THE COSTS.

Contact: Involving People Network, currently coordinated by the Involving People Team, Scottish Executive Health Department Tel: 0131 244 3028

Integrating Patient Focus and Public Involvement into Clinical Governance

Clinical Governance is only one of the areas where patient focus and public involvement must be integral. There follows a description of some of the possible opportunities for involving people in a very important area.

How do we KNOW that patients are receiving the highest quality of NHS care?

Clinical Governance brings together a number of important processes which impact on the effectiveness of care.

Effectiveness is not easily measured and there is plenty of scope for including the patient and public's perspective on what is acceptable, important and equitable.

Whose view of desirable outcomes do we consider the most important?

The clinicians'?

The patients'?

The carers?

Or is it a combination?

How often do we explicitly capture the patient's experience of their care and allow this to influence the development of standards?

Do questionnaires and surveys really do justice to the complete experience of patients?

Do we allow the patients' or the public's issues to feature in our Clinical Governance frameworks?

As described already, giving information is right and necessary, but it is only the bare minimum in terms of involving people. We need to ensure that all information, whether written or verbal, is accurate, relevant, timed appropriately and complete, as well as understood. A leaflet on its own will rarely meet these requirements.

Questionnaires, for example patient satisfaction surveys, have traditionally been written by the NHS professional and therefore may not reflect what is important to the people using the service. (see Surveys, above)

We need to find ways of capturing the experience of those who have used our service or who are supporting people who are using our service. Some of the approaches described above may be useful and patients or NHS staff may identify better or other approaches.

Some questions for you to ask of your Clinical Governance arrangements:

Who sets the standards against which practice is measured?
The evidence on which standards are based should include what the patient, carer or service user values and needs

Who writes the content of your information leaflets?
Patients and their allies will have excellent ideas on what should be contained in information leaflets and how it should be formatted, based on their experience of NHS service delivery and life experience.

How will service users, patients and their carers tell you what they think?
Use a range of ways, as described in the rest of this document.

Who designs your questionnaires?
Use a range of ways. Focus Groups might be particularly useful.

Do the results of surveys change or improve your service?
This reflects the importance of feedback - positive or negative

Do you believe that patients' experiences count and should influence aspects of clinical governance, for example:

- continuing professional development,
- research questions,
- standards for clinical audit
- desirable outcomes
- what is deemed as risk
- the way services are designed or delivered?

Have you considered how the patients' and public's input will be included in your Clinical Governance strategy when making important decisions about service design, delivery or monitoring?

Clearly the NHS in Scotland and the people it serves have started a journey to change their relationship and the influence they have on each other.

Listening to each other and acting on what is important to all sides will eventually bring us to the aim of 'Patient Focus and Public Involvement'

- A service where people are respected, treated as individuals and involved in their own care;
- A service where individuals, groups and communities are involved in improving the quality of care, in influencing priorities and in planning services; and
- A service designed for and involving users of the NHS.

Background Reading

Cusack, L and C. Seale-Lapes: Clinical Governance and User Involvement (2000)

Published by British Journal of Occupational Therapy, London
Vol 63 Issue 11 Pages 539 - 546

Derrett, H.: Clinical Governance and User Involvement. (2001)
Published by British Journal of Occupational Therapy, London
Vol 61 Issue 1 Page 49

Kelson, M.: User Involvement: a guide to developing effective
user involvement strategies in the NHS (1997)
Published by College of Health, London

Further reading and websites

Evaluating Public Involvement

Active Partners. Benchmarking Community Participation in Regeneration (1997)
Published by Yorkshire Forward

Audit Commission: Listen Up! Effective Community Consultation (1999)
Published by Audit Commission, London

Barr, A. and S. Hashagen: ABCD Handbook: A framework for evaluating community development (2000)
Published by Community Development Foundation, London

Burns, D. and M. Taylor: Auditing Community Participation: An assessment handbook (2000)
Published by Joseph Rowntree Foundation, London

Chambers, R.: Involving Patients and the Public - How to do it better. (1999)
Published by Radcliffe Medical Press, Abingdon

Coulter, A. and V. Entwistle et al: Informing patients: an assessment of the quality of patient information materials (1998)
Published by King's Fund, London

Drewett, A.: Evaluation and Consultation. Learning the Lessons of User Involvement in Evaluation (1997)
Published by Sage Publications, London

Entwistle, V. A., Sowden, A. J., and I. S. Watt: Evaluating interventions to promote patient involvement in decision-making: by what criteria should effectiveness be judged? (1998)
Published by Journal of Health Service Research and Policy
Vol 3 Issue 2 Pages 100

Frewer, Dr. L., and Dr. Gene Rowe et al: Public Participation Methods: Evolving and Operationalising an Evaluation Framework. Developing and testing a toolkit for evaluating the successes of public participation exercises. (2001)

Published by IFR, Norwich
Institute for Public Policy Research: The IPPR / Guardian Public
Involvement Awards 2001 (2001)
Published by Institute for Public Policy Research, London

Laird, A., J. Fawcett et al: Assessment of Innovative Approaches to
Testing Community Opinion (2000)
Published by The Scottish Executive, Edinburgh

Marsh, R., G. Rowe and L. Frewer: An Evaluation toolkit for
assessing public participation exercises. Report to Department of
Health and Health and Safety Executive (2001)
Published by Institute of Food Research, Norwich

Pawson, R. and N. Tilley: Realistic Evaluation (1997)
Published by Sage Publications, London

132

Yorkshire Forward: Active Partners: Benchmarking Community
Participation in Regeneration (2000)
Published by Yorkshire Forward

Excluded Groups **Children and Young People**

Dorrian, A-M., K. Tisdall and D. Hamilton: Taking the Initiative:
promoting young people's participation in public decision making
in Scotland (2000)
Published by Children in Scotland, Edinburgh

Save the Children: UK All Together Now: Community Participation
for Children and Young People (1997)
Published by Save the Children, London

Save the Children and Kirkless Metropolitan Council: Children's
Participation Pack - A Practical Guide for Playworkers
Published by Save the Children and Kirkless Metropolitan Council

Save the Children Fund / National Early Years Network: Never too
young: How young people can take responsibility and make
decision. A Handbook for early years. (1997)
Published by Save the Children Fund / National Early Years
Network, London

Save the Children Fund and Children's Right Office: Empowering children and young people: A training manual to promote involvement in decision-making
Published by Save the Children Fund and Children's Right Office, London

Children in Scotland
www.childreninscotland.org.uk
The website for professional organisations and people working with Children in Scotland. Aims to promote policies that will improve the lives of Children in Scotland.

National Youth Agency
www.nya.org.uk
The NYA promotes the voice of youth and promotes young people's development both socially and personally through advancing youth work.

United Nations Youth Information Network
www.un.org/esa/socdev/unyin
Aims to increase the awareness of youth within the United Nations and to give them a voice.

Disabled People

Bewley, C. and C. Glendinning: Involving Disabled People in Community Care Planning (1994)
Published by The Joseph Rowntree Foundation, York

Cole, A., B. McIntosh and A. Whittaker: We want our voices heard. Developing new lifestyles with disabled people (2000)
Published by The Joseph Rowntree Foundation, London

Herd, D. and K. Stalker: Involving Disabled People in Services: A document prescribing good practice for planners, purchasers and providers (1996)
Published by Social Work Services Inspectorate for Scotland

Scottish Accessible Information Forum: Standards for Disability Information and Advice Provision in Scotland (1999)
Published by Scottish Consumer Council, Glasgow

Deliberate Diversity

<http://www.deliberatediversity.org/>

Older people and disabled people are under-represented in the workforce. This is both unfair and costly for individuals, for employers and society. Deliberated Diversity will examine the challenge of creating a more inclusive workforce.

Mental Health

Carpenter, J. and S. Sbarini: Choice, information and dignity: involving users and carers in care management in mental health (1997)

Published by The Policy Press in association with Community Care Magazine

Everett, B.: Participation or Exploitation? Consumers and Psychiatric survivors as partners in planning mental health services. (1998)

Published by International journal of Mental Health
Vol 27 Issue 1 Page 80

Forrest, S., N. Brown et al: Involving Mental health Service Users an Carers in Curriculum Design and Delivery. A Strategy for Involvement. (2000)

Published by Faculty of Health Studies (Mental Health), Napier University, Edinburgh

Hancock, M. and L. Villeneuve: Effective Partnerships - Developing Key Indicators for Joint Working in Mental Health (1997)

Published by Sainsbury Centre for Mental Health, London

Hickley, G. and C. Kipping: Exploring the concept of user involvement in mental health through a participation continuum (1998)

Published by Journal of Clinical Nursing
Vol 7 Issue 1 Pages 83 - 88

Rose, D. and R. Ford et al: In our experience. User focused monitoring of mental health services in Kensington and Chelsea and Westminster Health Authority (1998)

Published by Sainsbury Centre for Mental Health, London

Scottish Development Centre for Mental Health: Allies in Change
Route Map (2001)

Published by Scottish Development Centre for Mental Health,
Edinburgh

Tierney, V.A.: How are Users' and Carers' Views of Mental Health
Services Incorporated into the Planning and Purchasing of Health
Boards and Social Work Departments in order to influence Service
Development? (1998)

Published by Department of Public Health, University of Glasgow,
Glasgow

Framework News, Lanarkshire

www.frameworklanarkshire.freeserve.co.uk

The User and Carer Involvement Team enable mental health
service users and their carers, families and friends to participate
in the planning, development, monitoring and evaluation of
services in Lanarkshire.

Sainsbury Centre for Mental Health

www.scmh.org.uk

Develops effective ways in which to deliver Mental Health
Services. This site has information on forthcoming events, details
of publications and a list of current and forthcoming work.

Older People

Barnes, M. and A. Walker: Consumerism versus empowerment: a
principled approach to the involvement of older service users.
(1996)

Published by Policy and Politics

Kelson, M.: A guide to involving older people in local clinical audit
activity (1999)

Published by The College of Health, London

Thronton, P. and R. Tozer: Involving older people in planning and
evaluating community care: a review of initiatives. (1994)

Published by Social Policy research unit, University of York, York

Other

Altering Attitudes

www.alteringattitudes.org

Altering Attitudes is a project funded by the European Commission and is looking at a range of training methods and approaches used by equality trainers to tackle discrimination based on race, age, sexual orientation and disability.

Scottish Community Development Centre (XGrp)

www.scdc.org.uk

This site looks at Community Development and has a variety of information on publications and conference reports. This site also has links to the Community Health Exchange (CHEX)

People from Black and Ethnic Minorities

Chasi, V.: Now we're talking! A report on services provided in Wester Hailes focusing on the views of black and minority ethnic women (2000)

Published by The REP Council Ltd

Scottish Executive: Fair for All (2001)

Published by Scottish Executive, Edinburgh

Wong, J. L.: Ethnic Environment Participation: Key Articles, Volume 2 (1999)

Published by Black Environment Network

People in Poverty

ATD Fourth World

www.atd-uk.org

ATD Fourth World is a human rights organisation working in partnership with families experiencing long-term poverty, to develop their potential and to enable them to participate fully in the life of their communities. Involving People in Poverty in developing policy.

People with Learning Difficulties

Lindsay, Dr. M. and Dr. O. Russell: Once a Day - one or more people with learning disabilities are likely to be in contact with your primary care healthcare team. How can you help them? (1999)

Published by NHS Executive, Leeds

Ritchie, P. et al: Changeover (1996)
Published by Scottish Human Services Trust Edinburgh

Sanderson, H. and J. Kennedy et al: People Plans and Possibilities (2002)
Published by Scottish Human Services Trust Edinburgh

Scottish Executive: The same as you? A review of services for people with learning disabilities (2000)
Published by Scottish Executive, Edinburgh

Sutcliffe, J.: Access and Inclusion. Developing education for carers across agencies (2000)
Published by The National Organisation for Adult Learning

Whittaker, A.: Look at Our Services: Service Evaluation by People with Learning Disabilities (1997)
Published by King's Fund, London

Women

Collins, P. and K. Meehan: How a person centred approach and commitment to collective action changed the balance of power between professional and citizen and reduced inequalities in health (2000)
Published by Derry Well Women Centre, Northern Ireland

Hooper, D., J. Farrell et al: Can they do that? Learning about active citizenship (1995)
Published by The National Organisation for Adult Learning

United Nations Women Watch
www.un.org/womenwatch
This website contains information on a variety of subject matters from throughout Europe. It can present useful information on related topics on involvement.

Other Background Reading

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Office for Public Management: Signposts, a practical guide to public and patient involvement in Wales (2001)

Published by OPM / National Assembly for Wales / NHS Wales, Cardiff

www.wales.gov.uk/subihealth/content/nhs/signposts/signposts-e.pdf

Scottish Office Health Department et al: Designed to Involve: public involvement in the new primary care structures (1999)
Published by Scottish Consumer Council, Glasgow

Signposts, a practical guide to public and patient involvement in Wales (OT)

This guide to patient and public involvement provides information and advice to NHS Organisations about how to develop work in patient and public involvement.

Other Websites of Interest

College of Health

homepages.which.net/~collegeofhealth

The website for the national charity set up to represent patient interests and patient-centred care.

Communities for Health

www.communitiesforhealth.net

Communities for Health support people to play active roles in planning and implementing action to help improve the health of communities. This site acts as a Gateway to health related sites including CHEx, Community Matters, The Health Living Project and Designed to Involve.

Designed to Involve

www.designedtoinvolve.org.uk

The Designed to Involve initiative was funded by the Health Department in October 1999 for two years with the aim of developing public involvement practice in Primary Care in Scotland. This site is now being run by the Involving People Team.

Health in Partnership Programme

www.aswcs.nhs.uk/aswcs/DoH/outline.htm

The programme has 12 projects under this initiative that explore the variety of methods of getting the public involved in health services.

Institute for Public Policy Research

www.ippr.org.uk/research/files/team22/project25/awards.pdf

A report of the Guardian and IPPR awards for 2001.

National Association of Patient Participation

www.napp.org.uk

N.A.P.P. aim to further the communication between Patient Participation groups and N.A.P.P. as well as between the Groups themselves; it also has a forum on Patient Participation which you can take part in.

National Consumer Council

www.ncc.org.uk

The body responsible for promoting what is right for the consumer - irrespective of who they are, all must be considered.

Office of Public Management

www.opm.org.uk

OPM works with people to develop high quality management, professional practice and public engagement in organisations that aim to improve social results. The site details the services they can offer and forthcoming workshops / seminars.

146

Patient and Public Involvement Virtual Resource Centre

www.doh.gov.uk/ppvrc/index.htm

Still in it's infancy but is hoping to have information, tools and practical examples which are available to anyone.

Research for Communication and Public Involvement

www.wpi.org/rcpi

Provides research results and practical tools for those with public involvement remits, especially those in Research and Development.

Scottish Consumer Council

www.scotconsumer.org.uk

Scottish equivalent of the National Consumer Council set up in 1975 to promote consumers rights, especially those who are disadvantaged.

Scottish Council for Voluntary Organisations

www.scvo.org.uk

This is the website for the SCVO which represents voluntary organisations in Scotland with the aims of promoting their independence and encouraging them to realise their potential.

Scottish Development Centre for Mental Health

www.sdcmh.org.uk

The Scottish Development Centre for Mental Health provides advice and assistance to agencies planning and developing mental health services - particularly around the development of partnership working. They also undertake research and training and run an ExchangeNet for people interested in exchanging information on Mental Health issues and services.

Scottish Health on the Web

www.show.scot.nhs.uk

This site has numerous links to most, if not all, things health related including organisations, health councils and trusts the length and breadth of Scotland.

Scottish Human Services Trust

www.shstrust.org.uk

Scottish Human Services Trust (SHS) believe that people of all ages and abilities have the right to the supports and services they require to enable them to participate fully in their communities. This site has links to many varying projects such as Partners in Change, Partners in Policy Making, Allies in Change and Better Futures.

Scottish Intercollegiate Guidelines Network (SIGN)

www.sign.ac.uk

Purpose to improve clinical effectiveness by developing, publishing and circulating guidelines to promote good clinical practice. Has a patient involvement network.

Scottish Policy Net

www.scottishpolicynet.org.uk

This site is about developing strategic conversation for social, economic and cultural change. This site contains information on projects and publications as well as contact details and a variety of links.

The Institute of Development Studies

www.ids.ac.uk

IDS is an internationally-renowned centre for research and teaching on development, established in 1966. Through the work of the Participation Group, the Institute of Development Studies serves as a global centre for research, innovation and learning in citizen participation and participatory approaches to development.

Voluntary Health Scotland

www.vhscotland.org.uk

VHS is the first national network of voluntary health organisations in the UK. The purpose of Voluntary Health Scotland is to maximise the impact of the voluntary sector on health improvement and health care in Scotland.

