use of patient surveys in the NHS
About the Scottish Consumer Council

The Scottish Consumer Council (SCC) was set up by government in 1975. Our purpose is to promote the interests of consumers in Scotland, with particular regard to those people who experience disadvantage in society. While producers of goods and services are usually well-organised and articulate when protecting their own interests, individual consumers very often are not. The people whose interests we represent are consumers of all kinds: they may be patients, tenants, parents, solicitors' clients, public transport users, or simply shoppers in a supermarket.

Consumers benefit from efficient and effective services in the public and private sectors. Service-providers benefit from discriminating consumers. A balanced partnership between the two is essential and the SCC seeks to develop this partnership by:

· carrying out research into consumer issues and concerns;

· informing key policy and decision-makers about consumer concerns and issues;

· influencing key policy and decision-making processes;

· informing and raising awareness among consumers.

The SCC assesses the consumer perspective in any situation by analysing the position of consumers against a set of consumer principles.

These are:

ACCESS
Can consumers actually get the goods or services they need or want?

CHOICE
Can consumers affect the way the goods and services are provided through their own choice?

INFORMATION
Do consumers have the information they need, presented in the way they want, to make informed choices?

REDRESS
If something goes wrong, can it be put right?

SAFETY
Are standards as high as they can reasonably be?

FAIRNESS
Are consumers subject to arbitrary discrimination for reasons unconnected with their characteristics as consumers?

REPRESENTATION
If consumers cannot affect what is provided through their own choices, are there other effective means for their views to be represented?

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An advisory group discussed the progress of the research at various stages, and the SCC is grateful for the constructive comments they made on the project. The members of the group are listed in Appendix 3.
INTRODUCTION

To create a patient-centred health service requires service providers to listen to patients and to involve them in the process of planning, designing and monitoring services. There are many ways of doing this, and there are already many examples of practice in Scotland, where planners, managers and service providers are engaging with patients and members of the public.

One of the most common activities in this wide field of public involvement is carrying out surveys of patients. The data derived from such surveys can be useful in providing a picture of the patient’s experience of healthcare, indicating where there are problems in service delivery and where improvements in services are needed. This information can be a useful tool both for service providers and those who commission services.

However, surveys are only one tool among many which can be used, and many people are seeking to promote methods of involvement requiring a more considered input than simply completing a questionnaire. Surveys, particularly satisfaction surveys, have been criticised for tending to paint a misleadingly rosy picture of services. At the same time their methodological validity has often been called into question. One commentator has stated that

"previous satisfaction surveys had little impact because they often did not meet minimal standards of conceptual or methodological rigour and were not designed to facilitate quality improvement efforts" 1.

The Scottish Executive Health Department considered that there was a need to assess the validity of the survey work being conducted within the NHS, and its usefulness in providing information which could be meaningfully used to assess and improve the service in question. As a result the Scottish Consumer Council was commissioned to review the use of patient surveys in NHSScotland.

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1 P D Cleary, "The increasing importance of patient surveys", BMJ, 1999; 319: 720-721
AIMS

The review aimed

- to provide information on current practice
- to assess the effectiveness of patient surveys in leading to improvements in quality of care for patients
- to identify key features which are conducive to the effective use of patient surveys at different levels as part of an overall strategy of public involvement
- to suggest ways in which the value of surveys could be increased.

These features might relate to strategic or policy issues, methodology, structures, to the attitudes of those involved or to the principles underlying the use of surveys. The findings of the review would enable the Scottish Executive Health Department to identify needs within the service, and to provide guidance on how to meet those needs.
METHODOLOGY

The research has been carried out in several phases.

1 Literature review

A short literature review was carried out focusing on developments in the use of surveys since the SCC/NHS publication Consulting Consumers in 1994, which provided guidance on the use of different methods for consulting health service users.

2 Overview of survey activity

An initial survey of all health board areas was undertaken to get an estimate of the range of survey activity taking place in different health board areas providing feedback on the methods and resources used and the subject areas researched. It asked for information about the scale and cost of the surveys being undertaken, as well as who had actually undertaken the survey. The survey also attempted to assess the extent to which surveys were used compared with other research methods.

This survey was carried out in order to enable us to select appropriate health board areas for more detailed examination in the following stage of the research.

A short questionnaire was sent to all boards, trusts and health councils. Forty nine organisations responded, a response rate of 80%. These responses were analysed and a short report was written describing the results. The research showed that the majority of surveys carried out had fairly small sample sizes (less than 100), and most were carried out in-house, using self-completion methods. Very few surveys were contracted to agencies outside the health service. The costs of the vast majority of surveys reported were very low, typically less than £1000, and often negligible, with only the cost of printing and postage being mentioned.

The volume of research being undertaken suggested that staff within the NHS have embraced the view that it is good to consult with patients and other users of health services. However, the research seemed to suggest that the majority of research that is being undertaken is of a very small scale using very limited resources. Given the small sample sizes being used, they are less likely to be capable of providing robust findings.

3 Review of the use of surveys in three health board areas

Three health board areas were chosen to research in greater detail. The three areas chosen all had distinct features which appeared likely to affect how surveys were used. These included the use of an independent survey provider to carry out large scale surveys of patients, the use of a locally based research centre specialising in health-related research, and, in one area, a wider vision of public involvement which involved some scepticism about the value of surveys. They were not chosen because they were typical, but because they might be able to provide evidence of varying policy and practice in using surveys.
There were two main components to this phase of the review: in depth interviews, and an evaluation of a sample of surveys from each area.

3.1 In depth interviews

The designated directors for public involvement within all trusts and health boards, and the chief officers of local health councils in the three selected areas were contacted. All agreed to an interview with the exception of two who delegated this task to another member of staff. Ten interviews were undertaken with designated directors or their substitutes and three with the health council chief officers. Each interview lasted between 40 minutes and two hours with a typical interview lasting just over one hour.

In addition a further eight interviews were undertaken with staff who worked in an audit, clinical effectiveness or clinical governance role within the trusts. One further interview was undertaken with the director of an independent research centre in one of the three areas.

Finally, nine interviews were undertaken with staff who had a direct role in a number of surveys which were selected for more detailed evaluation.

3.2 Evaluation

Twenty three survey reports were gathered in association with the interviews and examined with reference to:

- Validity
- Evidence of methodological rigour
- Appropriateness of methods to the aims of the survey
- Potential for generalisability
RESEARCH FINDINGS

This study has looked at practice in three health board areas, and examined in greater detail surveys selected for us to look at. The three areas were chosen for their potential to offer models of different approaches to using surveys. In one, the acute trust has chosen to use a large scale methodology developed by a specialist survey provider. In another the existence of a research centre meant that health service providers at all levels could have access to knowledge, expertise and advice about how to conduct surveys well, if they chose to take advantage of this. In the third, some of the key players were more reluctant to use surveys and had developed alternative mechanisms to hear the patient and public voice.

However, it was not possible to draw clear distinctions between the ways in which surveys were used in the three geographical areas covered. For example, while in one area there was less use of surveys in the primary care trust or through the health council, the acute trust used surveys in a similar way to acute trusts in the other areas. In another area the use of a particular methodology in an acute trust had no impact on the way surveys were used in the primary care trust.

1. Attitudes to the use of surveys

In the past some health service providers have been hostile to surveys, which they feared would be critical of the service they were providing. This attitude appears to be changing, and those involved in managing and commissioning surveys felt that front line staff were now generally supportive of surveys, recognising the ways in which they can contribute to change, although there was a range of attitudes, from those who were enthusiastic and supportive, to those who did not consider them worthwhile. It was believed that some staff felt that there were too many surveys, particularly when they were being asked to help in distribution or implementation.

Equally, patient research from a non-medical perspective has traditionally taken second place to medical research, which has been perceived to be more scientific and evidence-based. Our evidence suggests that this attitude persists, with more resource, both time and money, being devoted to medical research, and considerably less to work on patients’ experiences and views. Some of those we spoke to also felt that clinicians did not always value survey-based research, and that when all the staff affected by survey results did not support their use, this could make it more difficult for those surveys to be effective. The research suggests that the resistance of some doctors to patient surveys needs to be challenged. The attitudes of staff, of all kinds, could be affected by their experiences of surveys, which are not always well conducted.

Designated directors

Almost all the designated directors for public involvement were in favour of surveys playing a part in exploring patients’ experiences and their views about how services were being or should be delivered. They saw surveys as forming a part of the overall process of involving the public in the planning and improvement of services.
Those carrying out surveys

Amongst those actively involved in carrying out surveys, there was a range of attitudes as to how easy or difficult this task was. The majority of respondents recognised that it was a skilled task which required appropriate training and support, and which contained many potential pitfalls. Many also referred to the importance of having a source of expertise to refer to, which might exist within the organisation or which could be brought in from outside. Some staff involved in carrying out surveys felt that they did not have sufficient training. Some had only minimal training, for example a 3 day course, whilst others had found themselves having to learn on the job.

The public and patients

The attitude of the public and patients to surveys is also relevant to their effective use. There is perceived to be a danger that the public and patients might become weary of surveys and feel that no change would result from their input. It will therefore be important that those commissioning or carrying out surveys should ensure that those taking part are informed about the potential effect of their taking part. There should be a commitment to feedback to those taking part which should lay out the action that will be taken to push forward the work in a way that is responsive to public concerns and suggestions.

2 Principles

The principles which should underpin the effective use of surveys were identified in the discussions, and there was general agreement about the following:

- Surveys should be used only when they are the appropriate tool
- There must be clarity about aims and possible outcomes
- Surveys must be well designed, administered, and analysed
- There should be local ownership of surveys
- Patients, or where relevant the public, should be involved in the planning and design of surveys
- Survey work must be adequately resourced

Surveys were considered to be most likely to lead to change if they observed these principles. While those spoken to were reluctant to ascribe particular changes to survey results, they generally agreed that surveys formed part of the evidence which could lead to change.

Using surveys appropriately

Tools for exploring the patient experience, patients’ views, preferences or desires should be selected appropriately. There was a recognition that surveys are only one tool which can be used, and that in certain circumstances other, qualitative, methods might be more fruitful. Some respondents had a preference for qualitative tools and had reservations about the extensive use of surveys. They were concerned that understanding the patient experience could not be captured through the use of a survey. Others recognised the advantage of surveys in being able to access large numbers of patients, thus ensuring a better representation of the patient population. Designated directors were unsure whether the balance between different methods was correct.
**Clarity of aims and outcomes**

Those involved in using surveys should be clear what they hope to get from the survey, and how the results may be translated into improvements in services. Some staff spoke of the importance of not raising expectations about what could result from a survey.

**Methodology**

The need for surveys to be well prepared, conducted and analysed and for there to be a commitment to using the findings to influence change was recognised. There was also a recognition that surveys were not always well designed or methodologically sound. For this to be achieved it was important to know how to access appropriate skills and expertise. Increasingly, trusts have in place a team, usually dealing with clinical effectiveness, which will provide guidance and support in all aspects of survey methodology. This maintains ownership of surveys at a departmental level whilst allowing access to specialist help. Surveys must have credibility if they are to be accepted by other members of staff, and if they are to be used to design change in services.

**Ownership**

Several respondents emphasised the importance of local ownership to the success of a survey. Very often what they meant by this was the commitment and involvement of local staff. This raises the question of how local ownership can be combined with specialist back up and resource to ensure that the survey meets methodological tests.

Approaching this from the other direction, the Picker project, confident of the validity of its methods, works to create local ownership, so that its results are accepted at local level.

Many respondents had concerns about national surveys, based on their perception that there would be no local ownership of such surveys, and so no commitment to using their findings. This raises the question of how NHS staff can own a tool that is developed by patients or the public, or even previous cohorts of staff.

**Patient or public involvement**

There appeared to be little patient or public involvement in the design of surveys or input to questionnaire design. Where public involvement existed, this was either potentially tokenistic representation on steering groups, or through the use of focus groups before the survey is designed. Focus groups would only be used in the design of larger, better resourced surveys. There was, however, a widespread feeling that patients and the public should have a greater involvement in the design and content of surveys. There was a need for greater recognition of the patient perspective and patient priorities having equal standing with those of professionals.

It was also considered important to feedback the results of surveys to those who had taken part and to publicise change resulting from surveys. It can also help to check validity of measurements and interpretations if comments are received subsequently, as well as assuring service users and relatives that their time has been well spent and that actions may possibly emerge as a result. Without this positive feedback it is likely that future respondents will be increasingly hard to find.
Resources
It was agreed to be essential that surveys were adequately resourced, both financially and in terms of having access to the expertise and skills necessary to use surveys effectively. There were few resources provided to undertake surveys. The majority were undertaken in-house and whilst specialist staff were often available to provide guidance and support in undertaking a survey, including assistance with questionnaire design and analysis, departments often undertook all the administration attached to a survey as well as the subsequent reporting. It was rare to find any substantial budgets allocated to gathering feedback from patients. A lack of resources in the past had contributed to such work not being taken as seriously as it might have been.

There was perceived still to be a lack of resources, although the introduction of clinical effectiveness teams was seen as going some way towards addressing this. The lack of specific resources did not enhance the image of surveys nor create a culture where surveys are valued. Lack of resources continued to constrain what surveys were undertaken and the methodologies employed. Out-sourcing was not an option for many, due to the perceived expense involved.

3 Strategic approach

Very few organisations in the three health boards had a strategy in place for undertaking patient surveys, with the exception to the work being undertaken by a specialist survey provider on behalf of one acute trust. Within this programme there is a whole plan of research studies stretching over a number of years, with further surveys building on the previous findings.

There was a general recognition amongst those interviewed of the need for more effective management of surveys. For one trust in particular, more central direction of patient research would be preferred and more integration with the planning process. The lack of co-ordination of surveys may result in survey findings not feeding into the planning process at a more strategic level.

However, many trusts took the view that surveys should be initiated at a level close to patients. The more devolved the level at which surveys are planned, the less strategic direction is possible, and the greater the danger of duplication of effort. Such surveys are also likely to be more reactive than proactive.

Larger trusts admitted to the difficulty of maintaining a database of survey work, which would help reduce duplication. Another means of avoiding duplication would be to increase the level of networking within Health Board areas and between them. As technology improves there is a possibility of making use of this to a much greater extent to raise awareness of survey activity and providing contact details.

4 Existing practice

General comment on existing practice from interviews
Our research suggests that the reasons for carrying out surveys varied. Some surveys were triggered by complaints, or because of awareness of a problem with a service. Sometimes surveys were simply to get feedback as to how well a service was meeting
its objectives, while in other cases surveys were part of a process of managing change, where a proposal for change had already been made.

A wide range of staff were involved in carrying out surveys, and their level of knowledge and skill also varied considerably. There was recognised to be a skills gap, and lack of resources to support survey work, although in terms of expertise several respondents felt that there was now greater access to the necessary skills, for example through clinical effectiveness teams.

Respondents commented on what they saw as a failure to make maximum use of data obtained from surveys, and of a lack of co-ordination of survey activity within a trust.

In most areas, there were sources of support and guidance on methodology, but making use of this expertise depended on someone accessing it. These resources were reactive, and if those carrying out surveys did not know that they were there or what they did, then they would not contribute to the development of good practice.

The lack of resources, and quality issues being tagged onto another area eg nursing, has already been commented on.

**Specific comment on selected surveys**

The review looked at the validity, methodological rigour and appropriateness, and generalisability of the surveys submitted to us. A wide range of services were covered, and different levels of sophistication had been employed. While they were not claimed to be representative, they indicated the range of practice in the NHS at present.

Appropriate, although not necessarily ideal, survey methods had been chosen to meet the intended aims of the surveys, with more homogeneous populations receiving more sensitive measurement tools. Sampling methods and administration, however, were generally rather weak in terms of being able to make any generalisations, since virtually none actually used a random design. Sample sizes were generally quite large in total, although it was not always sufficient for the number of categories under consideration. Despite the apparent lack of reminders, the response rates for most were reasonably encouraging, although generally below what would be considered normal for this type of survey when conducted well.

There appeared to be virtually no consideration of the characteristics of non-responders and little for those who did respond, apart from age and gender in some cases. Very few studies considered a deeper analysis than simple description of responses to each question, although one study in particular was very good at investigating the explanations for some of the results and providing useful insights into what might lead to policy changes.

Various question styles were in evidence, although there appeared to be little attention to how well they worked from a measurement point of view. Very little evidence was apparent for considering validity or reliability, which casts doubt on the ability of the surveys to make generalisations. There was also little evidence of giving
feedback to the respondents in most cases, although some had clearly thought about the need for such a strategy.

Overall, it would appear that there is a need for basic training in survey methodology and analysis, and for resources to be made available to support such activity, if it is to be more effective in coming to some firm conclusions that may inform policy and practice. Good examples are in evidence, but these examples need wider dissemination to promote good practice across the NHS in Scotland.
RECOMMENDATIONS

The research has confirmed the view that consulting patients and obtaining feedback through the use of surveys is perceived to be an important and necessary part of involving patients, and of contributing to clinical governance and effectiveness, as a way of improving services in the health service in Scotland. Surveys are likely to continue to have an important role in accessing patients' opinions, attitudes and experiences. The research is to some extent critical of the way surveys are planned, designed, carried out and used, but there are various possible solutions to this poor practice, and these recommendations focus on how to make more effective use of surveys.

1 Surveys of patients should continue to be used within the NHS to obtain feedback on patients' experiences of services and their views on how services could be improved.

The key ways in which practice can be improved are by ensuring that:

• surveys form an integral part of the public involvement work carried out, and that they are planned and managed in a strategic way
• there are effective means of recording survey activity and its outcomes in a form which can be accessed by anyone with an interest in this
• those planning, designing, carrying out and analysing surveys have the necessary skills and support
• underlying principles such as public involvement and ownership are respected
• awareness of good practice and of sources of advice, support and assistance is improved.
• adequate resources are devoted to survey activity

In implementing the recommendations made in this section, there are various options for the approach which could be taken. A summary of the nature of these options is contained in Appendix 1. The various approaches to training staff are outlined in Appendix 2. Reference is made to both these appendices where this is relevant.

1 Strategic and organisational issues

There is evidence from the research that those with a responsibility for public involvement in boards and trusts are not aware of all the survey work currently being carried out in their organisations. Without a strategic overview it is difficult to avoid duplication, to fill gaps in knowledge or to ensure that consistent standards and effective methods are being used in different situations. At the same time it is important not to restrict the ability to respond to local needs, and this research shows that staff value the possibility of undertaking local surveys independently.

Surveys should be seen as being part of an overall strategy of involving the public and of obtaining the views and exploring the experiences of patients, with a view to improving services. Within the strategy there needs to be a clear statement of how surveys will be used to assist in the process of obtaining feedback from patients.
The questions which need to be answered are:

- At what level should public involvement strategies be developed? Should this be at national level, at NHS board level, at trust level, or at the level of individual hospitals or primary care organisations?
- Who should be responsible for developing and overseeing the implementation of the strategy?
- What systems are needed to ensure that it is possible to take a strategic view of activities?

To some extent the answers to these questions are part of the wider policy debate about public involvement in the health service, which has not yet been resolved.

**Strategy development**

It seems obvious that this kind of activity should not be happening in a highly centralised manner at national level, although there may be some developments at national level which would inform and assist in carrying out public involvement and patient research effectively. This is discussed further in section 6 below, Making Comparisons.

Strategy could be developed at NHS board level, trust level, or at a more decentralised level such as hospital or health centre. In deciding between these options the following considerations are relevant:

- The scale of current activity – this may make board level too large to be managed effectively, although boards may retain responsibility for research in relation to health promotion and other activities distinct from those carried out in primary care trusts or acute hospital trusts.
- The distance of staff from front line services – board level may be too remote
- Existing practice
- Ownership – it is important that staff feel involved and committed to the process
- Cost

The person who currently has the responsibility for public involvement strategy at trust or board level is the designated director. It will be a matter of policy as to whether a single post-holder such as the designated director continues to have the responsibility for this strategy, or whether this should be the responsibility of a larger group of people. It may, however, be desirable for one person to be ultimately accountable for the final decisions made about the strategy.

**Taking it forward**

- Representatives of patients and the wider public should be included in the group which decides on public involvement and patient research strategy.
- The research and public involvement strategies should be planned at least one year ahead with opportunity for input from front line staff about what is required.
- Research and public involvement strategies should clearly identify budgets and other resource implications.
• Strategies should allow for unforeseen research needs which may occur in the course of the year
• The responsibility for signing off research budgets should be clear

2 Those with the responsibility for public involvement in NHS Scotland should ensure that they have systems in place to enable them to take a strategic view of all such activity in their areas, including the use of patient surveys.

How this might be achieved in practice is discussed in the following section on organisational structures.

Organisational structures

The range of possible organisational structures reflects the decisions which have to be made about how a much greater degree of professionalism can be introduced into the day to day activity of carrying out patient surveys, alongside other social research.

Assuming that both a highly centralised and a highly decentralised model have significant disadvantages in terms either of cost or of lack of professionalism (see Appendix 1 for further detail), one possible approach would be to have a central research team within every trust and NHS board. Within larger trusts and in boards it might be necessary to have more than one team. The functions of these teams would be

• To ensure that patient research is of a consistently high quality throughout the trust or board
• To ensure that all patient research fitted into the overall research strategy of the organisation
• To carry out patient research
• To advise, assist and support other staff to carry out surveys and other types of research
• To advise on the out-sourcing of research
• To liaise with all departments or units, such as clinical effectiveness teams, clinical governance teams and public involvement workers, and to provide these people with services and support as needed
• To provide a strategic overview of research activity within the trust or board
• To act as a channel to those with the responsibility of drawing up and implementing the public involvement and research strategies at trust or board level.

3 Within trusts and boards there should be research teams with appropriate training, expertise and knowledge in social research methodology. The role of these teams would be to advise, assist, and support public involvement and clinical governance activity, including patient surveys and other research.
4 Research teams could carry out surveys themselves, as well as working with other members of staff in an advisory, supportive or training role.

5 One of the responsibilities of the central team would be to raise awareness of good practice and methods of involving the public.

6 The team should be proactive as well as reactive, with the power to initiate research or other activity when it is clear that this is needed.

Within the research team, there should be one person with a particular responsibility for surveys.

Research networks

All researchers in either trusts or boards should be encouraged to take part in local research networks covering each NHS board area. Other organisations involved in carrying out surveys of patients and other types of patient research, for example local health councils and patients’ organisations, should also be encouraged to take part. It would also be useful to encourage the creation of a health service research network at national level. Models for such networks already exist, for example through HEBS.

7 NHS boards should establish research networks in their areas, drawing together those working within the NHS and other organisations actively involved in research.

8 The Scottish Executive Health Department should consider encouraging the creation of a health service research network.

Register of research and public involvement activity

One element involved in developing and monitoring a public involvement strategy will be how to record the range of activities being undertaken. A register of public involvement activity and patient research would be helpful not only to those involved in carrying out surveys, but also to those involved in performance and accountability reviews, as a measure of public involvement. Members of the public, local health councils, patient organisations, and health organisations in the voluntary sector would all have an interest in the kind and extent of work being carried out.

Maintaining such a register would be a time consuming task. However, if surveys were being undertaken in a more strategic way, involving the research teams described above, it might become easier to create and maintain such a register.

Such a register could be

- held and maintained within the organisation (ie at trust or board level)
- made available to a body such as the local health council or, more radically
• held and maintained by an independent agency such as a local health council, which is both statutory and has a specific remit to represent the interests of the public in local health services.

Wherever organisation has responsibility for maintaining a register, it should be possible for the public and health service staff to access it through the internet.

9 Part of the public involvement strategy should be the maintenance of a register of research and other activities undertaken, including the use of patient surveys. This register should be open and accessible to all those who might have an interest in it, and should be kept up to date. Consideration should be given to where this register should be kept.

Taking it forward

- Budgets should be set aside for the creation of registers of public involvement and patient research activity and for their maintenance.
- To encourage national consistency in the recording of public involvement and patient research activities, the software for setting up such a register should be developed centrally.
- If the register was maintained on a web site this would allow for easy access.
- The register should include the subject area of the survey, its aims, some detail about sampling and method, the timing of the survey and contact details for those involved in undertaking or supervising the survey.

2 Skills and training issues

The research suggests that within most trusts and boards there is already some expertise available on research methods, including the use of surveys. At the same time there is also evidence that many of those involved in carrying out surveys have no training or understanding of how to make the best use of surveys. For example, almost none of the surveys made more than superficial use of the data obtained. This raises the question of who should carry out surveys, and what degree of professionalism should be expected. On the one hand it could be argued that anyone who wants to should be able to carry out a survey, and should be provided with either the training or the advice and support to do so. On the other hand it could be argued that surveys should only be undertaken by those with training in how to design, plan, administer and analyse the results of surveys. The range of possible scenarios is spelt out in Appendix 1.

At present, those undertaking patient surveys range from nurses carrying out small scale surveys as part of a degree course, to an international institute using tried and tested survey tools, and everything in between.
While recognising that this is a matter on which there may be considerable debate, the following recommendations propose a move towards a greater degree of professionalism than currently exists.

**Training**

10. All staff undertaking surveys should be appropriately trained, or be supervised by someone who is appropriately trained.

11. All trusts and boards should employ at least one researcher with an academic qualification in social research methods. Other researchers need not have such rigorous training, but where they are directly involved in undertaking surveys they should have training in survey methodology.

The numbers of research staff employed will vary considerably according to the size of the trust or board.

**Information technology**

In addition to sufficient staff, researchers must have access to appropriate software to prepare surveys and analyse data. Some of the shortcomings in the existing analysis of surveys appears to be due to a lack of access to a statistical package such as SPSS. It is important that such software, and training in using it is provided.

12. All trusts and boards should have an appropriate software package available for the use of research staff, and staff trained to use it.

13. At least one member of staff should have an in-depth knowledge of this software and be able to advise others on its use. Other researchers should have a basic understanding of the software.

There may, however, be occasions on which it is more cost-effective to out-source the analysis of surveys, and staff should be aware of this.

**In-house or out-sourced?**

The majority of surveys in the NHS are currently undertaken in-house, with external consultants being used only on larger, higher profile, better funded projects. The balance between work undertaken in-house and out-sourced will vary depending on the types of research being undertaken within the organisation at any point in time.
Taking it forward

The following points should be borne in mind:

- External researchers should bring professionalism and objectivity
- Staff may learn from the experience of working with external consultants
- In-house surveys should continue to have an important place in patient research
- External consultants are likely to be expensive, but in some cases this will be more cost-effective than attempting to carry out research in-house

3 Underlying principles

Public involvement

There was evidence in the research that patients and members of the public had not been significantly involved in the design or planning of patient surveys, although there were exceptions to this. It is an important principle that surveys which aim to explore the experiences of patients, should be based on their own concerns, rather than a professional’s view of what matters to patients. The questions asked in surveys should be the patient’s questions and not those of doctors, nurses or managers. The input of patients in the design and planning of surveys may be done in various ways: through the use of focus groups or through interviews with patients. An alternative approach would involve handing the whole process over to patient organisations.

It is also important to feed back the results of surveys to those who have taken part and to the wider public, so that members of the public become more aware of the role which surveys may play in improving services. In addition, without such feedback, potential respondents to surveys may become less willing to commit time to participating if they feel there is no explicit response and beneficial outcome.

14 Those involved in the planning and design of patient surveys must ensure that there is input from appropriate patients and their representatives in this process, so that surveys are firmly rooted in the concerns and interests of patients.

15 Those responsible for planning patient surveys should consider circumstances when it may be appropriate for patients and their representatives to be actively involved in carrying out the survey.

16 Those who have carried out surveys must ensure that the results of those surveys are fed back to those who have taken part as well as to the wider public; for example, survey results could be included in newsletters or in the local press.
Taking it forward

- Guidance on how to involve patients and the public should be provided, possibly in the context of relevant training courses. Written guidance could supplement any training.
- Where larger surveys are being undertaken, patients should be invited to sit on steering or advisory groups.
- When research strategies are being drawn up, patients should be involved in the process of determining what research is carried out.

Ownership

The research suggests that there is some confusion about what is meant by “ownership” of a survey, which was widely considered to be essential to a survey’s success. As noted above, it is important that a survey can be seen to derive from the concerns of patients, and to that extent it could be said to “belong” to patients. However, there is also a feeling that for a survey to be successful, those involved in administering and implementing it must feel a degree of commitment which is most often generated by their active involvement in its planning and design, and by the survey also taking account of the concerns of staff. Staff do not want to feel that survey questions have been imposed on them.

As the Picker project demonstrates, where a survey tool is used which has been generated by an outside agency, albeit informed by the concerns of patients in a particular setting, it is necessary to spend time with staff to generate the necessary commitment to the process of carrying out the survey and implementing any resulting changes.

17 All patient surveys should be based on the concerns or interests of patients as expressed by those patients or their representatives, supplemented, if necessary, by the concerns of the staff most closely affected by the survey.

18 The commitment of those staff who will bear the responsibility for taking forward the results of any patient surveys and for implementing any resulting change must be built into the survey process. This does not, however, require that they are responsible for determining the content of the survey.

Taking it forward

- If a more professional approach is taken, with more surveys being undertaken by professional researchers than by front-line staff, there will be a need for them to develop a strong rapport with the staff who will be affected by the outcomes of the research.
Dissemination and feedback

It is important that the results of surveys are fed back to those who have taken part and to the wider public (as discussed above), and also to others who may have an interest, particularly members of staff affected by the results of surveys. One effective method of feeding back to members of staff is through seminars.

19 The results of surveys should be disseminated through a range of mechanisms: through direct reporting to those who have taken part; through newsletters and other methods to members of the public; through seminars or meetings with members of staff affected by the results; and through open, accessible web sites for anyone seeking more information or advice.

Taking it forward

- There should be an assumption that the results of surveys are publicly available.
- It would be useful if survey results could be published in a similar format, as is currently done by the Scottish Executive Central Research Unit and Scottish Homes.
- Greater use of IT could lead to the publication of all research findings on a web site, which could be linked with the research register, discussed above.

4 Methodology

The central concern of this research focuses on how to improve the way in which surveys are being planned, designed, administered and analysed. The credibility of surveys will be undermined unless attention is paid to how well they are being conducted and used. A strategic approach, an increasing professionalism, and an observation of certain underlying principles will all contribute to good practice as discussed above. In terms of specific methodological issues which need to be addressed, the research highlights the following as areas where there could be significant improvement in practice:

- the choice of methods
- sampling and administration
- response rates
- analysis
- attention to validity, reliability and generalisability

20 Training for those involved in carrying out patient surveys should give attention to the areas of weakness identified in the research with a view to improving practice.
5 Resources

It is important that public involvement activity, including the use of surveys, is resourced sufficiently to ensure well-qualified staff and high standards of practice. Resources will be needed for training and continuous professional development for any central resource, and for others who are involved in carrying out surveys.

21 NHS boards and primary care trusts should ensure that when surveys are agreed to be the appropriate way to obtain patient feedback, adequate resources are available to ensure that this meets the standards required for good practice.

6 Making comparisons and benchmarking

The research suggests that there is little tracking either of what happens as a result of a particular survey, or in order to make comparisons over time. Surveys have the potential to be used to make comparisons over time, and between different organisations, provided that like is compared with like. This requires that consideration be given to the appropriateness of comparisons and the methods by which data can be standardised for this purpose.

22 The results of patient surveys should be used to track change over time.

The extent to which surveys can be used to compare one unit or organisation with another will depend in part on the extent to which core common questions and methodologies can be agreed. The research shows that there was some resistance to the idea of surveys which were not specifically designed for the needs of one particular situation, and this was often discussed in terms of the lack of ownership that would be felt. However, in practice many of those designing surveys use questions which have been asked before in similar situations. It would therefore be an improvement on the current situation if there were common core questions, developed in a rigorous way. For example, it may be possible, on a national basis, to develop an understanding of the core concerns of patients in particular areas, for example in primary care, and on the basis of this to develop some core questions which should be used in surveys in that area.

23 Consideration should be given to the development of core questions which could be used in similar settings.

The development of core or common questions would allow the aggregation of data from different areas to give a wider picture of patient experiences across Scotland. Developing a national picture in this way would not suffer from the disadvantages of carrying out national surveys, which are discussed below.

7 National surveys

The main disadvantage of national surveys is that they do not contribute in any meaningful way to improving services. Because the sample sizes involved are
relatively small it is difficult to analyse the findings in relation to particular patient groups, for example older people, people from lower social groups etc. These small sample sizes do not allow sufficient confidence in the findings to support changes to services.

There was widespread resistance to any use of national surveys amongst those we spoke to during this research for this very reason.

We therefore do not advocate the use of national surveys, preferring the development of core questions which would allow for some aggregation of local findings to develop a fuller national picture.

8  Raising awareness of the role of surveys

The research suggests that there are still those in the medical profession who are not convinced that surveys are a useful source of information or that they can contribute constructively to informing change. For surveys to be used more effectively it may therefore be necessary to change professional attitudes to the uses of patient research, particularly where this involves qualitative methods, for example when a survey is based on preliminary focus group work with patients.

24  Those responsible for the public involvement strategy should seek opportunities to inform the medical profession and other staff members of the potential of different methods of conducting patient-focused research.

Taking it forward

- A more professional approach to carrying out surveys, as advocated above, will improve the image of surveys
- Survey methods should always be explained in any survey report
APPENDIX 1 OPTIONS

The options for taking forward the recommendations contained in this report relate to the extent to which the arguments are accepted that

- there is a need for more professionalism in order to ensure higher standards in the planning, design and implementation of surveys and other patient research, and
- there is a need to be able to take a strategic view, which is likely to lead to a greater degree of central control or oversight than exists at present.

Professionalism

In relation to professionalism, there is a spectrum of how this could be achieved, depending on the extent to which research activity is to be carried out by specialist staff.

<table>
<thead>
<tr>
<th>More specialism</th>
<th>Less specialism</th>
</tr>
</thead>
<tbody>
<tr>
<td>All research carried out by professional researchers</td>
<td>Some research carried out by professional researchers, some carried out by front line staff under the supervision or with support of professional researchers</td>
</tr>
</tbody>
</table>

If the majority of research is carried out by front line staff, there will be a high degree of ownership of the research, but the cost of equipping staff to carry out research to the highest standards is likely to be prohibitive. If almost all research is carried out by professional researchers, there is a danger that front line staff do not feel ownership of the research, but standards and cost effectiveness are likely to be better.

Strategic overview

This is linked with the discussion about the degree of professionalism involved, but focuses on the level at which it would be most effective to be able to make strategic decisions about the patient research and public involvement activity which is carried out.

At one extreme all research could be planned, commissioned or carried out at national level, and at the other such planning would be done at hospital ward or primary care provider level.

With planning of research done at a national level, it would be well nigh impossible to get a grasp of what is going on nationwide. Conversely, if research was planned at a very local level, it would be possible to respond quickly to local needs, but very difficult to have a view of the bigger picture or to create coherent strategy across a trust or health board area.

The ways in which training could be provided are outlined in Appendix 2.
APPENDIX 2 TRAINING

This appendix aims to spell out the various training options that are available for the NHS in Scotland to put into effect some of the recommendations made above. Consideration is given here to some of the resource implications of pursuing each of the training options.

Appendix 1 summarises the discussion in the report concerning the tension between centralisation and decentralisation of responsibility versus the resource implications of increasing professionalism for the production of surveys. Recommendation 3 states the need for the “appropriate training, expertise and knowledge in social research methodology” to advise, assist and support all public involvement activities, of which surveys represent one method. Part of the reason for this recommendation was the evidence of a number of weaknesses relating to the specific use of the survey method, including its appropriateness to provide particular types of information, issues concerning sampling and administration, relatively poor response rates, minimal or weak analysis, and lack of consideration of many issues relating to validity, reliability and generalisability.

It needs to be stressed that the need for training is not confined to the survey method, but due regard needs to be given to the nature of social research itself, which will include more philosophical and theoretical concerns about the nature and form of evidence, as well as knowledge and skills in designing, implementing, analysing and interpreting the results using specific methods. In practice it may only be practicable for a limited number of personnel to acquire the full range of knowledge and skills, while others may only require specific skills to be learnt.

The choice of appropriate training, from the list of options presented here, depends on prior consideration of the degree to which such training is to be focussed on a core central team or dispersed throughout the front-line staff. It should also be emphasised that the optimal selection will probably include a range of options, depending on the current knowledge, skills and competencies, which may take place in parallel or sequentially. Consideration would also need to be given to whether staff who become trained in social research methodology are then the appropriate people to cascade some of those skills to others in the organisation.

Brief discussions were held with a number of different people and agencies in Scotland to see what options others had already thought of in terms of training requirements to do social research in the NHS. While most were not necessarily focussed on this specific issue, a broad view was gained that emphasised the need for some training and resources to be dedicated to the task, especially the provision of locum cover for trainees, and the need for consideration of alternatives to the survey method. Particular acknowledgement is made of the Health Education Board for Scotland (HEBS), through the work of Mary Duffy and Erica Wimbush, who are developing a professional development strategy for research and evaluation intended to benefit not only the NHS, but also local authorities and voluntary organisations.
Essentially there are eight types of training methods that would seem appropriate for consideration by the NHS to improve the knowledge and skills in social research. These include the following:

A  Class-based courses
   A1  External standard programmes
   A2  External tailored programmes
   A3  Internal tailored programmes

B  Distance learning
   B1  Courses
   B2  Toolkits

C  Mentoring

D  Shadowing

E  Fellowships

F  Secondment
   F1  Internal transfer within the NHS
   F2  Transfer from outside
   F3  Transfer to outside

G  Research Support Networks

These various options are outlined in detail in the Appendix, which provides the following considerations:

1  Training method.
2  Organiser / provider. This is categorised as being external (outwith the NHS) or internal (to the NHS).
3  Programme Type. Various types of provision are outlined.
4  Location. This indicates where the training is likely to take place.
5  Examples. These offer some possibilities, without intending to be exhaustive.
6  Advantages. These are in terms of the benefits to the trainee and the department.
7  Disadvantages. These are the converse of the advantages.
8  Resource Implications. These outline some of the time and finance issues.

In making the appropriate choices for training, the decision path will need to reflect on the degree of need for a broad critical appreciation of social research and the need for specific skills in particular methods and tools. External provision can offer training at all levels, although universities are generally more concerned with educational development, rather than training in skills per se. Increasingly, however, there is pressure on universities to offer a mix of both types of provision. It may be sufficient for a member of staff to attend an existing course, such as an M Sc (part-time or full-time), but increasingly higher education institutions are prepared to provide tailored
Many courses can offer CPD accreditation too.

Many types of training can be accommodated in-house, such as mentoring, or secondments, although due time needs to be provided by both mentor and mentee to ensure an effective programme of development. Routine distractions and needs of the workplace can interfere in the training time, which are more difficult to protect when the person is still on site.

Some training can be initiated and controlled by the individual, although skills in using remote sources of information and ability to work by oneself are key components to make this effective. Access to experts may still be necessary during this self-learning pathway.

Resources are essentially to do with the need to give adequate, protected time for training in an environment that is conducive to the application of the knowledge and skills that are acquired. Generally, this requires provision of locum cover, or recognition of a need to reduce the workload of a department to reflect the reduced capacity. External provision is generally expensive, although it may prove to be more cost-effective in terms of providing high quality training and a focussed environment for learning, with the support of relevant information and technology.
<table>
<thead>
<tr>
<th>Training Method</th>
<th>Organiser/Provider*</th>
<th>Programme Type</th>
<th>Location*</th>
<th>Examples</th>
<th>Advantages</th>
<th>Disadvantages</th>
<th>Resource implications</th>
</tr>
</thead>
<tbody>
<tr>
<td>A1 Class-based courses</td>
<td>External</td>
<td>Existing standard programmes</td>
<td>Usually External, occasionally Internal</td>
<td>Higher Education Institutions: postgraduate studies</td>
<td>Run by 'experts'</td>
<td>Often inflexible</td>
<td>Potentially expensive, although universities are often relatively cheap compared to commercial companies</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(i) Social Sciences MSc/Dip/Cert in Social Research, or allied subject</td>
<td>Potential for broad education</td>
<td>Can be context inspecific</td>
<td>Requires locum cover or reduced in-house work throughput</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(ii) Health Services Centres MSc/Dip/Cert in Health Services Research</td>
<td>Protected from work demands</td>
<td>Less opportunity to determine content</td>
<td></td>
</tr>
<tr>
<td>A1 A2</td>
<td></td>
<td>Tailored programmes</td>
<td>External or Internal</td>
<td>MSc/Dip/Cert in Social Research</td>
<td>Varied participant experiences</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>(a) Standard provision</td>
<td>- offered 1 - 3 times per year</td>
<td>Protected from work demands</td>
<td>Access to learning resources</td>
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<tr>
<td></td>
<td></td>
<td>- flexible according to demand</td>
<td></td>
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</tr>
<tr>
<td></td>
<td></td>
<td>(b) Ad hoc provision</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A3 Internal</td>
<td>Tailored programmes</td>
<td>Internal</td>
<td>H ealth Services Research Networks e.g. Primary Care Research Network</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>(a) Standard provision</td>
<td>- offered 1 - 3 times per year</td>
<td>More tailored to in-house needs</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>- flexible according to demand</td>
<td></td>
<td>Run by 'experts'</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>(b) Ad hoc provision</td>
<td></td>
<td>Limited to in-house participant experience</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>- flexible according to demand</td>
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</table>

use of patient surveys in the NHS 27
<table>
<thead>
<tr>
<th>Training Method</th>
<th>Organiser / Provider*</th>
<th>Programme Type</th>
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<th>Disadvantages</th>
<th>Resource implications</th>
</tr>
</thead>
<tbody>
<tr>
<td>B1 Distance learning (mixed media, inc. internet)</td>
<td>External or internal</td>
<td>Courses</td>
<td>Anywhere</td>
<td>Higher Education Institutions (British or international) e.g. Open University University of the Highlands and Islands RCN Institute MSc/BSc/Dip/Cert/credit-based modules</td>
<td>Local access to external tuition</td>
<td>Can be remote from tutors</td>
<td>Relatively cheap, although VFM depends on quality of materials and tutorial support</td>
</tr>
<tr>
<td>B2</td>
<td></td>
<td>Toolkits</td>
<td>Health Service (NHS) specific e.g. HEBS website General provision e.g. ESR C provision (TRaMSS: Training Resources and Materials for Social Scientists)**</td>
<td>Flexible to meet individual needs</td>
<td>Individualistic learning, remote from others</td>
<td>Requires skills in accessing materials effectively</td>
<td></td>
</tr>
<tr>
<td>C</td>
<td>Mentoring Internal</td>
<td>Standard staff development path Ad hoc provision</td>
<td>Internal</td>
<td>Part of H R M strategy for all professional staff Reactive to needs or individual demands</td>
<td>Continuous learning Specific to organisation and role</td>
<td>Variable quality of mentor (often demands time) Slow pace of learning No benefit of external views of solutions</td>
<td>Time demands on the mentor Requires some locum cover for mentee</td>
</tr>
<tr>
<td>D</td>
<td>Shadowing Internal</td>
<td>Standard staff development path Ad hoc provision</td>
<td>Internal</td>
<td>Part of H R M strategy for all professional staff Reactive to needs or individual demands</td>
<td>Specific to required skills Less demanding of the person shadowed than mentoring</td>
<td>Depends on quality of the shared experiences May not have relevant experience shared May not be immune from in-house demands</td>
<td>Requires some locum cover</td>
</tr>
<tr>
<td>Training Method</td>
<td>Organiser / Provider*</td>
<td>Programme Type</td>
<td>Location*</td>
<td>Examples</td>
<td>Advantages</td>
<td>Disadvantages</td>
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</tr>
<tr>
<td>E</td>
<td>Fellowships</td>
<td>External</td>
<td>External</td>
<td>Higher Education Institutions Research Councils, e.g. ESRC, MRC Research-based charities Royal Colleges</td>
<td>Often involved in multidisciplinary research Usually funded externally Protected from work demands Often working with experts or skilled mentors</td>
<td>Not necessarily specific to in-house needs</td>
<td>Often requires significant locum cover (possibly a few years), although this may be paid for externally</td>
</tr>
<tr>
<td>F1</td>
<td>Secondment</td>
<td>Internal</td>
<td>Internal</td>
<td>Cross-departmental transfers (perhaps 2-way)</td>
<td>Mutual synergy and benefit Wider transfer of skills Improves interdepartmental understanding</td>
<td>May not learn much new No opportunity to learn from external views</td>
<td>Depends on agreement about transfer of resources Locum cover required for original job, or reduction in work throughput</td>
</tr>
<tr>
<td>F2</td>
<td>Transfer from outside</td>
<td>Academic or agency staff working alongside NHS staff</td>
<td>Internal</td>
<td>Fresh perspectives on solutions Tailored to in-house needs</td>
<td>Lack of in-house receptivity to new ideas Potential for irrelevant perspectives May need tailoring to fit in-house needs Not immune from in-house demands</td>
<td></td>
<td>Depends on agreement about transfer of resources Supplying organisation may charge a consultancy fee</td>
</tr>
<tr>
<td>F3</td>
<td>Transfer to outside</td>
<td>External</td>
<td>External</td>
<td>Fresh perspectives on solutions Protected from work demands</td>
<td>Lack of in-house receptivity to new ideas on return Potential for irrelevant perspectives Contextual unfamiliarity may be time-consuming</td>
<td></td>
<td>Depends on agreement about transfer of resources Locum cover required for original job, or reduction in work throughput</td>
</tr>
<tr>
<td>Training Method</td>
<td>Organiser / Provider*</td>
<td>Programme Type</td>
<td>Location*</td>
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</tr>
<tr>
<td>Research support networks</td>
<td>Internal</td>
<td>Ad hoc</td>
<td>Anywhere</td>
<td>Health Services Research Networks; e.g. Primary Care Networks; e.g. seminars, conferences, web-based discussion groups</td>
<td>Guidance and support for meeting needs</td>
<td>Limited by the quality of knowledge in the network</td>
<td>Potentially very cheap</td>
</tr>
<tr>
<td>Joint Internal-External</td>
<td></td>
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</tbody>
</table>

* Internal refers to within the NHS and External refers to outwith the NHS

* http://www.data-archive.ac.uk/projects/alcd.asp
Appendix 3

Members of advisory group

Alison Bramley  Clinical Resource and Audit Group (CRAG)
Jackie Brock     SEHD, Primary Care Division
Charles Brown   SEHD, Economics and Statistics Division
Christine Campbell Scottish Association of Health Councils
Hazel Dench     SEHD, Economics and Statistics Division
Lyn Jones       Scottish Health Feedback
Helen Mansbridge SEHD, Economics and Statistics Division
Hector McKenzie  SEHD, Health Planning and Quality
Pat Straw        Lothian University Hospitals NHS Trust
Gary Sutton      SEHD, Economics and Statistics Division
Elaine Tait      CRAG