

# Refreshing the NHS QIS patient and public partnership – a reform agenda

### **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 is part of the National Consumer Council (NCC) and is sponsored by the Department of Trade and Industry. The SCC's Chairman and Council members are appointed by the Secretary of State for Trade and Industry, in consultation with the First Minister. Martyn Evans, the SCC's Director, leads the staff team.

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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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## Refreshing the NHS QIS patient and public partnership – a reform agenda

The Scottish Consumer Council welcomes the opportunity to respond to this consultation from NHS Quality Improvement Scotland. NHS QIS has been a champion of patient and public involvement in its work since its creation, and has done considerable work on the recruitment, training and support of lay people. Indeed, the forward-looking nature of this work has been used as a model by the Care Commission, and lay reviewers trained by NHS QIS are in demand in other parts of the NHS. Any critical comments in this response should be read in the context of the SCC's support for this ground-breaking work.

### General comments

#### **Scope of the paper**

The paper focuses on individuals who become involved as partners in the work of NHS QIS rather than looking more widely at the relationship between QIS and the wider Scottish public. If it had adopted a wider approach, we would have expected to see more about how NHS QIS communicates with the public, for example in connection with making information about standards more widely available to those who might benefit from having access to them. The focus on the role of lay reviewer means that the opportunity of reviewing the wider public focus and public involvement aspect of NHS QIS's work has been missed. In particular, it would have been interesting to have seen some evaluation of the impact of public involvement in a range of settings, including the review process and the development of standards.

#### **The nature of involvement with QIS**

It would have brought greater clarity to the paper if it had set out clearly the types of engagement with QIS which are covered in the proposals. The paper refers frequently to the fact that people are involved in different capacities than as lay reviewers, but the various types of involvement are not described. From our own experience of QIS, we would imagine that the types of involvement which are referred to, but not described in the paper, would include the following

- Taking part in reviews of NHS services (being a lay reviewer)
- Being a member of a group developing standards for use by QIS
- Being a member of an advisory group or a board member of QIS
- Taking part in consultation events about the work of QIS

In addition, the paper refers to people who have trained as lay reviewers for QIS being recruited to take part in other activities outside QIS. This is discussed in more detail below, but the SCC does not believe that it should be part of the remit of QIS to be training people to act as public or patient representatives in settings outside NHS QIS.

The SCC would argue that these different types of involvement will require different approaches, in terms of recruitment, training and support, and that to lump these types of involvement together can cause confusion.

For example, in a project group working on standard development there are likely to be several people taking part who might be described as “lay” in the sense that they are not health professionals and do not work for QIS. However, some of these people are likely to be there because they represent a wider group or interest. Someone who works for a patient group, such as Diabetes UK, is there because of their wide knowledge and understanding of the concerns and interests of diabetes patients and their families. Someone who works for the Disability Rights Commission is there to represent the interests of disabled people. The board of NHS QIS also contains a number of lay people. These people are unlikely to need a great deal of support or training to take part in this work with QIS. They do not need to be screened or checked to ensure they comply with equality and diversity policies. In contrast, if it is felt useful to ask a diabetes patient to take part in the project group, that person may have some training and support needs, which should be provided by QIS. To lump these people together as “lay people” obscures the different reasons for their involvement with QIS and their different needs.

### **The approach taken in the paper**

By focusing on people who have become directly involved in the work of NHS QIS, the consultation appears to be proposing processes and structures akin to employment which will not be appropriate for everyone who is involved in QIS’s work. For example, staff or members of the SCC might be involved in project groups working on standard development, or as members of the QIS board. These people would not necessarily expect or want to be subject to the recruitment, training, support, monitoring and evaluation processes described in the paper.

In some parts of the paper the analogy which springs to mind is not employment but military operations, with the rigorous deployment of lay people according to strict criteria. We believe that people representing patient groups or particular groups, such as disabled people, might have reservations about the highly structured processes described in this paper. The paper describes what will QIS will do in relation to the lay people involved with it, and presents this as a one-way relationship which overlooks the importance of what lay people can bring to QIS, and the kind of dialogue which there should be between lay people and QIS.

### **Impact of equality and diversity policies**

Much is made in the paper of the impact of Scottish Executive policies aimed at preventing discrimination within the NHS, and promoting equality and diversity. While recognising the importance of these policies, particularly in relation to service provision, we would be reluctant to criticise the work which QIS has done on this basis. It is important that the work being done by those currently involved in voluntary work on behalf of QIS, which often involves a

significant amount of time and effort, is not dismissed on the grounds that these volunteers were not selected using criteria to demonstrate their compliance with these policies.

### **The focus on lay reviewers**

The SCC thinks that it is important that NHS QIS continues to have specific procedures in place for the recruitment, training, support and evaluation of lay reviewers. However, many of these processes are not appropriate for other forms of involvement which members of the public may have with QIS. To avoid confusion, the SCC would be in favour of NHS QIS keeping a distinct focus on what is required in relation to lay reviewers.

### **The use of the term “lay reviewer”**

It is suggested in the paper that the use of this term is no longer fit for purpose “given that a substantial body of work currently undertaken by lay people is outwith the review function of NHS QIS”. As outlined above, the SCC would argue that the distinct role of people involved in reviews means that there will be a continuing need to focus on this role.

The SCC has argued in the past that the term “lay reviewer” is not helpful as it is unclear what this means. In 1997 we suggested replacing it with the term “public interest representative”. However, this has not been met with great enthusiasm, and in our recent report on the use of lay people in the inspection of public services<sup>1</sup>, we found that there was no agreement about any alternative term.

In the paper the term “lay person” is used, but this is not entirely satisfactory either, as can be seen in sections 6.2 and 6.3. In the latter section, it talks of “ending their lay person status”. If someone is a lay person, ie not a member of staff or a healthcare professional, there is nothing QIS can do to end their lay person status. The only thing it can do is end their role as a volunteer or reviewer in the NHS QIS setting.

### **External requests to NHS QIS for use of lay reviewers**

This is referred to in passing at various places in the paper, and is an interesting aspect of NHS QIS’s work on training lay people to be reviewers. The SCC is aware that with the increasing recognition of the importance of involving members of the public and patients in the work of a wide range of health related bodies, there is a demand for people to fill this role, and no obvious place to go to find them.

Where in the past local health councils or the Scottish Association of Health Councils might have been asked to nominate someone, this is no longer possible, and it is not part of the role of the Scottish Health Council to provide people to represent the public or patient interest. Various new structures may in the future prove to be useful sources of people with an interest in health and with the ability to represent the patient or public interest in different

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<sup>1</sup> Scottish Consumer Council, *Layman’s terms?: the involvement of lay people in the inspection of public services*, SCC, Glasgow, 2004

settings, but these are still in the process of finding their feet (examples include the Local Advisory Councils for local offices of the Scottish Health Council, and the Public Partnership Forums being set up by Community Health Partnerships).

However, at present, NHS QIS is unusual in that it is providing training for members of the public to play an active role in the monitoring of healthcare, and the resulting pool of lay people is seen to be a useful resource for other organisations. The SCC is aware of people taking part in groups such as the eHealth Information for Patients Steering Group and the short life working group on the retention and disposal of health records who have been recruited through NHS QIS.

While recognising why this is happening, the SCC does not believe it should be part of NHS QIS's role to train lay people to take part in groups external to NHS QIS. There is a serious gap in this area, and the SCC is considering how this gap should be filled. We will be developing proposals on this over the next year.

The current use of NHS QIS lay reviewers in national policy development groups does not give any real clarity to the lay reviewers as to what their role in this context is, and in general they have no network or constituency to report back to on their involvement or role.

## Specific comments

**Paragraph 2.6** suggests that the current person specification may cause people to de-select as it is quite demanding and may contribute to "institutionalised exclusion". The SCC would argue that it is important to be realistic about the qualities required to be a lay reviewer for NHS QIS.

### **Section 7 – continuing professional (sic) development**

It is perfectly reasonable to suggest that there should be continuing training and support for lay people in their role. It would be helpful in this context to state the position of NHS QIS in relation to what is sometimes called "professional capture" where the lay person has absorbed the values of the organisation to the extent that they are no longer sufficiently independent to play this lay role. While not necessarily sharing this concern, the SCC thinks it would be useful for QIS to be clear about how long people can continue as lay reviewers.

### **Section 8 and 17 - contractual relationship**

This section argues that a more formal agreement is needed between lay reviewers and NHS QIS. This is presented in terms of contract, which implies a similarity with an employment situation. The SCC believes that the issues which such a contract would cover would be equally well addressed in a clear policy on the use and role of volunteers/ lay reviewers, and that this should follow the model set out by Volunteer Development Scotland in its guidance *Engaging Volunteers*.

There is also a danger that introducing a system based on a contractual relationship could result in volunteers gaining employment rights. This was the experience of Citizens Advice Scotland when they considered introducing such a contractual relationship for its volunteers. They opted instead for a code of conduct for volunteers.