

# delivering a healthy future: an action framework for children and young people's health in Scotland

July 2006

## 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.

Please check our web site at [www.scotconsumer.org.uk](http://www.scotconsumer.org.uk) for news about our publications.

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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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## **SCOTTISH CONSUMER COUNCIL**

### **DELIVERING A HEALTHY FUTURE: AN ACTION FRAMEWORK FOR CHILDREN AND YOUNG PEOPLE'S HEALTH IN SCOTLAND**

This is a very wide ranging document, which aims to bring together in one document the key actions required to meet the challenges for children and young people's health. It sets out a structured programme of actions, drawn primarily from existing policy initiatives and commitments.

There are certain dangers in setting out an ambitious document such as this. One is that initiatives which might have a major contribution to the overall agenda can be overlooked, and another is that matters of detail are lost in the generality of the document. The main issue on which we want to comment is what is said about information for children and young people, which demonstrates these points.

There is, however, much in the document to be welcomed, and the SCC particularly welcomes the commitment to improving access for children and young people to primary care services (Action 26). Though we have no evidence that access for children and young people is currently problematic, there are undoubtedly opportunities to experiment with new ways of accessing services, such as through the use of the internet and mobile phones, which are likely to appeal particularly to younger people. Young people do not always know that they can go and speak to someone about their health without their parents being involved, and any improvements in access to services will need to be accompanied by effective information provision to young people about their rights to access services in their own right.

#### **Information for children and young people about their health, care and treatment, and rights**

Paragraph 183 states that "there is also a need to ensure that written and verbal patient information is appropriate for the age and stage of children and young people". One of the suggested milestones is that information that relates to children and young people is produced in accessible, age-appropriate formats by 2007.

Action 78 states that "all services have a responsibility to provide information to parents and young people about their rights". The organisations listed as having some responsibility in this area are NHS National Services Division, NHS boards and Community Health Partnerships.

The Scottish Consumer Council would argue that this is an area which would benefit from a strategic approach at national level. There are some parallels with the difficulties of providing information for patients in alternative formats and in community languages.

Health Rights Information Scotland (HRIS), a project based at the Scottish Consumer Council and funded by the Scottish Executive Health Department, has some experience of producing information for children and young people under the age of 16 about their rights. The project has prepared two pieces of information, which will be widely distributed to NHS boards once they are complete. One is about the patient's right to confidentiality of personal health information, and includes information about accessing health records. The other is a leaflet about consent to medical examination and treatment, and the rights of children and young people in this area. Both have been tested with young people to make sure that they are clear and meet their needs.

HRIS demonstrates a strategic approach to improving information for patients throughout the NHS in Scotland. By producing information centrally and distributing it to NHS boards for use locally, it prevents the need for this work to be done in each of the boards, and indeed in different settings such as hospitals and GP surgeries.

If, as a result of this Action Framework, there is an increasing need to develop information for children and young people covering a wide range of issues, from accessing services, through conditions and treatments, to the kind of rights information on which HRIS is currently taking a lead, then it is important that this work is done in a strategic way, which avoids the repetition of effort across different parts of the NHS. If one part of the NHS has already developed good information for children – the obvious examples being the specialist children's hospitals – then this information should be stored centrally and made available for use throughout the NHS.

While the Action Framework suggests that the primary responsibility in this area should lie with National Services Division, NHS boards and CHPs, the Scottish Consumer Council would suggest that this should be considered by the Scottish Executive Health Department as part of developing a more strategic approach to the creation and sharing of information for patients across Scotland. Health Rights Information Scotland is well placed to play a central part in such a development, for example, by creating and maintaining a central repository of approved, quality information for patients.

Finally, it is also important as a part of any information strategy that the information provided is evaluated to check that it is getting to the people who need it, and that it is meeting their needs effectively.