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4 July 2005

**RESPONSE TO SCOTTISH EXECUTIVE HEALTH DEPARTMENT  
CONSULTATION PAPER *A MENTAL HEALTH INFORMATION STRATEGY  
FOR SCOTLAND***

The Scottish Consumer Council welcomes the chance to respond to this consultation which deals with an area of great importance to people who use services: the provision of information and the use of personal information within the NHS. One of our objectives is to make public services work for all consumers, and we have a particular remit to lobby for disadvantaged consumers.

**1 General comments**

**1.1 A professionally driven agenda?**

We recognise the importance of using and sharing information about patients more effectively. However, we have some concerns that Scottish Executive strategy in the area of information sharing is rushing ahead, driven by technological possibilities and the needs of professionals, without always engaging fully with patients and service users, their carers and families.

There is a danger that strategies like this read very much from the top down, from the perspective of the service provider, whose interests and concerns often seem more important than those of service users. We would have liked to have seen more evidence in the strategy of a recognition of the diverse and sometimes contradictory interests of patients in the sharing of their personal health information.

## **1.2 Information for patients**

Most of the paper focuses on information about patients rather than information for patients. Information for patients is touched on briefly in section 2.6. In section 5, which is headed “Integrated service user information” the emphasis is on information about patients, and how this will contribute to patients’ care. Section 5.1 which is titled “Who needs what information?” is followed by a section headed “Users and carers”, but rather than addressing what information users and carers need, it explains why users and carers need service providers to share information about them, and how that information should be shared, and that service providers should communicate effectively with patients. There is no mention of service providers listening to service users, though one hopes that this is implied. Most users and carers would be surprised by this professionally driven approach, which fails to answer the question posed “Who needs what information?”.

Section 7 does deal with information for members of the public, service users and carers, but states that this type of information is not “the main focus of this strategy”. This is a useful section, but since it is not the main focus of the strategy it is not clear how much this will be promoted. There are many useful suggestions in this section, including the importance of asking service users what kind of information they would find useful, and the suggestion (not developed at all) that national templates should be used. This approach would be in line with the approach of the Health Rights Information Scotland (HRIS) project based at the SCC, funded by the Scottish Executive Health Department. The project uses templates to ensure national consistency in information available to patients, and produces all its information in a wide range of formats. HRIS would be interested in exploring whether it might have a role in producing information for service users and carers in this area.

The SCC would encourage the Improving Mental Health Information Programme to work towards including information for patients in its strategy, as a strategy which does not contain this is incomplete.

## **1.3 Information sharing and confidentiality**

It is difficult to generalise about the needs of people with mental health problems. There is an assumption in much of this paper that people will have complex care packages involving more than one agency, with social work services and voluntary sector organisations involved, or at least frequent contact with different people within the NHS. While this may often be the case, there will be many cases in which patients only have contact with one part of the NHS, for example with their GP or with a psychologist. In such cases, the idea that their health information will be accessible to a wide range of people within the NHS, and other agencies outside the NHS would be unwelcome to many patients.

While the strategy does mention confidentiality, and is covered quite clearly in section 4.1, the wider picture presented in this strategy is one which puts the importance of information sharing above the importance of confidentiality. Indeed it is almost implied on page 12 that there will be no caring without

sharing - "Consent to share should be embedded within consent to care". The SCC would prefer a clear statement in this strategy that caring for people with mental illness or disorder is not dependant on their agreement to the sharing of their personal information. For many patients approaching their GP about their mental health, confidentiality is an extremely important consideration, and not one which should be treated lightly.

## **2 Wider context**

Section 6 deals with the use of aggregated information and its contribution to service planning, delivery, policy making and research. Information is important for planning services, but not sufficient. In some areas of mental health, there are real problems in relation to diagnosis and recognition by health professionals of particular mental health problems. The recent enquiry by the Health Committee of the Scottish Parliament into eating disorders showed that many GPs fail to recognise these disorders or take them seriously, and so there will be no information to feed into such a system. This will be solved not by better information sharing, but by better training of GPs and more effective continuing professional development within front line health services.

Similarly, there are areas in which there is a dearth of provision of services for people with mental health problems. This may include the lack of emergency or crisis services, or a shortage of particular kinds of services, such as psychologists or counsellors, as well as specialist services. Better information systems will not necessarily identify these gaps.

## **3 Public involvement**

Finally, we would like to draw your attention to a recent publication by the National Consumer Council, *The Glass Consumer*, which explores the implications for consumers of technological developments and the explosion in the use of personal information by all sectors of the economy. This book recognises the many benefits which will flow to those who use public services from the more effective use and sharing of personal information. However, it cautions that it is vital that those affected by this information sharing are involved and included in these developments. It recommends that public and private organisations holding personal data build mechanisms to allow consumers ongoing access to, and choices about, their data. We would like to see a greater recognition of this in the strategy.

If you would like to discuss any of these points further, please don't hesitate to get in touch.

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Director