

Scottish Needs Assessment Programme



The Involvement of Service Users in Assessing the Need for, Commissioning and Monitoring Mental Health Services

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Priority Services Network

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Scottish Association for Mental Health

August 1997

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RECOMMENDATIONS

Introduction

The recommendations of this report focus primarily on Health Boards to ensure that consultation takes place. It should be understood, however, that other agencies have to cooperate in the process and are also responsible for carrying out such consultation.

1 Consultation (pages 5-8, 18-20)

Service users' experiences of being consulted have not always been satisfactory for either the Health Boards or for the users concerned.

It is important that consultation processes are planned in advance. This will mean having a budget dedicated to the consultation process, accessible information and a clear understanding of the time-scale involved, including adequate allowance made for longer time-scales in rural areas.

We recommend that local consultation frameworks be developed, giving guidelines on Health Boards' responsibilities in relation to consultation and outlining the task envisaged for the individuals being consulted. Both service users and Health Board staff must know what is expected of them.

Guidelines should detail how Health Boards will support service users involved in the consultation process.

2 Information (pages 4, 7, 8, 20-21)

The lack of information about Scottish Office or Health Board initiatives may mean that people are unable or become unwilling to participate in consultation meetings. Forward planning is essential - users' groups need at least six weeks' warning of meetings to which they have been invited to send representatives. Early access to local mental health service strategies is a particular concern at present.

We recommend that written and audio tape summaries of Health Board information be made available to users' groups, particularly where an original document is long or not readily understood. These summaries should be made available in minority languages as required locally.

3 Representativeness (pages 6-7, 14-15)

Where a service user or carer is asked to participate in order to represent others, it is important that the process for choosing who is to be consulted is clear so that tokenism is avoided. This is an issue of great importance to service users.

We recommend that Health Boards, in collaboration with user groups and forums, develop local mechanisms for choosing user representatives to be involved in mental health service forward planning.

As one possible method is to choose users from existing groups on a representative basis, Health Boards should consider how this might be done.

Improved liaison between patients' councils, local forums and national groups will provide a foundation of information and experience to be shared among user groups and help to strengthen the negotiating position of those involved in the consultation process.

We recommend that Health Boards provide additional funds to user and carer groups to enable them to develop and maintain links with each other and with statutory and voluntary agencies in order to increase the representativeness of those involved in the planning processes of Health Boards.

4 Expenses and consultation fees (page 9)

Service users involved in Health Board consultation exercises should be paid expenses to cover costs incurred by them. These include travel and subsistence costs, payment for child care and other caring costs and any administrative costs.

Consultancy fees should be paid for any planned pieces of work, with time-scales and remits agreed in advance and for all consultation meetings attended on a regular basis.

We recommend that expenses payments and consultancy fees available to service users for their contribution to consultation processes be paid at levels agreed prior to the beginning of the process. Where necessary, payment to individuals should be made in instalments to avoid affecting benefit levels. Reimbursement for expenses incurred should be made promptly and budgets and control mechanisms should be reviewed to address such issues.

5 User and carer involvement/feedback posts (page 18)

Many of the effective initiatives outlined in this report would not have come about without the support of key personnel in the Health Boards who have an understanding of and commitment to user participation. We wish to acknowledge their contribution to the services developed so far. Involving users and carers is, however, a slow process if done well and one way of facilitating the implementation of the processes described so far is to appoint Health Board staff with a specific user involvement remit.

We recommend that Health Boards consider funding user involvement/feedback posts in order to focus more clearly on initiatives aimed at facilitating user consultation and participation.

6 Training (page 10)

In order that staff become more sensitive to the needs of people experiencing mental ill health, users and carers should be asked to provide aspects of health service staff training.

We recommend that Health Boards and training bodies approach user organisations and arrange for them to contribute to staff training.

7 Joint planning (page 10)

The lack of GP participation in local health service consultation exercises was a source of concern.

It was noted with regret that the experiences of many service users and carers suggested that GPs participated less frequently in joint working arrangements than other health professionals. Service users wish to acknowledge the time constraints which GPs are under.

We recommend that Health Boards make available to GPs the necessary resources to allow the employment of locums for those GPs acting in a representative capacity on joint planning forums and in consultation exercises.

8 Local health councils (page 21)

Local health councils are often seen as more accessible than Health Boards. Information provided by health councils about Health Board initiatives in mental health service provision is welcomed by service users and carers. Users' and carers' groups as key recipients of health services would welcome more regular opportunities for liaison with local health councils.

We recommend that Health Boards should support local health councils in their efforts to liaise with users' groups about local mental health services.

9 Models of provision (pages 12-17, 21-22)

There is a wide range of models of service provision focused on enabling local people to participate in Health Board consultation processes on needs assessment and commissioning and monitoring of mental health services. There is, however, a shortfall between vision and current reality.

We recommend that Health Boards initiate local reviews of current models of provision aimed at facilitating participation. Boards should aim to have a range of groups and forums within each Health Board area to ensure that service users and carers are given ample opportunity to participate. Where such provision is lacking, Health Boards should make funding available to develop locally some of the following examples of service provision:

- patients' councils
- user and carer forums
- individual and collective advocacy
- conferences and seminars.

10 Monitoring

In order to raise awareness of new developments, regular monitoring of Health Board initiatives in the area of user participation will be necessary.

We recommend that a regular review of the steps that Health Boards have taken to implement these recommendations is undertaken on a national basis. Reports of the review's findings should be made publicly available.

11 Further research (page 23)

There is currently a lack of information on resources and services which facilitate user participation within mental health service provision.

We recommend that further research be commissioned to extend the initial information collection undertaken for this report and to provide a more in-depth evaluation of particular initiatives.

1 INTRODUCTION

Purpose of the seminars

This SNAP report takes a slightly different approach from that of previous reports. During discussions within the Mental Health Working Group, it was agreed that the most effective way of exploring different methods of involving users and carers in mental health service development was to meet directly with users and carers who have previous experience of being consulted.

The report is a record of discussions held during two day-long seminars, one held in Glasgow, the other in Edinburgh. All participants in the seminars had experience of using mental health services and we had originally hoped to include the views of carers of mental health service users but due to practical difficulties this was not possible. It should be noted, however, that many of the participants do have experience of caring for someone who uses mental health services. Many of them also have experience of providing services.

The seminars were designed to identify ways in which Health Boards may effectively consult service users about planning and reviewing mental health services. They brought together users from a variety of groups along with representatives from the SNAP Mental Health Topic Group and the Scottish Association for Mental Health (SAMH) in order to discuss models of participation.

The seminars included brief presentations on the background to the Scottish Needs Assessment Programme and to the Mental Health Topic Groups and an outline of the report we hoped to produce, based on the discussions and points made by participants during the seminars.

Some participants had been consulted previously by the SNAP Mental Health Working Group while compiling their first report 'Mental Health: Overview and Programme' (1994). This linked the views obtained at the first report stage with those offered at the seminar and provided some continuity.

Attendance at the seminars was by invitation. Participants needed to have a prior understanding of the planning process and some previous experience of being consulted on a local level about Health Board or Social Work Department mental health services planning. There were no health care professionals present as the aim of the report was to reflect the concerns and opinions of mental health service users and it was important that they felt free to speak about their experiences as openly as possible. Participants were not asked to represent other service users and carers, rather they were asked to contribute as individual members of user and carer forums and voluntary agencies.

Purpose of the report

The report aims to:

- explore individual experiences of consultation and other forms of involvement
- examine what works and what doesn't for different agencies and participants
- record discussion points raised during the seminars
- outline different models of service provision which enable participation
- make recommendations for future initiatives by health boards.

Additional information was supplied by a number of projects and individuals, and seminar participants assisted with the editing of the report.

2 PARTICIPATION

One of the main recommendations of the Griffiths report on community care (HMSO, 1988) was that lines of accountability between service users and the providers of services should be strengthened. This concern was also reflected in the NHS and Community Care Act (HMSO, 1990) where changes in the delivery of community care services included:

- community care plans to be developed in consultation with service users
- needs assessments to be carried out on an individual basis with the aim of planning packages of care based on individual preferences

The 'Patients' Charter' (Scottish Office, 1991) states that:

*from April 1992, all hospitals and other health care providers
will be required to involve patients* (our emphasis).

Service users' and carers' views should therefore be taken into account and used in the planning and implementation of future community care and health services.

Our focus in this report is not only on involving users and carers through consultation but also on other forms of involvement. Individuals could for example participate in the planning and development of a specific service rather than simply having their views sought as to the type of service to be developed. Therefore, we have also considered appropriate models of participation for activities other than consultation. One participant commented that service users want "the responsibility to do more than just be consulted".

As more user consultation initiatives are set up, we are beginning to see evidence of the benefits of such involvement. Some examples of the ways in which user involvement can improve the quality of services have been documented as follows:

the benefits of user involvement include greater consumer satisfaction, more effective services through better take-up and higher staff morale
(NHS Executive Mental Health Task Force, 1994).

empowering service users leads to the enhancement of the service generally and of the role and work of practitioners particularly
(Philpot, 1995).

The different ways in which people might become involved can be summarised in Box 1 overleaf:

Box 1
Aspects of User Involvement

receiving information	a key facet and one that is often skipped or done half-heartedly or too late in the consultation process
being consulted	preferably carried out in the early stages of drafting a report or making a decision and repeated at a later stage in the process
participating	enabling people to attend meetings and planning groups means being clear about the time commitment involved, about the payment of expenses and fees and about how any training needs may be met
having control	users and carer groups require resources which are under their control if they are to participate on a regular basis in Health Board planning - this enables individuals to be trained and to gain information on particular topics while allowing the group to maintain its own functions and to introduce new people to the planning process

3 CONSULTATION PROCESS

When should users be consulted?

A recent report by the Health Committee (1994) suggested that:

in some respects, the preparation of the health strategy should be regarded as almost the end of the consultation process rather than as the beginning: the earlier consultation takes place the easier it is for purchasers to react to the views expressed.

In a recent judgement involving Kingston and Richmond Health Authority (Vellenoweth, 1995), Mr Justice Potts drew attention to a definition of consultation which outlined acceptable standards for health authorities:

- *consultation must be at a time when proposals are still at a formative stage*
- *sufficient reasons must be given for any proposal to permit of intelligent consideration and response*
- *adequate time must be given for consideration and response*
- *the product of consultation must be conscientiously taken into account in finalising any statutory proposals.*

(See Chapter 6 for an example of ongoing consultation by Ayrshire and Arran Health Board).

Stages in service development

Service users may be consulted at any stage in the process of developing mental health services within the NHS. Since effective consultation will facilitate the development of more appropriate and relevant services, we have attempted to identify at which stages in the development of new services users and carers are most likely to have influence. This will have bearing on which models for consulting users and carers may be used most effectively by Health Boards.

The service development and planning cycle can be divided as follows:

- 1 assessment of need
- 2 planning and drafting strategy
- 3 setting priorities - attaching budgets and timescales
- 4 contracting with service providers
- 5 managing services
- 6 monitoring and evaluation
- 7 inspection.

Which stages offer the best opportunities for users to become involved in an effective and personally worthwhile way? Experience has shown that, so far, in both the early stages and the later stages of the process there has been some success in gaining and maintaining user participation.

needs assessment

Ayrshire and Arran Health Board initiated a consultation exercise very early in the process of identifying mental health service users' needs. By asking 'what makes an excellent mental health service?', users and carers were enabled to express their views at the beginning of the cycle (see page 19).

planning and drafting strategy

Greater Glasgow Health Board consults with the representative user forums developed by Glasgow Advocacy Network on a regular basis. The Network is consulted **before** draft plans are drawn up - a point of central importance (see page 14).

contracting

Informed service users and carers would welcome the opportunity to participate in making planning decisions, but there has been little experience of this to date.

monitoring and evaluation

Newcastle Health Authority funds the Newcastle Mental Health Consumer Group to monitor the purchasing contract between the health authority and the mental health trust (see page 22).

inspection

Lothian Regional Council Inspection and Registration Team involved service users in setting standards for supported accommodation in mental health services (see page 18).

Rural and remote areas

Effective consultation requires a somewhat different approach in rural areas from that taken in urban areas.

Many agencies will have small numbers of workers with large areas to cover. Public transport is not readily available and transport costs are higher. For these reasons it is doubly important that the consultation process is planned well in advance, advertised widely and taken out to individuals and groups in their own communities.

Representativeness

Discussion in the seminars focused frequently on the way that ostensibly efforts are being made to include users in the consultation process but their involvement often turns out to be required on a superficial basis. Another problem which arises is that a core of well-known individuals are always consulted regardless of whether their

background is relevant or not to the consultation in question - what one user called the 'you'll do' syndrome. What can be done to avoid this?

It was highlighted that at this stage in the development of participatory mechanisms by Health Boards and Trusts it is not possible to guarantee representativeness. Also, that it is important to recognise that there is not one single user voice and that not all users have the same views about service provision or choose to participate in groups. Many of those involved in consultation are those with the least severe illnesses or those who are currently feeling well. It can be harder to obtain the views of people with more severe difficulties.

However, it is possible to ensure that where a service user or a carer is asked to participate in order to represent others, the process for choosing who is to be consulted is clear so that tokenism is avoided. Ideally users and carers should be drawn from existing groups on a representative basis.

This in turn means that the user movement itself needs a structure to enable it to become more accountable and representative.

Framework for consultation

For many users and carers, 'being consulted' means being invited to a meeting and turning up. They are not given active responsibility and rarely receive feedback afterwards. They may be asked to comment on long documents which they have had no role in drafting, often within an unrealistic timescale. They should be provided with summary documents and enough time to comment.

It was felt that a framework to enable local consultation would be useful. This should outline the responsibilities of each agency involved and give clarity to the task involved. The pace of the consultation procedure must go slowly enough for the newest people to remain involved. Those with the responsibility for organising consultation have to be aware that there may be times when a service user will have to withdraw from the process if they become unwell.

There are often problems with numbers of participants - structures can only provide opportunities for people to participate if they wish. If only a few people wish to become involved in an initiative, it may mean that people have not been given enough information at the right time about what is planned.

It is important to set up and maintain structures at national and local levels which are open to people to participate in at a level they feel comfortable with.

Resources and supports

Resources should be invested in ways which will enable users and carers to express their needs and preferences about mental health services (SAHC 1993). For example, rather than setting up new structures, additional funds should be made available to existing user and carer groups:

- to obtain training in committee and communication skills
- to provide information on other agencies' roles and responsibilities
- to offer support to new service users and carers
- to offer continuing support to those who are already involved in the consultation process.

4 EXPENSES AND PAYMENTS

While hospitals and health care providers are required to involve service users, there is no obligation to pay fees or even travelling expenses to the user consulted. Many institutions are keen to show that they have consulted users yet have no provision for funds to be made available to reimburse participants.

Users choose to participate because of the perspective they can bring from the basis of their experience of the mental health system and the benefits this may bring to other service users. One user participated in a review because it was an important subject and he wanted to show that users can make a valuable contribution. On the other hand, it took seven months for one Health Board to pay the travel expenses of a service user to allow him to get to a meeting at nine o'clock in the morning.

It is important that the goodwill of service users and carers is not abused. It was felt that if there is no commitment to ensure attendance at meetings, users cannot feel that their efforts are truly valued. At the very least users involved in the consultation process should not be out of pocket. Expenses should include travel and subsistence costs, payment for babysitters and carers and any administrative costs incurred. **It is vital that expenses are reimbursed promptly. Most users would recommend that expenses should be paid on the day of the meeting or consultation exercise.**

Where consultancy fees are paid, it is expected that both expenses and consultancy fees will be paid at an agreed level. Often, payments for consultancy work made to representatives of user groups will be given to the groups being represented as a matter of course. Some users have been paid in kind, for example in book tokens. This is seen as at best patronising and at worst insulting.

One user commented that it was important that payment for consultancy should not compromise the independence of the users concerned.

Where service users are asked to participate on a regular or time-consuming basis, it is vital to give consideration to the fact that agencies will require sufficient resources to ensure that expenses can be met. Similarly, agencies will require additional resources to free up staff time to allow them to participate in consultation and joint planning initiatives, for example, voluntary organisations with small numbers of staff and GPs.

5 OTHER CONCERNS

Staff training

One of the issues that seminar participants identified as being of primary importance was creating a change in staff attitudes towards them. They thought that the best way of addressing this was through staff training initiatives. Past experience has shown that the success of projects seeking to involve users may depend on staff understanding of participation and their willingness to cooperate.

Users and carers would like more consistent input to the training of staff working in mental health services. It was felt to be important that professional staff, including hospital-based nursing and medical staff and staff based in community resources such as care managers, social workers, housing and education services staff, should gain an awareness of the perspective of the service user and of the carer and of the effect on the individual of being in receipt of mental health services.

Retraining

With the redeployment of hospital staff as bed numbers are reduced in psychiatric hospitals throughout Scotland, opportunities for user involvement in staff retraining should also be made available.

Joint planning

Users and carers are currently questioning the effectiveness of current joint planning mechanisms within mental health services. The involvement of GPs in local planning initiatives was seen as being of central importance to the success of such undertakings. With GPs' increasing role in delivering care in the community, it is difficult to see how appropriate services may be developed without their involvement in joint planning initiatives with service users and carers.

Health promotion

Some participants expressed concern that the Health Education Board for Scotland (HEBS) does not have a mental health strategy. We have now received information that HEBS has established a Specialist Development and Evaluation post and that the Specialist Development and Evaluation Officer is currently working on the development of a mental health promotion strategy.

Accessibility and equity of service

There is a need to establish national standards of quality, range and accessibility of services. Particular concerns in this area were expressed about services offered via fundholding and non-fundholding GP practices.

Users felt strongly that patients should receive equity of service and that this should not be dependent on the practice or GP attended. Participants were also concerned about the apparently arbitrary divisions being drawn between 'health' and 'social' care in order to determine whether the user should pay for the care being offered.

6 MODELS OF PARTICIPATION

Introduction

In this section we look at six models of participation:

- projects and posts established to facilitate participation (page 12)
- one-off consultations (page 18)
- on-going consultations (page 19)
- information provision (page 20)
- conferences and seminars (page 21)
- monitoring and evaluation (page 22).

The examples provided are not intended to be an exhaustive list but offer an outline of the range of projects which facilitate user and carer participation in the provision of mental health services. Most of the projects and initiatives are concerned primarily with health service provision or with health and community care services together as it is health services which are the main focus of this report.

For those considering developing such innovative models of service, the following points should be borne in mind:

- long consultation periods are necessary in the development of new services which are to facilitate user involvement
- opportunities for users to learn of options tried elsewhere are important if users are to bring an informed viewpoint to the consultation process
- the very existence of many projects is in itself an achievement - many have had to struggle to obtain funding.

It should also be highlighted that some service planners prefer to create short term working groups which are clearly linked with specific objectives and are appointed to deal with specific problems. Such groups can be set up in addition to or alongside some of the models described in this chapter.

Rural environment

Many models for involving and consulting with users and carers have been developed in urban areas where people are more easily contacted and transport costs are lower. It is important to bear this point in mind during the following discussion of models of participation, to see where existing models may need adapting for a more rural setting or where entirely new models may need to be developed (White, 1995).

PROJECTS AND POSTS

Royal Edinburgh Hospital (REH) Patients' Council

This patients' council is a recognised group which provides direct access for service users to hospital management. It campaigns on issues which affect people experiencing mental ill-health and offers service users a say in their treatment and care. It also offers individual and collective advocacy.

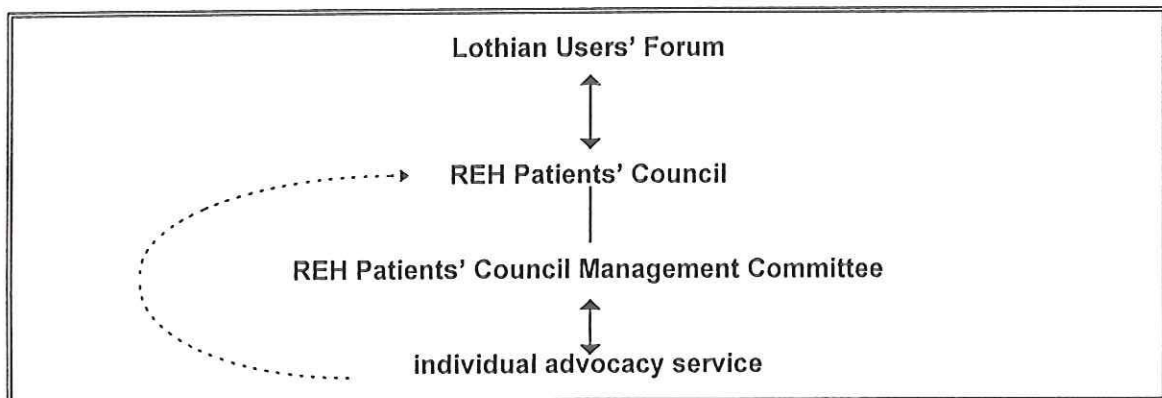
REH Patients' Council began in 1990 and a support worker is now employed 30 hours a week. Patients' Council meetings are attended by between six and fifteen people and the Clinical Director of the Trust attends alternate Patients' Council meetings.

The Patients' Council is run by a management committee and the support worker is responsible for the individual advocacy service as well as for the day-to-day running of the Patients' Council. Complaints by individual patients which are brought to the advocacy service may be referred on to the Patients' Council if they can be generally applied i.e., to other patients.

The links between the local forum (Lothian Users' Forum) and REH Patients' Council can be seen in Box 2 below:

Box 2

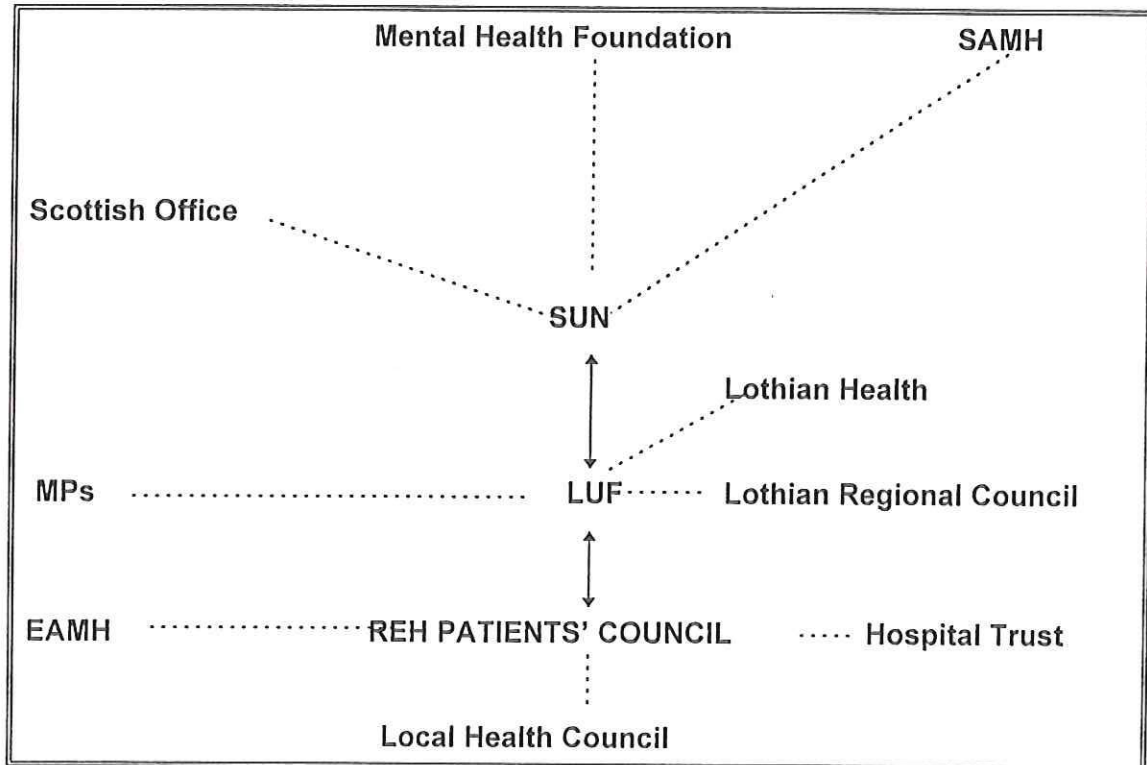
Structure of REH Patients' Council



The office bearers of the Council attend Lothian Users' Forum (LUF) meetings, where there is a slot for the Patients' Council. Links with LUF are important for work on community issues and on forms of practical assistance such as welfare benefits.

The Patients' Council has contacts with the Edinburgh Association for Mental Health, Lothian Local Health Council and the Trust. Through liaising with LUF, it also has links with MPs, Lothian Health Board and the local authorities. LUF liaises with Scottish Users' Network (SUN) which has contacts with the Mental Health Foundation, SAMH, the Scottish Office and others. Box 3 overleaf shows some of these relationships.

Box 3
REH Patients' Council - links with other agencies



Achievements of the Patients' Council so far include:

- having the 'No Smoking' policy restricted
- getting ramps built on pavements to allow access for people in wheelchairs
- arranging regular meetings with the MP whose constituency the hospital is in
- securing a management decision to provide more acute beds.

The **Voice Advocacy Project** is based at Ailsa Hospital. Two workers share a full-time job visiting patients in their different wards and acting on their comments about the hospital. There is a weekly social club for people in hospital and a support group for ex-service users.

Meetings on the wards are for users only. Once a month, project workers and users meet with hospital managers. These meetings give users the confidence that their views are being attended to and are an effective way of communicating users' views.

Achievements of the group include:

- getting the lighting in the hospital ground improved
- securing the installation of public telephones in the hospital

- arranging for the hospital coffee shop to remain open later in the evenings.

In the future, the group hopes to hold meetings outside the hospital, for example at the Turn Around drop-in centre run by Ayr Action for Mental Health.

Consultation and Advocacy Promotion Service (CAPS)

CAPS is a Lothian-based project which works with user groups and individuals to promote understanding of advocacy and to increase opportunities for service users' voices to be heard in the planning, management and development of services.

The organisation began in 1991 with the introduction of the Specific Grant for Mental Illness and now employs two development officers and an administrative worker. It offers training and support for user groups and information on national and local user organisations. CAPS' main achievements to date include:

- establishing Lothian Users' Forum and facilitating its participation in service planning processes.
- playing a key role in the organisation of the two Scottish Users' Conferences (see page 21)
- setting up the Advocard peer advocacy scheme.

Glasgow Advocacy Network

The project has its origins with the establishment of the CURE Group (Carer and User Representation and Empowerment) which began in 1989. As the group developed its policies, it was invited to participate in meetings set up by mental health service providers in Glasgow about changes in current provision. Subsequently, funding was provided to set up the Glasgow Advocacy Network (the Network). Two full-time workers are now employed, with users working on a sessional basis.

The project promotes the civil rights of current and former patients in mental health via self and citizen advocacy. It also aims to promote:

- patients' councils
- good practices in mental health services
- user and carer forums.

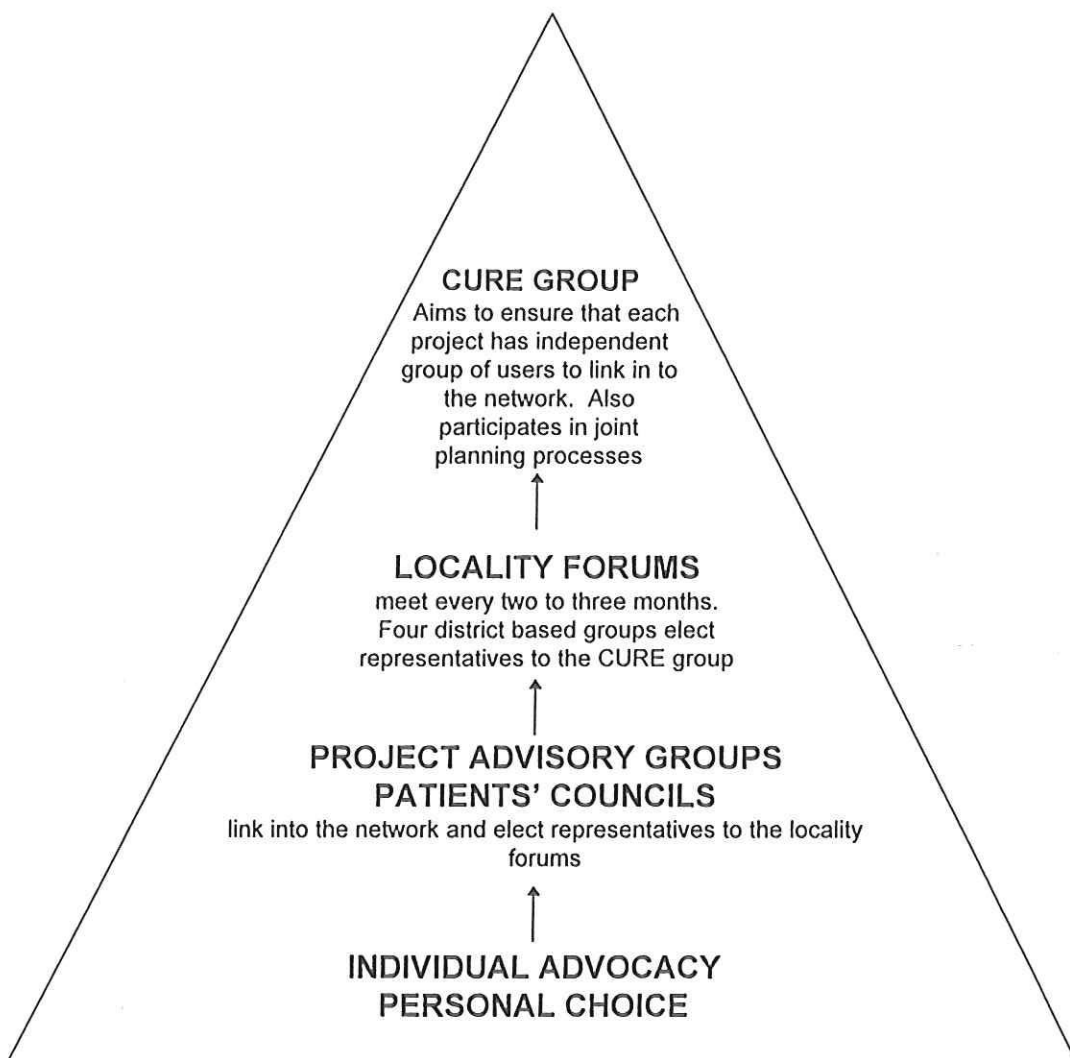
The Network has been designed to coordinate the development of a mental health advocacy service in the Glasgow area. It does this by developing locally-based groups of representatives of mental health service users and by establishing a structure of service users' councils within each of the city's health sectors. The Network is user-led with service users involved in the planning, management and evaluation processes.

Training is an important part of the Network's remit, with local user groups being trained in advocacy and representation skills.

Representation is a central concern of the Network - it is felt to be so important because of the way in which service users have been disempowered for so many years. Ensuring proper representation for service users provides a structure which people can use to make their views known.

The structure of the Network can be shown as in Figure 1 below.

Figure 1
Glasgow Advocacy Network



Local projects and services covering housing, health, advice and so on link into the Network on an individual basis.

Good links are also maintained with Greater Glasgow Health Board via a Health Board 'link person' in each of the four Health Board sectors.

Scottish Users' Network (SUN)

SUN is an independent Scottish organisation founded by and managed by people who use or who have used mental health services in Scotland. SUN began in 1988 and aims:

- to promote the rights and interests of people with mental health problems in Scotland and their families
- to raise awareness of the needs and wishes of users and ex-users of psychiatric services and to provide information about services in the community
- to campaign for improvements in mental health services through mutual support and co-operation with other agencies.

Both individuals and groups can join SUN. Those people who have not used mental health services become 'associate' members.

SUN has a role in linking people together and in promoting networks of interest around specific issues. It has recently received funding for two part-time posts and has an office in Edinburgh based at the Scottish Council for Voluntary Organisations.

Advocacy and Empowerment Training Group

This group was set up in 1992 by SAMH to promote the role of service users in training professional staff.

The group's main aim was to empower individuals with experience of mental health problems to take part in the design and delivery of training. Group members received training in confidence building, presentation techniques, role play and empowerment.

Through their experience of giving talks and running training sessions, members found that one of their central tasks was to make clear to mental health service staff and to the general public how easy it is to become a service user.

As a training group, they have also found that on-going support was vital following a period of training. In other words, it is not enough to offer training to service users. It is also important to consider who controls the training process, how the training will be used and what its impact might be on the person being trained.

Mental Health Services Consumer Group Grampian

The Consumer Group was originally brought together following a conference organised by Grampian Action for Psychiatric Services in 1989. The group began to meet regularly in 1990 with the support of a worker from the Pillar Project in Aberdeen.

Since then, the Consumer Group has grown in numbers and stature and now employs both a support worker and an administrative worker. The group's aims include:

- to promote mental health by encouraging and supporting the development of facilities within the community for those affected in any way by mental health problems, those recovering from such problems and those involved in the care and welfare of such individuals or groups
- to be available for consultation on the planning stages of any new provision
- to monitor existing services
- to develop an awareness and understanding of the existence of mental health problems by members of the public.

The following are some examples of the work of the Consumer Group:

- convening two conferences on mental health with 250 people attending from Grampian, Shetland and Orkney
- setting up the Rosebank Drop-In Centre, which is managed by the Consumer Group in association with the Manic Depression Fellowship
- contributing to training courses at the Northern College, Foresterhill and Royal Cornhill Hospitals, and Robert Gordon University
- participation in a Grampian Television Programme on mental health.

Edinburgh Healthcare Trust Strategy for Ethnic Minority Communities and Mental Health Services

In 1992, an internal report on the Royal Edinburgh Hospital's services made recommendations for changes to the way the hospital worked with minority ethnic groups. The Trust has recently employed two ethnic minority development workers to act as a link between its mental health services and the ethnic minority communities.

The aims of the strategy include:

information - to make available information designed to improve access to mental health services for under-represented sections of the local population

mental health - to ensure that the mental health services of the Edinburgh Healthcare NHS Trust are culturally sensitive in the context of a multicultural society

user involvement and cultural advocacy - to support the development of the existing mental health users consultation process to include black and ethnic minority communities and to foster a continuous process of consultation and to support the various forms of advocacy required by users.

ONE-OFF CONSULTATIONS

Ayrshire and Arran Health Board Consumer Feedback Manager and **Greater Glasgow Health Board Consumer Involvement Coordinator** recently organised a research briefing meeting for service providers from Health Boards, Trusts, primary care, secondary care and community care services in the west of Scotland. The meeting presented a range of initiatives for involving service users, including those with mental health problems, and reviewed recent research projects aimed at finding out users' views of health services (see also page 19).

Options Appraisal Group, Woodilee Hospital

A representative of the Charlie Reid Centre was invited to attend this group to discuss future changes in the delivery of mental health services. She felt there was need for a clearer consultation framework to enable people to participate effectively in such meetings. Insufficient information was made available about the process and there was a lack of consistency in the meetings she attended.

Lothian Regional Council Inspection and Registration Team

This team involved service users in setting standards for supported accommodation in mental health services in two ways. Staff met with a group of four to eight mental health service users at a place convenient to the users to discuss the standards which were to be adapted from those used for the care of the elderly. The standards were discussed one by one, with the pace of the meetings being set by the service users.

One service user then went on to attend meetings to look at the standards across different social work department client groups. These meetings were held in different places in Edinburgh and she was offered lifts to the various venues. Meetings were attended over a period of six months with the process seen as being very successful - users' views were listened to and used to create appropriate standards.

Visit to Lewis and Harris Local Health Council and to the Local Health Council for the Uists and Barra

During an initiative to explore the need for a local Association for Mental Health in the Western Isles, a policy officer from SAMH was invited to meet with representatives of local community groups and mental health service users to discuss the range of services available and the issues affecting service provision within small island communities. These views were subsequently included in the recent report on planning mental health services in rural areas, 'On the Margins' (White 1995).

ON-GOING CONSULTATIONS

Greater Glasgow Health Board (GGHB) Joint Planning

The Glasgow Advocacy Network (see page 14) has been funded to develop and support user representative forums in local areas. The Network is consulted before draft plans are drawn up. Regular meetings are held between GGHB and the user representative forums with the Network taking on a facilitating role.

User and Carer Consultation in Ayrshire and Arran

This was a joint initiative between Ayrshire and Arran Health Board, Strathclyde Social Work Department and voluntary agencies in Ayrshire, including the Church of Scotland (Ayrshire and Arran Health Board 1994). The main aim was to inform the joint mental health strategy at an early stage by:

- planning and organising local seminars and reporting back to the Mental Health Joint Strategy Group on user and carer views and what they felt their needs to be
- recommending procedures which would ensure on-going user and carer involvement in making decisions about service development

A steering group was set up to plan the initiative. Service users and carers involved in the group were offered training in facilitating meetings and were involved in running the seminars.

A total of 16 local meetings were held throughout Ayrshire over a three week period in 1994. They were advertised in the local press and were open to all, not only to representatives or to specific groups.

People were asked: 'What in your opinion would make an excellent mental health service?' A group list was then drawn up and from this people chose their priorities. Following the seminar, people were also asked to fill out a questionnaire on future consultation.

The mental health strategy is now in draft form and the intention is to take it back to the original groups for further comment. The meetings will again be advertised to allow new people to contribute to the process.

Lothian Health's Mental Health Strategy

Lothian Health decided to hold stakeholders' meetings to discuss their strategy for purchasing mental health services.

At the first meeting, a talk was given by one of the workers from CAPS (see page 13) on what service users would like to see in the strategy. A second stakeholders' meeting was then held to discuss the draft strategy which CAPS and members of Lothian Users' Forum (LUF) were invited to attend. Following this second meeting, the Health Board's strategy development manager and the area planning and purchasing

manager attended LUF meetings to discuss the strategy further and LUF produced a response to the strategy.

LUF also has two representatives on the mental health strategic planning team.

INFORMATION PROVISION

In Touch project

This is a new user-friendly database of community information developed at the Royal Edinburgh Hospital. It allows people to access a range of information from one point without needing to know how to use a computer.

The main focus will initially be on housing, education and health facilities, including topics such as:

- day centres
- counselling services
- services for ethnic minorities
- advice services

The main site is based at REH in Morningside with four secondary sites elsewhere in Edinburgh. It is hoped more sites will be developed in the future.

Grampian Caredata

Grampian Caredata is funded by Grampian Regional Council and Grampian Health Board with support from the North East of Scotland Library Service to gather and organise information on a wide range of community and health services.

The Caredata database is made available on 70 computers throughout Grampian Region based in libraries, health centres, advice centres and so on. It can be accessed by members of the public or used by organisations to provide their own information and advice services.

There is also a telephone information service which can answer individual enquiries, send out printed information or refer callers on to other information services.

Further information requirements

Participants at the seminars identified a lack of useful information in the following settings:

Hospital

There is a need for a personalised information service in hospitals for first time users to inform people about services both within and outside of hospital. Information leaflets may be available in hospitals but the contents are often not explained to patients.

Health centres

Information projects based in the community to provide information about local health services are also needed. These may be based in GP surgeries or in health centres.

Local health councils

Local health councils are often seen as more accessible than Health Boards. Information provided by health councils about Health Board initiatives in mental health service provision is welcomed by service users and carers. Users' groups as key recipients of health services would welcome more opportunities for regular liaison with local health councils.

CONFERENCES AND SEMINARS

Scottish Users' Conferences

The first Scottish conference (Scottish Users' Conference 1992) for users of mental health services was held in Falkirk in 1992. A steering group of workers and service users was set up to plan the conference with service users always being in the majority.

140 people attended the conference, with 100 free places for users and 40 paid places for workers. The conference was 100% over-subscribed.

Service users from Nottingham and Scotland opened the conference and participants then attended workshops on a variety of topics which had been drawn from suggestions made previously by service users. These included:

- users working with professionals
- users and management committees
- campaigning and education
- what is empowerment?
- rural issues
- stigma and discrimination
- alternatives to hospital and drugs

The second Scottish Users' Conference, held in 1993, took the theme of community care (Scottish Users' Conference, 1993). Workshops were arranged on a geographical basis and participants were asked to answer three questions:

- what services do you know of in your area?
- what kinds of services do you want which are not available?
- which three gaps in current provision are the most important?

These discussions allowed service users and workers together to identify priority needs for different regions and towns, information which can be used to inform the forward planning of mental health services.

CRAG/SCOTMEG seminar

The Clinical Resource Audit Group (CRAG) and the Scottish Management Executive Group (SCOTMEG) held a seminar (Scottish Office, 1995) to consult with users about their preferences for new topics for the CRAG/SCOTMEG mental health group to investigate. Approximately 40 users from many different groups across Scotland were invited to attend.

Users participated in workshops on electro-convulsive therapy (ECT), schizophrenia and primary care services. These were followed by user-led sessions on priorities in mental health, with three topics being identified by all groups:

- crisis services
- complementary therapies
- mental health education.

MONITORING AND EVALUATION

Newcastle Mental Health Consumer Group

In Newcastle, it was made a requirement by the purchaser of services that service users and ex-service users should be asked to monitor the contract between the Health Authority and the Mental Health Trust.

Consumer Group members looked at how services are provided on wards and in day resources and regularly fed information back to both purchaser and provider. They were also asked to identify gaps in current contracts with a view to information about unmet user needs being incorporated into future negotiations on contracts (Sherlock 1993).

Drumchapel Community Health Project

During the pilot phase of the Drumchapel Healthy Cities Project, it was decided that it was necessary to find appropriate ways of evaluating its activities in the field of community health work (SEF/NCCCS 1994). It was important that both the evaluation methods and the evaluation process should reflect the principles of what the project was about i.e. they should be participative, empowering and collaborative.

Research aims were kept simple:

- to explore a variety of approaches to the project
- to seek the views of a range of participants as to indicators of the project's success
- to assess the feasibility of reflecting the principles of participation, empowerment and collaboration in the research process itself.

A variety of methods were used, including focus groups and group interviews. The most popular were those which were creative and informal and which allowed different groups within the project to exchange views.

One example is the creation of the project's tree. A tree was chosen to symbolise the life of the project and participants were asked to consider:

- where the project has come from - the roots of the tree
- what its values are - its trunk
- what its principal activities are - the branches and the leaves on each branch.

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APPENDIX 1

ABBREVIATIONS

CAPS	Consultation and Advocacy Promotion Service
CRAG	Clinical Resource Audit Group
CURE	Carer and User Representation and Empowerment
EAMH	Edinburgh Association for Mental Health
GGHB	Greater Glasgow Health Board
GPMH	Good Practices in Mental Health
HEBS	Health Education Board for Scotland
LUF	Lothian Users' Forum
REH	Royal Edinburgh Hospital
SAMH	Scottish Association for Mental Health
SCOTMEG	Scottish Management Executive Group
SNAP	Scottish Needs Assessment Programme
SUN	Scottish Users' Network

