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Scottish Health Council Lothian

‘Engaging Communities’

Event

15th Sept 2006

Report



If you require extra copies of the report or an alternative format please do not hesitate to contact us.

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INTRODUCTION



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The Scottish Health Council was set up in April 2005 to ensure that the views of patients, their carers and members of the public are properly taken into account by health boards.

It was recognised that in order to provide a better Health Service it has to involve patients, carers and the public in decisions which will affect them.

“Participation should mean that patients, carers and local communities’ views are actively sought, listened to and acted on, and treated with the same priority as clinical standards and financial performance. “
(Partnership for Care, Scottish Executive February 2003)

It is not the function of the Scottish Health Council to speak on behalf of patients but to make sure that both patients and the public have the chance to express their own views and opinions and ensure that they have been listened to, understood and have had their views acted upon.

As part of its remit, The Scottish Health Council has to independently verify that Local Health Boards have taken adequate and appropriate steps to ensure that all sections of society, including “hard to reach” groups are involved in decisions affecting them and their specific needs.

We live in a diverse and multicultural society and as such there should be representation of the views and opinions of society as a whole. As an organisation we have to be aware of some of the issues and barriers that “hard to reach” groups have in participating in this process and to

“ensure that individual patients and carers who have views about their health services that they wish to express have the opportunity and, where necessary, the support to do so”.

(A New Public Involvement Structure for NHSScotland, Patient Focus and Public Involvement, A draft for Consultation, 2003).

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THE EVENT

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The aims of the event were:

- to raise awareness of Scottish Health Council in Lothian amongst voluntary sector organisations working with people who might be excluded from planning health services relevant to their needs
- to gain an understanding of the key health issues facing these groups
- to gain an understanding of their experience of patient focus and public involvement¹ within Lothian
- to identify ways of working together on an ongoing basis to see what improvements can be made to patient focus and public involvement in Lothian.

Presentations were made by the local officers for Lothian, Narmeen Rehman and Louise Baxter. The first of these covered the background to Scottish Health Council, its role and functions. The second looked in more detail at Scottish Health Council's role in assessing how effectively NHS Lothian delivers patient focus and public involvement and in helping to identify areas for development. Particular reference was made to the annual assessment process, Public Partnership Forums and assessing public involvement in areas of significant service change.

See appendix 4 for a copy of the presentation slides.

Questions and comments in plenary:

- NHS Lothian were good at consulting with sex workers in drawing up a prostitution strategy but the failing in this was the partnership with other agencies, particularly the local authority (City of Edinburgh Council), who had ignored the research the NHS had done. The situation could be improved if clear criteria for partnership working between the council and the NHS were put in place beforehand.
- The same problem with the local authority was identified in relation to the development of the Carers Information Strategy in Edinburgh
- Older People's Equality Forum do not know how to engage with the Public Partnership Forums due to a lack of accessible easy to understand information. They need to be engaged in a way that suits them.
- Public Partnership Forums are not doing anything to support people with learning disabilities to be involved (there is national guidance on how to do this).

- There needs to be additional support within the NHS to help people with learning disabilities to participate meaningfully both in public involvement and to assist them to achieve a more patient focused service. The support they get from social work is limited.
- What are the Public Partnership Forums doing to engage with drug users?

Priority Health Issues

What do you think are the priority health issues for your client group?

- Many of the organisations were concerned about not having guaranteed, sustainable funding and were anxious about the possible loss of services. Councils, the Scottish Executive and charitable trusts place too much emphasis within funding criteria on doing something new and innovative (the NHS is not too bad in this respect). It was stressed that the needs of the communities are not changing and a lot of good, effective practice is often sidelined for new innovations and as a consequence some of the organisations feel that in order to secure funding there is a pressure to keep reinventing themselves.
- Often there is a lack of consultation from about removal of funding from individual projects.
- Information about patient pathways for elderly people. More support at home for elderly people and availability of low level support to support prevention of deterioration in conditions.
- Better partnership working between local authorities and the NHS in order to deliver services to ensure effective through-care.
- Access to drugs treatment for sex workers and drugs issues training for staff and professionals.
- A fast track specialised sexual health clinic for sex workers who often lead very chaotic lives and don't access many primary care facilities. Many of these individuals are not even registered with GP's.
- Better support for carers of people with mental ill health to minimise impact on their mental and physical health. Ongoing support for 2-3 years, together with information on how to access this, e.g. self help groups.
- Difficulty in accessing translated information into Polish and Ukrainian. White Europeans are often overlooked as a minority.
- Many Eastern European sex workers need a contact point for information that will give them access to services, particularly the NHS.
- the way social work prioritise services for those with the highest level of need means many people with learning disabilities can't get social work help and support.
- Experience of health workers in primary care for people with learning disabilities is very patchy. There is a learning disability liaison officer in one area of NHS Lothian, but there need to be more in order to support people to articulate their needs.

- There was also a general consensus that there aren't enough advocacy and support services for service users who need to be supported across all groups. Support for making a complaint was also identified as a gap.
- The efficacy of having an independent advocacy service for sex workers was questioned. They would be more likely to access it if it was linked to a service, and they would be more likely to access the service if there was an advocacy worker linked to it. Much of the difficulty they encounter with services is receiving a service sensitive to their individual needs. A dedicated sexual health unit would be helpful.
- Travel and transport issues, as well as accessing information for parents of children using services.

Facilitation Workshops

Do you feel NHS Lothian do enough to engage patients, carers and members of the public in bringing about changes to services?

- Some of the agencies felt that the service users they represented could not vocalise their views and needs. This could be due to language barriers, clients feeling intimidated, having a learning disability, Alzheimer's, or being afraid that their comments would affect their care. Health boards use a lot of jargon and medical terminology which their service users are unfamiliar with.
- Involvement should not only be about talking to user/ carer/ parent groups, -it should be a two way process. Decisions are often made before health boards start the consultation process and the input of community groups has very little impact if any. However some groups did feel that NHS Lothian generally made a good effort to consult although this did not make a difference to the outcome. The NHS should be more honest about what funding is available when consulting with communities. All organisations will have a shopping list for services that will improve the lives of their clients but need to be realistic about getting everything they ask for. Choices have to be made. They would like to be asked what their priorities are and where the money/ resources should be best targeted.
- Feedback could be better so that people understand why certain decisions are made. Participants were also critical of consulting over the summer when many people are on leave and agencies often find it more difficult to contact people when staff resources are low.
- Advance notice of consultations would be helpful. Learning disability strategy review has had limited involvement of service users because of limited time available. Transition is a key issue – key worker support should extend from education and employment to support access to health services.
- There is a difficulty with people being 'consulted' rather than involved. They will be asked questions about services but it stops there and they are not actively involved in developing solutions.

Do you feel you have the necessary support to enable your voice / clients voices to be heard?

- Asking people how they would like to be involved would be helpful to service users as certain groups may have preferences based on factors such as physical or mental disability, additional support needs, childcare, limited time, resources etc.
- If consultation activity was facilitated by someone people trusted and felt comfortable with they would be more inclined to participate. Trust was a recurring theme and that for some user groups it takes a great deal of trust for them to open up and feel comfortable enough to share their views and needs. Some individuals may not be physically able to attend meetings and may be housebound; in this case development workers could be contacted.
- Local venues, ease of accessibility, carer/ sitter, transport costs were also factors to be considered and that reimbursement of reasonable costs would help users on low incomes or have dependents to participate.
- Translation could also be provided for people whose first language is not English. More could be done to engage people who are new to Scotland and do not understand the healthcare infrastructure. This could be done through translation of materials, interpreters etc. Providing feedback in the form of minutes and summary reports would also be helpful as it would enable service users to see what difference has been made.
- Sub groups (e.g. for learning disability) within Public Partnership Forums would assist with addressing issues for certain groups and allow ongoing dialogue.
- Public bodies have a duty under the Disability Discrimination Act to demonstrate how they involve disabled people in developing service provision.

Working Together and the way forward

The purpose of this event was to gain a better understanding of some of the barriers to engagement that “hard to reach” groups face, the main health priorities for their user groups, and their experience of Patient Focus and Public Involvement with the NHS. It gave us an opportunity to learn, from issues raised during the discussions, about areas where patient focus and public involvement practice could be improved.

We wanted to listen to the groups invited, take on board all of the information given and ask the groups how we could work with them in future. We recognised that these organisations were often staffed by one or two members and we were anxious not to increase their already demanding workload further.

All of the groups invited had said that they would be happy to work with us in the future in some capacity. The general consensus was that this should be an open and two way relationship. We received evaluation questionnaires back from over 50% of attendees. All of the comments received were positive and the organisations were in agreement that it was a good and worthwhile event, although it was commented that the event would have been better if more organisations had attended.

Suggestions about future engagement:

- Identify areas from NHS Lothian's annual self assessment of its patient focus and public involvement activity relevant to individual groups and ask them to comment and assist Scottish Health Council's verification.
- Individual groups asked to comment on assessment of significant strategy consultations where appropriate
- Groups to use awareness of Scottish Health Council's role to feedback issues where further areas for improvement within patient focus and public involvement have been identified and could be fed back to NHS Lothian as part of overall assessment.
- Use issues discussed at this event and identify generic development issues for NHS Lothian.
- Groups to raise awareness of Scottish Health Council where a relevant issue arises with other community organisations and encourage feedback of issues to us.
- Training needs were also identified. Some of the organisations felt that they would benefit from some Patient Focus and Public Involvement training. They felt that if delivered to both staff and service users this would help them to participate in meetings. Scottish Health Council will look to develop this.

We also plan to feedback the comments made to NHS Lothian and hope it will give them a useful insight into how they can best involve "hard to reach" groups in their work.

4 Appendix



Appendix 1 – Planning The Event

Appendix 2 – National Standards for Community Engagement

Appendix 3 – Organisations Invited and Attended

Appendix 4 – Programme

Appendix 5 – Review Questions

Appendix 6 – Presentation

PLANNING THE EVENT

Appendix 1

The Process

The initial stage in the planning process was to identify our target audience, primarily “hard to reach groups”. We invited a wide range of local and national voluntary organisations which have a local presence in Lothian. This event aimed to build sustainable and effective mechanisms of communication to enable service users to have their voices heard by health boards.

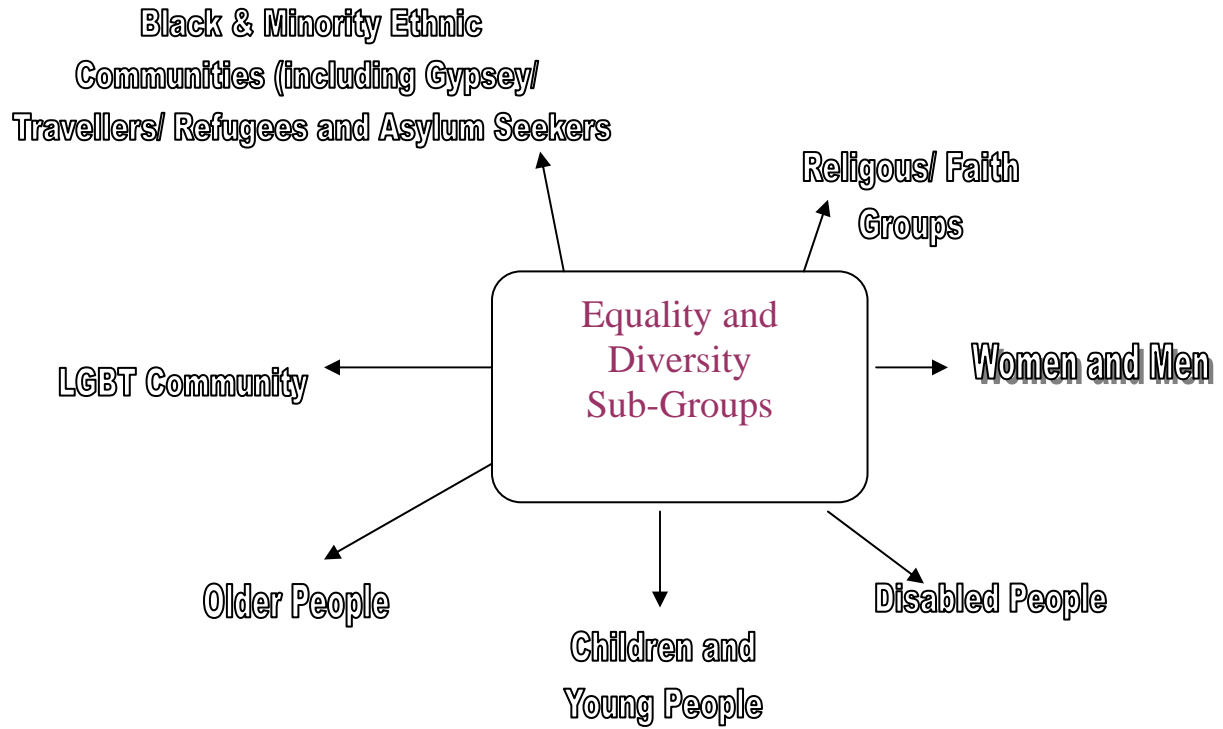
In order to gain a better understanding of some of the relevant Patient Focus and Public Involvement issues we had to identify and define clear objectives and how best to achieve them. We recognised that this would have to be an, open, transparent and, most importantly, two way process. The intention was that this event should initially be an opportunity for information sharing and discussion on how patient focus and public involvement can improve the services provided to the client groups of these organisations and gain an understanding of the role of Scottish Health Council in helping to achieve this.

Equality and Diversity Strands

On March 16th 2005, the Scottish Executive Health Department sent a letter to all NHS boards informing them of the need to undertake Equality and Diversity Impact Assessments (EQIA).

“To comply with our Partnership for Care and National Health Service Reform (Scotland) Act commitment and to ensure that all policy and service developments within NHS Scotland can be shown not to disadvantage any of the people we serve. Boards should in particular ensure that their policies, procedures and service developments do not disadvantage individuals because of their age, ethnicity, gender, religion or faith, disability or sexual orientation.”

The Equality and Diversity Strands are illustrated below.



National Standards for Community Engagement

Appendix 2

The Scottish Executive commissioned Communities Scotland to produce a set of community engagement standards.

“These National Standards for Community Engagement will help to develop and support better working relationships between communities agencies delivering public services”

(Malcolm Chisholm, Minister for Communities)

The standards are listed below along with some ways in which we aim to use them in our engagement with the organisations involved.

1. INVOLVEMENT: We will identify and involve the people and organisations who have an interest in the focus of the engagement.

After discussing the aims and objectives of the event and how best to achieve this we set about trying to identify the people and organizations we would invite. We contacted a number of organisations spread across the Equality and Diversity strands.

2. SUPPORT: We will identify and overcome any barriers to involvement

Around forty organisations were contacted by telephone prior to inviting them to the event to gauge their level of interest and find out what their experience of patient focus and public involvement with NHS Lothian was. By doing this we gained a better understanding of their concerns and needs and could use this information to answer some of their concerns. Some reasons people gave for being unable to attend included staffing problems, lone workers, scepticism, no previous engagement, negative experiences of Public Focus and Public Involvement or simply a lack of awareness of who we are and how we fit into the PFPI equation.

3. PLANNING: We will gather evidence of the needs and available resources and use this evidence to agree the purpose, scope and timescale of the engagement and the actions to be taken

Prior to the event we sent out a list of facilitation questions to allow the organisations to prepare for the event. The data gathered from the facilitation sessions will form the basis on any further engagement.

4. METHODS: We will agree and use methods of engagement that are fit for purpose

We asked the organisations directly what methods of engagement they would like to use, e.g. email, telephone, face to face contact etc.

5. WORKING TOGETHER: We will agree and use clear procedures that enable the participants to work with one another effectively and efficiently

We sent them out the format of the day and questions to consider in advance and facilitated the day in a way that allowed everyone to participate.

6. SHARING INFORMATION: We will ensure that necessary information is communicated between the participants

We will send out this report to all participants. We plan to set up a network steering group which will be administrated by local officers who will keep members updated on relevant information and will co-ordinate meetings.

7. WORKING WITH OTHERS: We will work effectively with others with an interest in the engagement

The purpose of this event was to invite organisations that have an interest in Patient Focus and Public Involvement along to see how we can work together effectively in the future. We will continue to reach out to a range of voluntary organisations.

8. IMPROVEMENT: We will develop actively the skills, knowledge and confidence of all the participants

We can identify development needs within the voluntary sector to ensure more effective patient focus and public involvement across NHS Lothian.

9. FEEDBACK: We will feed back the results of the engagement to the wider community and agencies affected

We will send out a summary of the report and findings to the organisations involved and further a field. In addition to this we will provide feedback around any future relevant work we do.

10. MONITORING AND EVALUATION: We will monitor and evaluate whether the engagement achieves its purposes and meets the national standards for community engagement

This will be discussed internally and with the organisations on an ongoing basis as further engagement develops.

Consideration was given to how we could incorporate these standards into our engagement with the invited organisations. By using these standards in our engagement with these groups it was felt that this would lead to more effective, meaningful and useful communication which would provide a good foundation on which to build relationships.

Organisations We Contacted

Appendix 3

Organisations Invited

- Chinese Elderly Support Association
- Age Concern Scotland
- Alzheimer Scotland
- Asian Welfare Association
- Caring in Craigmillar
- Contact A Family
- Scottish Council for Minorities
- Streetwork UK
- Health in Mind
- Form on Discrimination
- Lothian Community Health Project Form
- Eke-out Project
- The Action Group
- Disability West Lothian
- Carers of West Lothian
- Edinburgh Youth Council
- Contact a Family
- West Lothian Young Carers
- Waverly Care Solas
- Minority Ethnic Health Inclusion Project
- The Ark Trust
- Lothian Autistic Society
- Saheliya
- Edinburgh Refugee Centre
- See Me
- LGBT Centre for Health and Wellbeing
- The Scottish Gypsy Traveler Association
- National Schizophrenia Fellowship
- Epilepsy Enlighten- Action for Epilepsy
- Penumbra
- SCOT-PEP
- Pilmeny Development Project
- City for All Ages, Edinburgh City Council

- Polish and Ukrainian Support Service, Alzheimer Scotland
- NSF Scotland Carers Support Project

There were 12 attendees on the day and are listed below. A number of organisations could not attend due to unforeseen reasons and sent their apologies, as did a couple of our Local Advisory Council Members. We have offered to visit organisations that could not attend in the future and hopefully engage with them in the future.

Organisations Invited and Attended

- Anne Elliot, City for All Ages
- Ruth Morgan Thomas, SCOT- PEP
- Anne Little, Alzheimer Scotland
- Andy Foreman, The Action Group
- Elena Goodall, Polish and Ukrainian Support Group, Alzheimer Scotland
- Lorraine Keith, NSF Scotland Carers Support Project
- Anne Wilson, Contact A Family

Scottish Health Council Attendees

- Narmeen Rehman, Local Officer, Lothian
- Louise Baxter, Local Officer, Lothian
- Richard Brewster, Regional Officer, East
- Elaine Cunningham, Local Advisory Council Member, Lothian
- William Peacock, Local Advisory Council Member, Lothian.

Engaging Communities Event
The Engine Shed, St Leonard's Lane, Edinburgh
15th Sept 2006

Appendix 4

Programme

10:30 am- 10:45 am	<i>Registration and Refreshments</i>
10:45 am- 10:50 am	<i>Welcome and Introductions</i>
10:50 am- 11:15 am	<i>Presentation</i>
11.15 am– 11.25am	Q & A Session
11:25 am- 12:00 pm	Round the room Introductions
12:00 pm- 13:00 pm	<i>Lunch and Networking</i>
13:00pm- 14:30 pm	<i>Workshops</i>
14:30 pm- 14:45pm	Refreshments/ Comfort Break
14:45 pm- 15:00 pm	Feedback
15:00 pm- 15:15 pm	Summary and Conclusions
15:15	<i>CLOSE</i>

REVIEW QUESTIONS

Please consider the following questions prior to the event. These will form the basis of the facilitation sessions.

1. What do you think are the priority health issues for your client group and how could they best be taken forward by NHS Lothian?
2. Do you feel that Lothian Health Board do enough to engage patients, carers and members of the public in bringing about a change to services? If possible provide supporting examples.
3. Do you feel you have the necessary support to enable your voice/clients voices to be heard?
4. Would your organisation benefit from receiving some Patient Focus Public Involvement training?
5. What would be your expectations of The Scottish Health Council and how can we assist in making your voice heard?

ⁱ Patient focus and public involvement – “a health service where people are treated with respect, treated as an individual, and involved in decision making at all levels of planning and delivery of health services within NHS Scotland” (Scottish Executive definition)