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Scottish Health Council Fife

‘Engaging Communities’ Event

1st November 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



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

The logo for the Scottish Health Council, featuring the text 'scottish health council' in a purple, lowercase, sans-serif font inside a light purple speech bubble shape.

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The aims of the event were:

- to raise awareness of Scottish Health Council in Fife 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 Fife
- to identify ways of working together on an ongoing basis to see what improvements can be made to patient focus and public involvement in Fife.

Presentations were made by the local officer for Tayside, Wendy Lees. The presentation covered the background to Scottish Health Council, its role and functions and looks at Scottish Health Council's role in assessing how effectively NHS Fife delivers patient focus and public involvement and in helping to identify areas for development. Particular reference was made to the annual assessment process and assessing public involvement in areas of significant service change.

See appendix 4 for a copy of the presentation slides.

Priority Health Issues

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

- 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 NHS Fife in order to deliver services to ensure effective through-care.
- Better support for carers of people with mental ill health to minimise impact on their mental and physical health.
- Experience of health workers in primary care for people with learning disabilities is very patchy. There needs 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.
- Independent support for making a complaint was also identified as a gap.
- Travel and transport issues, parking and public transport were a concern for many participants client group.
- Access to addition services and GP's for people with drug and alcohol can be problematic as can be getting specialist referrals for these user groups.
- Equity in service across the board.
- People with mental health problems don't always receive a proper assessment.
- People should be treated on an individual basis for their problem.
- Accessibility to services/ buildings can be an issue for people with a physical disability and often staff have not received adequate training in moving patients with physical disability.
- Hospital staff need to be more supportive of parents and carers as well as patients.
- Communication with staff on wards can be problematic. Providing training to allow nursing/ hospital staff to recognise and communicate with deaf people, people with sensory impairment appropriately.
- Recognising that an individual who needs a great deal of support in their home environment then needs the same level of support in a hospital environment.
- Change to service is often not communicated until the change has been implemented.
- Time constraints mean that training of staff often takes a back seat.
- Accessing specialist training can be difficult.
- Staff in care home/ carers etc can be provided with basic training to help them carry out simple procedures, e.g. tube feeding without a heavy reliance on district nurses.
- Despite the Disability Discrimination Act people with a disability still receive 2nd rate care.
- There is a shortage of signers and lack of awareness of who needs signers within the community. NHS Fife could do more to address this.
- More cognitive and family therapy is needed to help people with mental health problems. Fife Health Board should look to evidence based research.
- Fife health board should look to other boards to share good practice. There is a good counselling service available in Forth Valley which other areas could benefit from.

Facilitation Workshops

Do you feel NHS Fife 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, cultural and social barriers, clients feeling intimidated, having a learning disability, 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. The information provided needs to be user friendly and accessible.
- 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.
- Feedback could be better so that people understand why certain decisions are made.
- 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. Many participants feel that decisions have already been made before the consultation process.
- The case of the new forensic unit was discussed, some participants felt that the board had already made it's decision and did not feel as though NHS Fife appropriately consulted with the public and do not communicate consultations well.
- Participants felt that NHS Fife only involved patients, carers and the public to tick a box.
- NHS Fife should use link workers to liaise between voluntary groups , public, patients, carers and the NHS.

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.

- People could be consulted with in their own environment or where their group meets and at a time which suits them.
- Health boards should recognise that there is a power imbalance; a drug user for example may feel threatened and afraid to give an opinion in case their support is taken away. This can be resolved by the board building up trust by attending some of their meetings and support groups.
- Carers should be more involved and should sit on relevant NHS steering groups.
- 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. .
- Public bodies have a duty under the Disability Discrimination Act to demonstrate how they involve disabled people in developing service provision, some participants at the event felt that this is an area which the Health Board has not addressed.
- The NHS could help improve participation in consultation activities by providing advance notice of meetings. They could advertise in libraries, doctors surgeries etc.
- NHS Fife could speak to groups who have consulted well and share good practice.
- It was felt that certain groups are more in favour politically and are consulted with more frequently, and that more topical issues are often take precedence over other relevant issues.
- Health boards could encourage people to participate by advising them of the different ways to filter in their comments or suggestions without attending a public meeting, e.g. through email, send information in writing or over the phone.
- People need feedback in order to see what difference their contribution has made. Some participants felt that their clients have been asked for their opinions years ago and feel as though it has had no impact.
- Taking into consideration language, cultural and communication barriers when consulting with people would encourage participation.

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.

Suggestions about future engagement:

- Identify areas from NHS Fife'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 Fife as part of overall assessment.
- Use issues discussed at this event and identify generic development issues for NHS Fife.
- 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.
- Cascade information to participants as and when appropriate
- Participants were invited to contact the Fife office for further information/ partnership working.

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

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 Fife. This event aimed to build sustainable and effective mechanisms of communication to enable service users to have their voices heard by health boards.

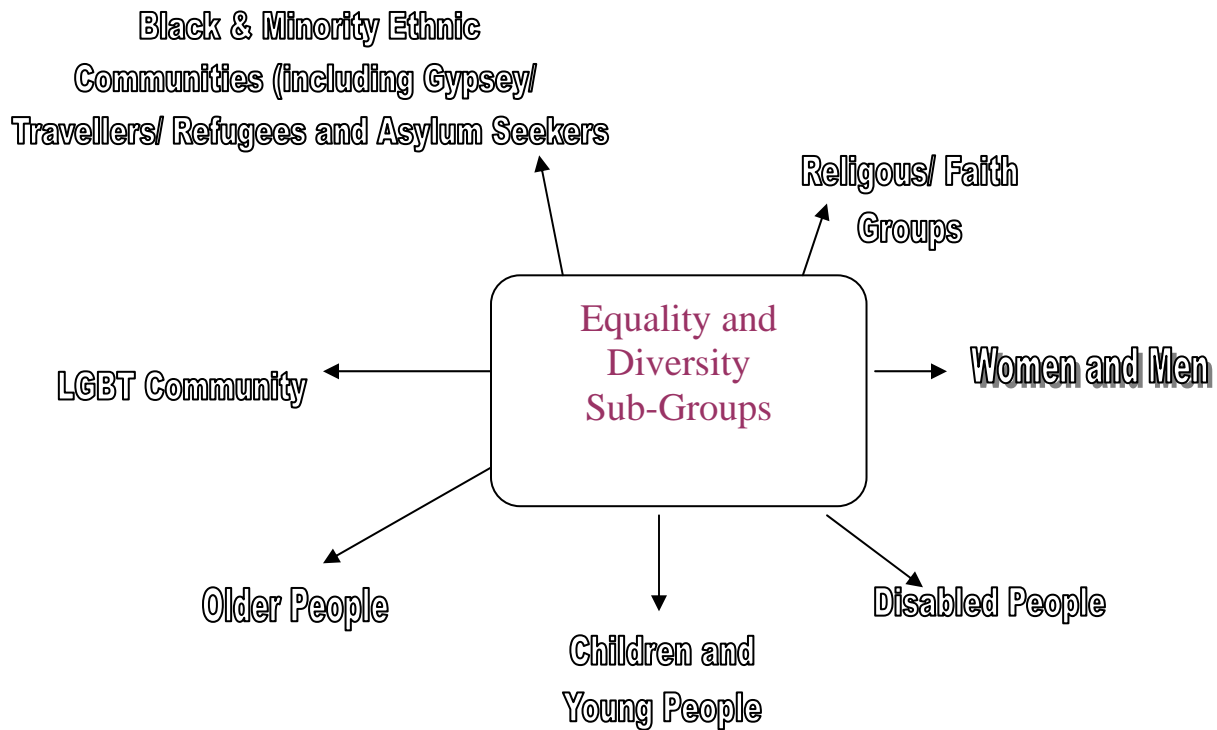
In order to gain a better understanding of some of the relevant Patient Focus and Public Involvement issues we had to identify and define clear objectives and how best to achieve them. We recognised that this would have to be an, open, transparent and, most importantly, two way process. The intention 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.



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

- Fife User Panels
- Princess Royal Trust Fife Carers Centre
- MS Society Scotland
- Fife Families Support Project
- Stepladder-Women Promoting Positive Mental Health
- SAMH, Central Area Office
- West Fife Supported Living Service
- Hearing Voices Network (Fife)
- Fife Advocacy
- Central Fife Association for Mental Health
- Alzheimer Scotland Action on Dementia
- Fife Women's Network
- Fife Men's Project
- Local Forum for Community Care
- DARE Foundation
- Capability Scotland
- Fife Independent Disability Network
- Leonard Cheshire Services in Fife
- The SAY Project
- The Richmond fellowship Scotland
- PAMIS in Fife
- Law & Administration Service
- Auchtermuchty Health Centre
- Fife Council
- Fife Elderly Forum Executive
- Drug and Alcohol Project Levenmouth
- Fife Alcohol Support Service
- F.I.R.S.T
- West Fife Communities Drug Team
- Fife Chinese Association
- Kirkcaldy Islamic Cultural Centre
- Open Door Fife
- Shelter(campaign for Homeless People)
- Cornerstone Leven
- FRAE Fife

There were 20 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 some 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

- Stuart Pryde, Fife Families Support Project
- Joan Scott, Penumbra
- Daksha Patel, F.R.A.E
- Ernie Michie, The Richmond Fellowship
- Margot Wilkie, Leonard Cheshire
- Elaine Harkens, Leonard Cheshire
- Isobel Price, Leonard Cheshire
- Robert Grant, Drug and Alcohol Project, Levenmouth
- Lisa Hemphill, Open Door Fife

Scottish Health Council Attendees

- Liz Taylor, Regional Officer, East
- Shelagh Martin, Regional Officer, East
- Wendy Lees, Local Officer, Tayside
- Narmeen Rehman, Local Officer, Lothian
- Suzanne Mack, Administrator, Fife
- David Reid, Local Advisory Council Member, Fife
- June Dryburgh, Local Advisory Council Member, Fife
- Grace Skinner, Local Advisory Council member, Fife

Engaging Communities Event
Rothes Hall, Glenrothes
15th Sept 2006

Appendix 4

Programme

10:30 am- 10:45 am	<i>Registration and Refreshments</i>
10:45 am- 11:00 am	<i>Welcome and Introductions</i>
11:00 am- 11:15 am	<i>Presentation</i>
11.15 am– 11.30am	Round the room Introductions
11:30 am- 12:15 pm	<i>Q & A Session</i>
12:15 pm- 12:45 pm	<i>Lunch and Networking</i>
12:45pm- 14:45 pm	<i>Workshops</i>
14:45 pm- 15:00 pm	Refreshments/ Comfort Break
15:00 pm- 15:30 pm	Feedback
15:30 pm- 15:45 pm	Summary and Conclusions

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 Fife?
2. Do you feel that Fife 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)