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# Scottish Health Council Tayside

## ‘Engaging Communities’ Event

24<sup>th</sup> October 2007



**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 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.

**“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)***

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 groups that may find it difficult to have their voices heard 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 “seldom heard” 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 NHS Scotland, Patient Focus and Public Involvement, A draft for Consultation, 2003).***

# THE EVENT

## **The aims of the event were:**

- to continue promoting patient focus and public involvement within NHS Tayside
- to allow those attending to share their experiences of accessing health services within NHS Tayside
- to identify areas of good practice around accessing health services within NHS Tayside
- to identify and discuss areas where people felt their experience of accessing health services could have been improved
- to find out if people know how to get involved in influencing change
- to share our discussions and any questions posed during the workshops with NHS Tayside

Many of those who attended our last event in March this year told us that a similar event within the year would be useful.

Some of those had said they would like to see NHS Tayside represented at the next event to hear the discussions at first hand and also to address some of the issues arising from the discussions. NHS Tayside was represented on the day by a Cancer Services Manager, although some of those invited were unable to attend due to prior commitments.

We invited three speakers to give short presentations about their work in the voluntary sector to set the scene for the workshops that followed.

We felt the event would give groups from similar backgrounds an opportunity to meet and we were keen to include time for those attending to have the opportunity to network with each other and with us, with a view to working together again in the future.

During the workshops, discussion was concentrated around people's experience of accessing health services and then later looking at ways in which they thought access could be improved, especially for vulnerable groups or individuals.

## Speakers

The following gives a flavour of the issues presented by the speakers on the day.

### George Millar, Council for Voluntary Services

George began by congratulating NHS Tayside for involving patients and stressed how important it is to include carers. However he felt it was more difficult to include patients/carers with physical difficulties in the consultation process.

He advised that NHS Tayside need to listen to the people working at the sharp end and that the structures need to be in place to ensure a robust partnership and mutual respect so that the consultation/engagement process can be successful from the outset.

He spoke of an overwhelming number of groups feeding into each other forming health improvement networks and of a continuing need to bring these together with planning and service provision. George did add that Community Health Partnership Committees have been helpful in bringing these partners together. He stressed that patients and carers just want a say in how their health service is delivered and advised that NHS Tayside gets to know the wider voluntary sector, not just the bigger organisations. The NHS needs to know in each instance who to consult with and should listen to what they have to say.

### Laurie Matthew, 18s and Under

Laurie began by saying that although she is happy with her own experience of accessing services within the NHS she feels that the abused young people she works with do not get quite the same high level of service she does.

She described seven barriers that young people face when trying to access health services:

- abused young people want to speak to a doctor but sometimes find that they are unable to do so without a parent or carer present
- 'can't tell, won't tell' – this is a complex problem with no simple solution
- STD and pregnancy – a big problem - if they do not want to continue the pregnancy, they require a termination and are often treated with indifference or worse, are lectured. They are unable to tell that they have been raped and are treated as if they are promiscuous. There needs to be dialogue to uncover underlying problems
- 'Runaways and throwaways' (American term) – young teenagers can be thrown out of home for acting out, or they may run away. They may be self-harming or living rough, cannot readily access health services and may be afraid of being sent back home. The Health Board needs to engage in a non-threatening way and ask pertinent questions
- Mental Health – the difference between adolescent and adult services means that some young people may be treated by either/or, although it does seem that those still in school will be treated as children and those having left school, as adults
- Other Issues – **not all abused children are the same** – they can have very different backgrounds and histories. It can seem that NHS assumes that all abused and young people are heterosexual. Those who find it most difficult are transgender young people who have to go to Edinburgh to access services. If the NHS engages with young people the services must be there.

## Fiona Bartley-Jones, Action for Sick Children

Action for Sick Children supports families where a child is ill or has complex needs. Fiona felt that those present might not have heard of the organisation previously although it has been in existence for 37 years and has six area co-ordinators one of whom is Fiona, who covers Tayside. The co-ordinators work autonomously in their own areas and also collaboratively. For instance each co-ordinator may link with travellers, children with complex needs or dental care problems.

A recent survey in Tayside looking at the impact on families with sick children showed that people wanted a more holistic approach to the care given. For example families with doubly incontinent children, may only have fortnightly rubbish collections – this obviously causes problems with overfull bins and it may be worthwhile to contact the Local Authority to discuss other options.

Children are falling through the net. Their sickness impacts on their education, especially at secondary level. There are regulations around this issue. After 15 days off school a child can have a home tutor, but one problem is that regulations and entitlements are not readily accessible to families.

## Facilitated Workshops

The delegates were divided into three groups for the morning workshop sessions with each group discussing the same topic. The reason for this was so that during the lunch/networking break people could continue their discussions if they wished and bring in the wider view from other group members.

**For the first part of the morning session we asked people to tell us about their experience of accessing health services or the experience of someone they care for.**

There were mixed responses to this. Although most people were positive about the clinical services they receive, there were some issues that still cause people some concern. One of these was transport, with some people saying they were unaware of the availability of patient transport. Another comment was about a booking mix-up for an appointment although that particular problem was solved for the return journey by a nurse on the day, and another was around the lack of availability of transport to Stracathro Hospital, with patients having to cancel appointments or treatment because they had no access to transport.

Another issue of concern was around carers who felt they are sometimes not listened to and one carer talked in particular about access to GP services. She felt that the requirement to contact the surgery early in the morning to secure an appointment was not always possible for either patients with disability or for carers. If there are no appointments left on the day people are often told to phone back the next morning instead of being able to book a day or two ahead. It was generally felt that there is a need for a more flexible approach to booking GP appointments.

Another issue was around translation services. Whilst the lady expressed her delight with NHS Tayside's services, she did say that translation services still require to be better promoted so that there is more awareness of the translation service for those who require it.

Access to an NHS dentist is still a major concern for many people in Tayside.

**The second part of the morning session asked the groups to consider whether accessibility to NHS Services is focussed on the patient.**

Several people agreed that the answer to this question depended on the ailment.

For example, one delegate felt there was good recognition and rapid assessment of needs for people who have drug related issues and that voluntary organisations supporting people with drug related issues are very positive and pro-active.

However, some concern was expressed that people suffering mental ill-health felt that communication was sometimes poor between themselves and staff and that they were not always involved in decisions or consulted about their own care and treatment. One person said that some patients are not told what is going on with their treatment until something is

about to happen, while another felt that people mental and physical health issues are treated differently.

One person said they felt that that young carers are not adequately catered for in the NHS and there was some agreement that front line staff can appear judgemental in their dealings with young people. There were mixed views around how well carers were involved, and some people felt there was a lack of engagement with young patients with perhaps a need for advocacy services for young people, especially young carers.

### **The third question asked the delegates to consider how they felt the NHS could improve patient involvement in service provision**

Several people agreed that evaluation forms could be more user friendly, inclusive and research based, and also suggested using British Sign Language or interactive video boxes to encourage feedback from services users and carers.

There was agreement that there should be a wider spread of representation from the public and more openness, consultation with, and feedback to, services users and carers as well as more support for NHS staff. People also felt they do not always receive feedback.

One suggestion that met with general agreement from the group was that there would be benefit from an independent evaluation of the patient journey to discover where patients and carers could have greater or more meaningful involvement in their own treatment and care.

### **Finally we asked if the people present knew how to get involved in influencing service provision in the NHS.**

Several people suggested ways in which to become involved such as through groups, letters to the NHS Board or through the NHS Tayside website. Gillian, the NHS Tayside Cancer Services Manager told the group about her cancer patients' support group whose members meet to discuss and have a real say in how their service is delivered.

However, it would seem that the majority of those present did not know how to get involved. Although there is some awareness of the work of NHS Tayside's Public Partnership Groups who work across Tayside, most people had not come across them previously. The facilitators took the time at this point to pass on contact details to those expressing an interest in contacting the Public Partnership Groups via the Public Involvement Manager.

Many felt that there has to be real motivation for people to get involved and that NHS Tayside needs to be more proactive in contacting and involving people in influencing service provision. Front line staff should be encouraged to see the benefits of a patient focussed service and of consulting patients about service change.

## Summary of Questions Posed on the Day

Several of the questions were around the availability of patient transport. One lady talked about having been refused transport to take her home following a stay in hospital. In response it was felt that organising transport would not be considered the responsibility of the NHS in this case. Patient transport can be arranged prior to an out-patient appointment in some cases, and there is a taxi service for those accessing out of hours treatment who cannot otherwise get home.

One delegate asked if and when she would be likely to receive a response to her question to the Minister at the recent Ministerial Review. Although the questioner was not from Tayside, Gillian, the Cancer Services Manager, who has a special knowledge of the subject, was invited to respond and was able to reassure the lady that all the written questions sent to every Health Board review and not answered on the day, would be answered in writing, although she could not say when that would be.

We were asked why the NHS is not doing more to engage with or to involve people who have a disability. It was stressed that Health Boards have a responsibility to give people the opportunity to be involved whatever their circumstances and the responsibility of Scottish Health Council is to assess the quality of the involvement and to promote better patient focus and public involvement.

The same delegate asked why more disabled people were not visible at this event. In response we said that we in the local office continue to communicate with the network of people we have contacted over the past couple of years all of whom received an invitation to attend our event. Our database of contacts represents a diverse range of people but not everyone chose, or was able to attend on this occasion. We are continually building up our database of contacts and trying to ensure that people from all walks of life are included. We will continue to liaise with these groups and to add to our list of contacts and would therefore hope to see even wider representation at our next event.

Finally, we were asked where we go from here? This was an opportunity to assure those present that a report of the day would be shared with them, our network of community and voluntary contacts and NHS Tayside and that any issues arising would be followed up and reported back not only to those attending, but to those who could not attend the event.

### **Previously Asked Questions**

Three questions were asked by delegates at our last Engaging Communities:

- If NHS Tayside is consulting or engaging the public about service change, does it involve service users from Fife?
- How are people in rural communities informed, how are they heard and how can they get involved especially when transport is an issue?
- How can the ordinary person in the street influence the Patient Focus and Public Involvement agenda in Tayside?

These same or broadly similar questions still continue to be asked and seem to indicate a low level of awareness about Patient Focus and Public Involvement.

## Feedback from the Day

From the 26 evaluation sheets given out at the event we received 24 returns (92%). All of the respondents felt the venue was good or very good. Twenty-three said the workshops were informative or very informative. Twelve felt the duration of the workshops was very good and five good. Six people scored duration of workshops average and one, poor. Twenty-two people intimated they had a good or very good opportunity to give their opinions, while two people marked this section average.

### **The delegates were asked if they would like to address specific issues at another event.**

Delegates said:

- improving access to mainstream services for patient with learning disabilities.
- more effective use of patient support groups.
- involvement/consultation/engagement with mental health patients with regard to drafting NHS policy
- Independent Advocacy provision
- Access to palliative care services in deprived or difficult to reach areas

### **How could we build on this event?**

Delegates said:

- Ensure NHS are represented from all grades if possible
- Co-ordination with other patient involvement groups
- Continue with discussions
- Take our concerns to the NHS then arrange another event to let us know what they said/what they propose to do about it
- Keep communicating and informing
- Keep going, suggest a youth event
- Ensure representation from LGBT
- Feedback on points raised
- Possibly smaller half day more local events would suit some people better
- Money wasted on packs, want more time in workshop sessions
- Wider publicity

### **Other Comments included:**

- Very enthusiastic gathering of people
- Excellent organisation of event
- very interesting, really enjoyed
- happy to attend
- good networking opportunity
- event very well presented
- workshops a huge step in right direction, really enjoyed it
- very useful information day, good networking
- interesting people, a good day
- very useful informative day, good networking opportunities, met a lot of interesting people, a good day all in all
- workshops could be longer as a lot of good opinions to be heard
- useful to have prior notice of questions to be discussed

- very informative
- groups attending forums should be kept up to date with feedback
- good event, especially for networking, very well organised and good information available
- facilitator spent too much time talking
- worthwhile day but our group discussion was dominated by “lack of resources”. Need to ensure these days are timely to ensure cost effectiveness, not just because they are a good idea. Would appreciate feedback on how points made at this event are being tackled
- much smother than last event, we had real group discussion
- thanks for opportunity to network and raise issues
- good food, thanks

All 24 respondents said they would be interested in attending future events in Tayside.

## Conclusions

The following are some of the key issues that were raised at the event although these should not be viewed in isolation from the full list of issues described elsewhere in the report.

- The people who attended this event were generally happy with the clinical services they receive from NHS Tayside
- Transport availability and accessibility gives cause for concern, i.e. there appears to be a lack of information with regard to transport entitlement and the service might benefit from a review
- GP access could be more flexible with regard to forward booking appointments
- Translation services are generally good but need to be more widely promoted
- Younger people would like a bigger say in their own health care and in service change, perhaps some young people would be empowered to do this if they had access to independent advocacy services
- People suffering mental ill-health sometimes feel their wishes are ignored
- The patient journey could benefit from independent evaluation to ensure patient focus
- There appears to be a general lack of awareness of Patient Focus and Public Involvement, and a need for an awareness raising programme across Tayside.

The Scottish Health Council recommends that NHS Tayside establish engagement mechanisms, where these do not already exist, to assist health professionals and patients to begin addressing solutions to the issues described here. It is accepted some issues will be quicker and easier to address than others, but by following the necessary process of engagement it is hoped that a better sense of understanding about health service constraints can be arrived at with patient groups.

Scottish Health Council welcomes the opportunity for continuing dialogue both with the groups that attended this event, NHS Tayside, and other patients, to see how these issues are being addressed.

# Appendix

1. Organisations Invited and Attended
2. Event Programme
3. Lead Questions and Summary of Comments
4. National Standards for Community Engagement

There were 34 attendees on the day including Scottish Health Council staff and Local Advisory Council members as listed below. A number of organisations could not attend due to unforeseen circumstances and sent their apologies. 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

- Tayside Cancer Support (1)
- Dundee Independent Advocacy (1)
- Lochlands Adult Resource Centre (2)
- Augment (3)
- Action for Sick Children (1)
- Council of Voluntary Services (1)
- Cancer Services (1)
- Angus Cardiac Group (2)
- Whitfield Inclusion Group (2)
- 18's and Under (2)
- Chinese Senior Group (1)
- Aberlour Outreach (1)
- Tayside Ritual Abuse Advice & Support (1)
- Independent Advocacy (Angus) (1)
- Chinese Womens Group (1)
- The Princes Royal Trust, Carers Centre (1)
- Involving People Team, NHS Fife (1)
- National Eczema Society (1)
- Members of the Public (2)

## Scottish Health Council Attendees

- Christine Johnstone, Regional Manager (East)
- Anne Christie, Local Officer, Tayside
- Dave Davidson, Local Officer, Tayside
- George Cuthill, Local Officer, Fife
- Neil Munro, Local Officer, Fife
- Pauline Marland , Administrator, Tayside
- Robert Purves, Local Advisory Council Member, Tayside
- Patricia Millar, Local Advisory Council Member

**Venue: West Park Conference Centre, Perth Road, Dundee**

**Date: 24 October 2007**

**Time: 10.00am – 3.45pm (approx)**

## **Programme**

<b>10.00am – 10.30am</b>	<b>Registration</b>
<b>10.30am – 10.45am</b>	<b>Welcome and Introduction, Christine Johnstone, Regional Manager East</b>
<b>10.45am – 11.15am</b>	<b>Presentations by Mr George Millar, Council of Voluntary Services (CVS), Perth &amp; Kinross. Laurie Matthew, 18's &amp; Under. Fiona Bartley-Jones, Action for Sick Children.</b>
<b>11.15am – 11.45am</b>	<b>Refreshments</b>
<b>11.45am – 12.30pm</b>	<b>Workshop Session 1</b>
<b>12.30pm – 1.30pm</b>	<b>Lunch and Networking</b>
<b>1.30pm – 2.15pm</b>	<b>Workshop Session 2</b>
<b>2.15pm – 2.45pm</b>	<b>Refreshments</b>
<b>2.45pm – 3.15pm</b>	<b>Feedback from Workshops</b>
<b>3.15pm – 3.30pm</b>	<b>Question &amp; Answer Session</b>
<b>3.30pm – 3.45pm</b>	<b>Close</b>

## Facilitation Workshops – Lead Questions and Summary of Comments

### Question 1

*“Have you or someone you care for had recent experience of accessing NHS services?”*

#### Response Group 1

- Asthma – Positive
- Kidney – 14 year old admitted to adult mixed ward as a 15 year old now referred to Paediatric
- NHS 24 – Family member was told “only for emergencies” is it a 24 hour service?
- Ambulance unable to accommodate mobility scooter
- Morning appointment – However told on arrival appointment was not until PM. Issue of booking system
- Systems not co-ordinated
- No record of ambulance booking – however nurse was able to arrange return journey
- Transport should be relevant to peoples needs, staff could ask at time of booking
- Unaware of transport availability – Do we have a Patients Policy for transport
- GP’s automated response, if phone lines are busy being asked to phone back

#### Response Group 2

- Lack of notification i.e. appointments/operations being cancelled
- Communication is poor – Department to Department to Patients
- Transport to Stracathro Hospital – patients having to cancel appointments/operations due to not having transport
- Appointments being on different days in the same week. Why can the appointments not be on the same day?
- Communication between hospitals for record purposes. Records in one hospital but appointment in another hospital
- Disjointed treatment – seeing various consultants but the consultants not communicating with one another about the patients treatment
- The further the staff are up the promotional scale the further away they are from hands on care with the patients, bogged down with bureaucracy and paper work
- Time wasted at appointments having to give the same information to different doctors numerous times

#### Response Group 3

- Need better/smoothier links between Health and Social Services
- Hospital Care – Diagnosis
- Questions should suit individual
- Questions are NHS orientated
- Chinese people – delighted with NHS
- Interpreting services needs to be better promoted by NHS

- Appointment times – GP’s – difficult to make early morning – does this cater for individual patients needs, consider disability
- Sell benefits of PFPI to health professionals
- Listen to carers
- Need better access to hospital telephone numbers
- Need better access to transport for patients
- Need more access to dentists

## Question 2

**“ Do you feel accessibility to NHS Services is focused on the patient?”**

### Response Group 1

- Fair systems – patient condition “flare up”
- Quick referral for some ailments
- Open appointments for registered patients
- “Red Tape” – Health and Safety Patient/Carer focus!
- Accessibility for disabled patients
- Specialist Nurses
- Patient Focus - Carer not included?
- Carers voice – services should recognise carers
- Role and advocacy – young carers
- Doctors lack of understanding – conditions
- No consultation with patients/young patients
- De-complicate
- Cardiac patients seen quickly
- Seeing patients in context – NHS does put patients in touch with carers groups
- Need Integrated Care
- NHS focused on clinical treatment but problems accessing services
- Co-ordination with voluntary sector important
- Good patient focus - recognition by NHS of sector positive and pro-active voluntary sector
- People with drug issues assessed quickly but sometimes waiting too long for treatment
- Young carers not always catered for in NHS
- Need holistic assessment of needs which includes family for older people
- Physical and mental issues treated differently

### Response Group 2

- If patient has mental health difficulties, not being consulted about their treatment, not involved in their care
- Can be asked irrelevant questions
- Not telling patients what is going on with their treatment until something is about to happen
- Initial contact with NHS is important from GP to Hospital

### **Response Group 3**

- Depends on needs
- Basic needs missing

### **Question 3**

**“How do you think the NHS could improve patient involvement in service provision?”**

#### **Response Group 2**

- Patients Union
- Questionnaires given out when patients being discharged
- Feedback events
- Listen to patient forums
- More independent advocacy for those that need assistance to get their voice heard
- Committees that are set up should be relevant and meaningful – not a tick box exercise
- Have a computer system that holds your info and can be accessed by medical staff in any hospital
- Have a better system for young people to allow better access

#### **Response Group 3**

- User friendly research based evaluation forms and use of Deaf BSL, graphics, video boxes, DVD's to encourage wider feedback
- Wider spread of representation from public – need feedback
- More consultation with service users (new services should seek views of users/carers)
- Need more openness
- Should be more support for NHS staff
- An independent evaluation of patients journey would be useful

### **Question 4**

**“ Do you know how to get involved in influencing service provision in the NHS?”**

#### **Response Group 2**

- Letters to the authority/board
- NHS Web Site
- Through focus groups
- Via Scottish Health Council
- Motivation to get involved – NHS should be more pro-active getting people involved. E.g. Fundraising – how should the money be spent, should be decided by the public
- Most people probably don't know how to get involved

### **Response Group 3**

- Average NO!
- PPG's not well known

Awareness raising re services in order to improve changes in the service

## **National Standards for Community Engagement**

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

- 1. INVOLVEMENT:** We will identify and involve the people and organisations who have an interest in the focus of the engagement.
- 2. SUPPORT:** We will identify and overcome any barriers to involvement
- 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
- 4. METHODS:** We will agree and use methods of engagement that are fit for purpose
- 5. WORKING TOGETHER:** We will agree and use clear procedures that enable the participants to work with one another effectively and efficiently
- 6. SHARING INFORMATION:** We will ensure that necessary information is communicated between the participants
- 7. WORKING WITH OTHERS:** We will work effectively with others with an interest in the engagement
- 8. IMPROVEMENT:** We will establish with participants development needs within the voluntary sector
- 9. FEEDBACK:** We will feed back the results of the engagement to the wider community and agencies affected
- 10. MONITORING AND EVALUATION:** We will monitor and evaluate whether the engagement achieves its purposes and meets the national standards for community engagement

Equality and Diversity Strands

On March 16<sup>th</sup> 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.

