

**Patient Focus and Public Involvement
Annual Self Assessment Report 2008-2009**



8th May 2009

Introduction

This report presents information about a few of the actions of NHS Highland staff and how they have worked with patients, carers or other members of the public. There are two main purposes to this report. One is to feedback to patients, carers and local people about some of the ways you have contributed to local services, and to highlight the value of your input and your expertise. The second is to allow our staff to share their experiences and any learning from that, in order to encourage staff right across NHS Highland to apply good practice in their day to day work.

As well as being made available and circulated to the key patient and community groups with whom we have contact, this report is also provided to the Scottish Government. It will form part of the discussion at our Annual Review where Government Ministers hold the NHS Board to account for our overall performance over the year.

The Scottish Health Council has a role to support NHS Boards in developing good practice in relation to patient focus and public involvement to ensure the voices of patients, carers and others are heard. Over the year, colleagues from the Scottish Health Council have been involved in supporting the actions in this report, and contributing to the ongoing review and learning from experience. The format of the report follows national guidance from the Scottish Health Council.

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Part 1: Summary

1.1 Patient Focus and Public Involvement Governance arrangements and how these work

The NHS Highland Board has overall responsibility for Patient Focus and Public Involvement. There is strong leadership at Board level through the Designated Director for Patient Focus and Public Involvement and two Non-Executive Directors with a specific leadership role.

Board members hold Middle and Senior Managers to account for their actions through formal performance systems. In addition, each of the five operational units has its own Governance Committee which includes public members, so there is accountability locally for actions, decisions and performance. Board meetings and the operational Governance Committee meetings are held in public, so that key aspects of the business of NHS Highland are open to scrutiny.

Papers submitted to the NHS Board in relation to service change, design or development must include information which reassures the Board that there is or has been appropriate patient and public involvement in the process.

The emergence of the proposed national Participation Standard is likely to have a significant impact on how Boards record and report aspects of patient focus and public involvement activity in future. We hope this will help NHS Boards to account for our actions in a more coordinated way.

1.2 What progress has been made with the development of Public Partnership Forums (PPFs) and how are these influencing the delivery of services?

There are two well established Public Partnership Forums in NHS Highland. The Highland HealthVOICES Network - the Highland-wide Public Partnership Forum, and the Argyll and Bute Public Partnership Forum. Each of the PPFs has an action plan which has guided their ongoing development over the year.

The Highland HealthVOICES Network (HHVN) Steering Group has guided implementation of the 2008-09 HHVN Action Plan which is nearing completion. A recent snapshot survey showed there is an active core of approximately 40 members who are currently involved in activities with NHS Highland and other health related groups, and members continue to contribute to a diverse range of services, themes and initiatives.

In Argyll and Bute, there is a focus on developing locality-based forums to encourage involvement at local community level. These are at varying stages of development. A Public Engagement Conference was held in Argyll and Bute in November 2008, and the action plan updated. PPF members are involved in a wide range of activities across the area including service redesign, health improvement, and local initiatives.

In addition to the one to one personal support provided to individual PPF members, a joint development session was held for those members serving on the main Governance Committee of each of the Community Health Partnerships and on the Highland HealthVOICES Network Steering Group. The Voluntary Sector members on the Community Health Partnership committees were also invited to participate. The main topics included exploring the meaning, purpose and implications of “governance”, and training in the impacts of equality and diversity. A key aim for the session was also to promote networking across this group of active participants.

The appointment of at least one member of the Public Partnership Forums to all four Community Health Partnerships and Raigmore Hospital Governance Committees is an important way of influencing service delivery, but it is only one part of a much bigger picture. NHS Highland continues to use a broad range of methods to ensure people are supported and enabled to participate and have their views heard.

1.3 What has worked well in progressing Patient Focus and Public Involvement?

- The wide range of activities involving patients, carers and other members of the public demonstrates a very broad commitment from the NHS Board, and from managers and staff across all parts of NHS Highland.
- The Public Engagement Team, with the involvement of public partners, managers and staff, have developed and circulated new Communications and Engagement guidance. The guidance contains golden rules, hints and tips in an easy to use format, and also includes some sample documents to support evaluation of methods used, and to encourage feedback from participants.
- Providing equality and diversity training for NHS staff through out Highland. Courses are designed to support staff in the provision of healthcare that is fair for all and sensitive to each and to ensure that all NHS Highland staff are supported in their work.
- The ability to link into a wide range of patient and carer groups, and other community-based organisations who are very willing to get involved.
- The regular face-to-face Public Partnership Forum meetings in Argyll and Bute, which involve both the public and NHS Highland staff, are developing a better understanding of the needs of local communities.
- The Remote Service Futures Project run by the Centre for Rural Health. This included developing a health care service planning exercise for remote and rural areas to allow them to consider hypothetically the future of locally based healthcare services, and to explore the following:
 - the health needs of the community, based on hard evidence
 - the current budget for local healthcare services
 - the clinical and other caring skills required for the community's needs
 - the opportunities and constraints associated with different types of staff
 - the community's priorities and preferences

- the difficult choices and decisions that health care managers have to make
- Ongoing work to develop and update the NHS Highland website, for example:
 - developing a carers section
 - promoting local or national consultations through the “Hot Topics” section, with all necessary documentation and appropriate links to allow people to become involved and contribute directly to the consultation,
 - Learning and good practice from consultation exercises is recorded and shared via the Getting Involved section of the website,
 - A helpful guide has been prepared and is available on the website, explaining to people the various ways in which they can get involved (Public Partnership Forum, Patient Participation Groups, Patients’ Councils, Scottish Health Council Local Advisory Council member).

1.4 Where further work is required

- Complete the survey of NHS Highland staff experiences of working with patients and the public, and from this develop recommendations to target direct support and training and ensure efficient use of resources.
- Implementing “Better Together” the national Patient Experience Programme, during 2009.
- Contributing to the development of the national Participation Standard, identifying and responding to the associated training and support implications.
- Influencing the development of the national Volunteering Strategy.

1.5 How public/patients have been supported to be involved and the difference it has made

NHS Highland leaders, managers and staff provide many forms of support to individuals and groups. The corporate NHS Highland Public Engagement Team provides direct support, guidance and facilitation to promote good practice in working with patients and communities, assisting front line staff to develop further their own knowledge, skills and confidence. Examples given previously (Self- Assessment 2007-08¹) are still relevant but for additional examples in more detail please refer to the case studies.

¹ www.nhshighland.scot.nhs.uk/GetInvolved/HowHaveWeDone/Pages/ScottishHealthCouncilAssessment2007-08.aspx

Part 2: Case Studies

Objective 1	Patients, carers and the public are assisted to locate information about health and health services.
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1a Implement the Carers' Information Strategy Action Plan

How patients, carers, others were involved in the piece of work, what they did, how they contributed, what was the impact of their involvement/contributions?

Within the area of Highland Council and in partnership with the Council, Carers have been involved in the development of the revised Highland Carers Strategy and the new Highland Carers Information Strategy through consultation sessions facilitated by the Highland Community Care Forum during 2007 and 2008.

Carers were initially asked to identify the key outcomes they felt would make the biggest difference to the lives of carers living in Highland. They identified 17 outcomes they felt were important. These outcomes formed the basis of the key objectives within the Integrated Carers Strategies Implementation Plan which was produced in August 2008, so their involvement has been crucial to the development of the Plan.

A key action within the Integrated Implementation Plan for 2008/09 is to engage more widely with stakeholders, especially carers, to secure their involvement in the ongoing development and monitoring of the Implementation Plan to ensure that it delivers on the key outcomes identified by carers in Highland.

A Stakeholder Forum is in the process of being established with representation from carers across Highland. The Highland Carers Project will continue to use their Carers Network to engage and involve those carers who are not able to participate in the Forum in person in the ongoing development and delivery of the Implementation Plan actions.

What worked well or less well – methods, techniques, positive and/or negative feedback from participants?

The local, facilitated sessions for carers appear to have worked very well because of volume of information which came back from them. The independent facilitation undertaken by the Community Care Forum staff seems to have encouraged carers to discuss issues openly because of the friendly, informal nature of the sessions.

The feedback received from carers about the consultation process has been positive. For those carers who were not able to come to the local sessions, the Carers Project used their Carers Network to distribute information and gather feedback from them.

Any learning points for the future

Consultation with carers needs to be done locally and in a variety of ways as carers often find it difficult to attend meetings. Increased use of the internet for the delivery and sharing of information, and for consulting with carers will enable many more to become better informed, and involved in the delivery of services and other forms of support. Work is underway to improve the information available for and about carers' issues on NHS Highland's staff intranet and public web sites to improve the accessibility of information for carers.

For further information contact: Jan Baird, Director of Community Care,
Tel: 01463 704908.

1b Implement the "Sharing Information and Knowledge" Action Plan

Information literacy

Information is one of the essential ingredients which enables people to understand and manage their own conditions. Information literacy (IL) is a key skill which improves skills and confidence in finding and using quality assured information. Two NHS Highland activities are in progress to develop staff and patients' IL skills, to assist them in locating quality information about health and health services. The Princess Royal Trust Highland Carers' Project, hope to make use of this with the unpaid carers they work with. Their input to initial evaluation will be invaluable.

How patients, carers, others were involved in the piece of work, what they did, how they contributed, what was the impact of their involvement/contributions?

A Health and Wellbeing zone in Fort William Public Library is to be launched in March. It is a partnership between NHS Highland, Highland Council and Macmillan Cancer Support. It will provide a wealth of health information for people. A stakeholder event was held in Fort William Library on 26th November 2008, over the afternoon and evening, to seek individuals' involvement in the design and development of the new service.

We were keen to find out, for example, what information individuals might look for and in what format; would they prefer a drop-in service or an appointment system; would they prefer to be approached when they came in, or left to browse. As well as a general invitation across Fort William (via the media, posters, radio announcement), specific invitations were sent to carer and voluntary organisations and cancer services groups. Despite the small numbers, those who attended wish to maintain their involvement as the project moves forward.

The partners, plus NHS Education for Scotland, have developed "Cancer Information+", a patient information web site. As part of the promotion of the zone, patients and carers have been supported to learn IL skills to help them access quality online health information. Sessions are also planned for a Cancer Patient group in Thurso.

Cancer Information+ website

Patient groups were involved in shaping the content of this new web site, in particular by highlighting the need for non-medical information. The site is due to launch in March 2009, and will provide patients and carers with round the clock access to good quality information about cancers, as well as information on emotional and practical issues such as work and finances. The site will also provide maps of cancer help lines and support for patients, and the network of information points available to patients, e.g. public libraries.

For further information contact: Anne Gent, Director of Human Resources
Tel: 01463 704865

Objective 2	Implementation of the recommendations of the national Remote and Rural Steering Group is informed by patient and public involvement at local level
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Identified areas of service change affecting local community hospitals during 08/09

2a Cowal Joint Older Peoples' Service Plan

How patients, carers, others were involved in the piece of work, what they did, how they contributed, what was the impact of their involvement/contributions?

Patients, carers and other members of local communities have been contributing to changes in local services for older people. The aim is to shift the balance of care for older people so that services support people to remain safely at home for as long as possible, and to provide a range of modern local hospital services as part of an integrated local health service. Members of the Cowal Community Care Forum, the Public Partnership Forum, voluntary groups and other members of the local community have been working with staff from NHS Highland and Argyll and Bute Council on forming a Joint Older People's Group, and leading the development of a plan which addresses the needs of our growing elderly population.

Care in the community and the ability to stay at home with the required support is a right of older people, but is it not currently available to all. In order to provide improvements in community care services it was clear that we would need to shift some resources from hospital into community based care. Through a whole range of dialogue, events, and engagement work we spoke to patients, carers and interested groups, such as the Elderly Forum. Dialogue was based on exploring the rights to home based care, the choices for older people when they become unable to remain in their own homes, and the role of the local hospital in supporting the wide range of healthcare needs of older people.

Patients, carers and other local people were initially very concerned at the idea of losing some local hospital beds, although most people agreed with the value of improving community care. People had understandable fears about what would happen to older people who need long term care as well as concern about the implications for existing hospital staff.

One key event was a "Choices" day with participants from the Joint Older Peoples Group and local staff so that the Plan was informed by the community and staff working together on finding local solutions to the gaps in community services. Feedback and comment indicates that the majority of the community and all of the staff affected understand and support the aims of this work.

What worked well or less well – methods, techniques, positive and/or negative feedback from participants?

We used factual newspaper articles to raise awareness of the work in progress, and to provide information about why this was happening and the benefits we are aiming to bring to older people in the area. Feedback from local people and groups helped us to identify key groups who had particular concerns, some of whom were concerned about any change affecting hospital bed numbers.

We had an outreach session with the local Elderly Forum to share information and to explore issues, questions and concerns. In addition, members of local community groups were invited onto the working group, and were supported through 1-1 meetings where we were able to reinforce and clarify any points or questions from community members. We also had a multi stakeholder event where staff and community members discussed and debated the aims, and the associated issues or concerns. This was helpful in coming to a common agreement on key points. It was also important in reassuring people about the future.

Comment from patients, carers and older people highlighted a real fear that there would not be hospital care there if they need it. We made it a priority to spend time with older people to reassure them that hospital care will continue to be available at times of illness. This included the meetings outlined in the paragraph above, and through contact with individuals. In addition the local Cowal Community Care Forum and the Public Partnership Forum made this topic a regular agenda item at their meetings and were very helpful in conveying any questions or issues to us. It was important to help people to understand that the aims of this work are to have better services to keep people well, to enable them to remain at home even when they need greater healthcare input, and to have an appropriate range of clinical care available at their local hospital when admission is unavoidable.

Any learning points for the future

There is ongoing dialogue with the community. We are currently planning a mapping process which makes clear to an older person how they can access support and care, and the options available to them so that they can make informed choices about their individual situation.

For further information contact: Viv Smith, Locality Manager
Tel: 01369 708345

2b Modernising hospital care and facilities in Sutherland

Background

Work has been progressing towards replacing the old Migdale Hospital with a modern facility capable of supporting modern healthcare to local people. The hospital currently has 12 GP-led beds serving Central and West Sutherland, and 12 mental health beds for older people providing a service to the whole of Sutherland. In addition to improving the care environment, the development will improve the rehabilitation service which is essential to promoting recovery, independence and self care.

Planning permission has just been passed for a new hospital in Bonar Bridge, Sutherland. The site which has been identified is close to the GP surgery and local day centre. A design team was tasked with drawing up plans for the hospital, with input from the Project Team which has been in existence for several years to progress the Sutherland Older Adults Business Case. The Project Team includes members of Migdale Hospital staff and a representative from the Migdale Action Group who is also a community councillor.

How patients, carers, others were involved in the piece of work, what they did, how they contributed, what was the impact of their involvement/contributions?

2008/09 has been a time of considerable public involvement in the plans for the replacement hospital. The whole development process is being led by a Project Team which includes a member from the Access Panel and a public partner from the local community working alongside the technical partner (architect) and NHS staff. Local people were kept informed by the Project Team as the plans developed through local networks, and the plans were shared and discussed at a meeting with Community Councils on 11th August.

An open public event took place on Tuesday, 23rd September in Bonar Bridge Village Hall, in the afternoon and evening to allow people to view the hospital's plans. The hall was accessible to all and the timing of the event was to try and accommodate people with carer, family or work commitments. Letters of invitation were sent to a large number of individuals and community groups, asking that they also let others know of the event. Public notices were inserted in the local newspaper and notices put up in key local establishments, for example, the village hall, Migdale Hospital, GP surgeries, local libraries, local newsagents / Post Offices, churches and the North Highland Community Health Partnership website pages. Approximately 70 people attended the event and viewed the plans for the replacement hospital. People took the opportunity to ask questions of NHS Highland staff and members of the design team who were present on the day. 20 individuals completed an evaluation form following this event, and the feedback was very positive.

As a result of the above event a question and answer sheet was produced. This was shared with some HealthVOICES members who hadn't been

involved previously, to ensure it was written in a clear way that addressed the majority of questions people might have. The question and answer sheet was distributed widely through Sutherland community groups and sent individually to those who had provided addresses on their evaluation forms. It is also available on the North Highland Community Health Partnership website page, where there is a section dedicated to this development.

There is ongoing dialogue with local patients and community groups. For example, in January 2009 the Locality General Manager joined a Friends of Migdale Hospital meeting to keep people updated on progress. There are also regular articles in the local newspaper.

What worked well or less well – methods, techniques, positive and/or negative feedback from participants?

- Having public involvement in the Project Team, which has overseen the full Sutherland Older Adults Business Case.
- Being clear in the publicity and at the event that the September open event was an opportunity to view the final plans, and to inform people that they had been developed following NHS technical guidance and with creative input from staff and public partners.
- Regular use of the local media to keep the public well informed.

What next?

- Individuals who attended the event in September 2008 were given the opportunity to be involved as the hospital developed e.g. input into the design of the outside space, art for the hospital communal areas. From this we have identified volunteers for the ongoing work.
- There will continue to be regular updates in the local media as building starts and progresses.

For further information contact: Georgia Haire, North Highland Community Health Partnership Locality General Manager.
Tel: 01408 664031

Objective 3	NHS Highland develops better knowledge of methods of engaging with service users and carers who have specific needs or lifestyles, and for whom we need to find imaginative approaches to promote inclusion in service design and delivery
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3a Implement updated local guidance for staff in communicating and engaging with the diverse population

Communicating and engaging with patients and communities occurs at every level across NHS Highland. Although many managers and staff are skilled and experienced in using the wide range of methods and tailoring them for individual purposes, others are less experienced, and perhaps unsure where to get help. The aim was to produce a short, simple guide to help staff plan and deliver effective communications and involvement activities as part of their day to day work, and to assist them in evaluating the methods used.

One of the most important aims was to help staff to recognise the need to target people who are less visible, and less frequently heard, and to equip staff with some tools and techniques to help them engage people in ways appropriate to their personal needs. With the help of a group of public partners, managers and staff, new guidance was completed, and launched in December 2008. The guidance contains golden rules, hints and tips in an easy to use format, as well as sample documents. We are now investigating the potential of a new software tool to assist in recording engagement actions in a more systematic way using the Visioning Outcomes in Community Engagement (VOiCE) tool.

For further information contact: Gill Keel, Head of Public Engagement
Tel: 01463 704775

3b Continue learning from public feedback and experience, and incorporate into future practice

Three of the key findings from experience of working with patients, carers and communities are:

- Be imaginative and creative – people have many individual preferences about how they wish to get involved, so don't be afraid to try something new.
- People with complex health and / or social issues are the people we most need to hear from, but often the least likely to get involved, so careful planning with relevant experts is essential.
- Find out who can help - tap into the expertise and the networks of the wide range of voluntary sector, service user, carer, and other expert groups to make the most of our combined energies.

These are particularly important in relation to people who are less likely to be heard or actively involved. The following paragraphs provide a few examples of actions in NHS Highland during 2008/09.

(i) Children and Young People

Highland Children's Forum has been leading the development of an on-line library of tools and techniques to promote engagement with children and young people, particularly those with complex communication needs. Once this website has been finalised, we will promote awareness across NHS Highland staff, for example through our own staff intranet and will signpost staff to these web resources through the above NHS Highland Communication and Engagement Guidance.

For further information contact: Nicola Morrison, Project Manager
Tel: 01463 704862

(ii) Health & Homelessness

Many people and families who are homeless have a number of health and social problems as well as not having a home. We know that there can be very real barriers between people who are homeless and the services they need, and that there are many reasons for people who are homeless not giving direct or indirect feedback or comment about their experience of the services they do use. A key part of the NHS Highland Health and Homelessness Action Plan (joint plan with the two local Councils and voluntary sector partners) is to raise staff awareness of the impacts and health consequences of homelessness, so that this insight helps to inform and influence working practices and systems.

In connection with this, a group of people affected by homelessness were brought together in November 2008, to feedback on their real experiences of services, and to describe the obstacles they face trying to reach the care they need. Key to the success of this group discussion was the decision to work through a known and trusted intermediary – someone who is seen as independent of the NHS, and with whom the participants felt comfortable and able to talk freely. The personal stories and other comments from participants were fed into multi-agency workshops in March 2009, bringing their voice, their messages and their challenge directly to those who provide services and support people affected by homelessness. These sessions were organised in partnership with the Scottish Health Council and will include an evaluation to assess the impact on staff of these messages.

For further information contact: Margaret Brown, Policy Development Manager
Tel: 01463 704913

(iii) Equality Schemes

The progress of long term engagement mechanisms between NHS Highland and equality groups continues to evolve. Working with community planning partners we distributed over five thousand questionnaires across the region building up a picture of attitudes, values and experiences of people in

Highland in relation to race and ethnicity. The results formed part of the NHS Race Equality Scheme. Over 100 local disability and equality groups were involved in the development of guidance to help NHS Highland staff make services more accessible. As a result the document is already being cited as good practice locally and nationally.

We have also been working with other Boards to engage with new residents in Scotland from Central Europe, to help improve understanding of the impact of cultural issues on perceptions of care and service provision. This has resulted in the development of resources that are being distributed across all Health Boards in Scotland.

A piece of work is also underway with community partners to identify how we can strengthen community involvement and engagement activities over the coming year, with a particular emphasis on working with equality groups. Outcomes of this work will inform the development of services.

For further information contact: Esther Dickinson, Policy Development Manager
Tel: 01463 704791

(iv) Violence Against Women

The need for a Violence Against Women Strategy has been identified locally by agencies and practitioners and at Government level. As well as tackling a major inequality that women experience, the 2008-11 Highland Violence Against Women Strategy will go some way to fulfilling public agencies' obligations under the Gender Equality Duty and in the promotion of women and girls' human rights.

The draft Violence Against Women Strategy was circulated to a number of statutory and voluntary partners. To maximise participation and accessibility, three consultations ran concurrently on the Strategy – one on the full document and one on the framework. The third ran for service users, who were supported to complete the respondent information by the support organisation they were involved with.

We were keen to ensure that service users were engaged in the whole consultation process and wanted to provide them with a space within the consultation to discuss their own experiences of services in Highland. We realised, however, that this may not be simple as many women who have experienced abuse are reluctant to come forward, for a number of reasons, including fear of the perpetrator, fear of not being believed and shame at what has happened to them. To assure service user involvement we used contacts within the support services to talk women through the consultation itself and we used a number of different methods to advertise the consultation to the wider community, including local newspaper coverage and highlighting the consultation on statutory agency websites.

A positive outcome from the process has been the inclusion of a number of targets within the Strategy to develop a service user consultation framework. This will ensure that services can continue to be developed and informed by the real experiences that women, children and young people in Highland have had.

For further information contact: Gillian Gunn, Development Training Officer
Tel: 01463 704814

(v) Email Discussion Forum

In December 2008, the Scottish Government launched its public consultation on “Arrangements for NHS Patients receiving Private Healthcare”. Although this topic is relevant to everyone with an interest in the NHS, the issues and questions behind the consultation proposals were very complex, and we were concerned that few people would respond. In addition, the timescale for this consultation was short at only 4 weeks, and that period included seasonal holidays around Christmas and the new year. Our plan for encouraging patient and public comment and feedback was therefore based on an email discussion forum.

We targeted an identifiable group of 16 well informed individuals i.e. people involved in NHS Highland’s Area Drug & Therapeutics Committee and its various sub-groups, the Area Clinical Forum, and the public partnership forum members of the Governance Committees of the Community Health Partnerships and Raigmore Hospital. Our role was to seek the individuals’ agreement and then set up a group email. We did not use a moderator, so the participants were able to share comments freely with each other. It was time limited to one week in order to stimulate rapid exchange of views and replies between the group. Of the 16 approached, six members participated actively. Once the first comments were circulated, others responded and they bounced ideas and views around the group.

At the end of the discussion, our role was to collate the feedback into a report which was forwarded to the Scottish Government. Although this was a very rapid piece of work, the method worked well for those who participated, and the group were able to provide a response in spite of the very technical subject and the short time allowed.

For further information contact: Nicola Morrison, Project Manager
Tel: 01463 704862

(vi) Staff evaluation

A survey of NHS Highland staff is in progress to assess their experience of involving patients, carers and public partners. This follows suggestions from public members of the Highland HealthVOICES Network Steering Group. It will help to identify the learning and development needs of staff to enable them to support public partners to participate in a constructive way, and to recognise and value their diversity. The survey responses will also illustrate

the value and the difference made by people's involvement. The evidence provided will give an indication of the kind of support public partners typically require, and will indicate where the corporate Public Engagement Team should focus supporting actions. The survey has been developed jointly by a member of the public with research experience, the Clinical Effectiveness Team and the Public Engagement Team.

For further information contact: Karen Burnett, Public Engagement Team
Tel: 01463 704702

3c Identify learning from feedback and experience of involvement in development of Hepatitis C care pathways

This is a 3-year Action Plan so while the work is at a relatively early stage, there has been significant learning about engaging with some of the key target groups most likely to be affected by Hepatitis C. This includes people who are or who have been intravenous drug users, their partners, and their children. The aim of this work is to develop a care pathway to guide people into health screening and treatment services.

The development process was launched at an initial stakeholder day in June 2008, with a mix of health professionals, voluntary organisations, service users and others interested in contributing to the development of a clinical network for Hepatitis C.

In order to recruit people with real insights and experience, we drew on the networks and knowledge of voluntary sector contacts who work closely with current and former drug users, as well as the more general methods of circulating information, publicity and materials. From this, two volunteers became actively involved. At the very first stakeholder day, the volunteers set the scene for the professionals through an interview style presentation. They described the real impact of the attitudes of staff and of friends, and talked about the complex mix of questions, concerns and potential barriers to progressing with treatment. In this way, their experiences and insights were able to inform each of the working groups which emerged.

A subsequent workshop was then held with the volunteers and some of the voluntary agencies on Patient & Public Involvement to explore how to raise awareness of Hepatitis C and the impact it has on health; the challenges e.g. stigma, attitudes, how to reach people; how we can work together across the existing networks and groups. It was agreed that the volunteers and the voluntary agencies would be integral to each of the work streams developed from the Stakeholder Day e.g. directly involved in developing care pathways, as well as on the Hepatitis C Steering Group.

With the input of the volunteers, a public awareness poster for Hepatitis C has been developed. The volunteers are working with the Public Engagement Team in finalising a wide distribution list for these posters e.g. GP surgeries, hospitals, Council Service Points and wider list of venues e.g. public toilets, Pubs, Barbers, Sports Centres, and Job Centres.

The Scottish Drugs Forum (SDF, Highland office) have been commissioned by NHS Highland to carry out a survey with service users to determine patient experience of referral, access, treatment, staff attitude, follow-up, advice, etc. This is almost finished and it is expected that, as well as being designed with service user input, the surveys will be carried out by volunteers, with appropriate back-up from the voluntary sector. The survey will be carried out across NHS Highland's area.

Under 'Your Health' on NHS Highland's website, a Hepatitis C section has been created. Through this, we hope to further our awareness raising work, offer people other sources / places of information and support; and through a short questionnaire, establish people's experience of using NHS services for Hep C. It is noted that this will reach out to a different sector of the population than the SDF questionnaire.

A proposal has been developed to try and educate young people in the risks of Hepatitis C and what it is like to live with it. The proposal is that those in upper secondary schools would, after some time with volunteers, take on particular roles in a setting of their choice (e.g. family wedding, first date, talking to parents, etc) and write their own short drama piece, for delivery to their school peers. Again, this has sought the involvement of volunteers in the development of the proposal and will involve them in the successful delivery of this exercise.

NHS Highland has recognised the challenges in reaching this group of patients and those potentially living with or at risk of this virus and are pursuing different methods to engage and inform them, directly and indirectly. We are very much reliant on the good relationships we have with the voluntary agencies and the links and trust they have built in communities and with service users.

For further information contact: Nicola Morrison, Project Manager
Tel: 01463 704862

3d Implement locally "Better Together", the national patient experience programme

The Better Together programme aims to ensure that feedback from patients about their experiences of healthcare leads to improvements in the quality of care. This work is being led by a national project team, and our role is to support them in the development and subsequent implementation of the patient surveys and other methods of gathering feedback.

As part of the development stage, NHS Highland welcomed the efforts of the Scottish Health Council to ensure that local patients/ residents participated in reviewing an early draft of the first inpatient survey. Local people also participated in a national event run by the Better Together team in November. At the time of reporting, there is further preparatory work in progress through the national team, and the first patient survey is due to start in autumn 2009.

For further information contact: Nigel Hobson, Associate Director of Nursing
Tel: 01463 704786

Objective 4	Implementation of the Community Health Nursing project in the pilot sites is informed by patient and public involvement at local level
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Background to Objective 4.

Following extensive engagement with communities across Scotland, the Community Health Nurse is a new role being developed in a number of pilot areas across Scotland. The key aim of this work is to provide a long term future for accessible community based care, taking account of the changing needs of communities – our ageing population and the increasing incidence of long term conditions such as diabetes, heart disease and stroke. The pilot areas are each developing local, team based community nursing and healthcare, and contributing to the development of new training and education programmes for community nurses of the future. The following paragraphs outline some of the patient and community involvement in Badenoch and Strathspey and in Thurso.

4a Badenoch and Strathspey

How patients, carers, others were involved in the piece of work, what they did, how they contributed, what was the impact of their involvement/contributions?

Much of the recent work has been on developing a profile of the health and social needs in the area, as this is essential to informing the project. This requires hard evidence which is being gathered from a variety of existing sources - census information, council household survey, epidemiological and demographic data. Once this piece of work is finalised, staff, patients and the public will be brought together to consider what this then means for local services – how should they be shaped and what supporting structure is required to deliver these.

In the meantime, in order to raise awareness generally that this work is in progress, the national leaflet has been adapted for local use, with key names and contact details for further information or questions, and these have been distributed to local people through local community networks.

What worked well or less well – methods, techniques, positive and/or negative feedback from participants?

This is at an early stage. There has been general awareness raising, but other information gathering has to be completed before we can have informed dialogue with local patients and communities.

Although the Local Implementation Group leading this work has approached some local community groups, they are finding that the local groups tend to have a very specific interest, and will need additional support to become involved.

Any learning points for the future?

- Judging when to get people involved can be difficult. It is important to have enough information for a constructive dialogue, but it can be difficult to avoid the risk of people feeling left out.

For further information contact: Hilda Hope, Lead Nurse SE CHP
Tel: 01463 706947

4b Thurso

How patients, carers, others were involved in the piece of work, what they did, how they contributed, what was the impact of their involvement/contributions?

A key event to raise awareness of the project was an open event held in a central, accessible location, the Pentland Hotel in Thurso in November 2008. This ran between the afternoon and evening to accommodate as many people as possible. Display boards, posters, patient information leaflets, presentation and evaluation sheet (incorporating a form to encourage further feedback and contact details of the local Project Facilitator) was available on every seat in the hall. The event was advertised through press notices, posters and individual letters of invitation to identified interest groups / stakeholders. Approximately 40 people participated, a mix of service users, local staff, and members of the local press. A PowerPoint presentation was used to introduce the project and was well received. The presentation was followed by an opportunity to ask questions of Lead Nurse, Doreen Bell and Project Facilitator, Carena Macivor. People had many questions so we spent about an hour on this before tea and coffee were served. During the relaxed, informal coffee break, patients, carers, members of the Local Implementation Group and local staff circulated, and continued the dialogue. Useful comment and feedback was gathered from this. Feedback about the proposed nursing development was positive.

The following week there was a significant press report, of around half a page, in the local newspaper. This was a positive piece which also included contact details for the Lead Nurse for anyone wishing to give further feedback.

In addition, we disseminated information in local newspapers through reporting, press releases, and public notices. Display boards and posters are used in public areas such as GP surgeries, nurse clinics, library and hospital waiting areas. Face to face, communication and dialogue is ongoing. All written materials contain advice on how to get more information and how to feed in comments

A plain English Patient Information Leaflet has been distributed. This includes contact details for people to comment or feedback directly to staff or Project Leaders.

What worked well or less well – methods, techniques, positive and/or negative feedback from participants?

In July 2008, we conducted an exercise to identify the main groups of people affected by the project. The information gathered allowed us to develop a record of the main stakeholders, and we have used this to target information and communications, including invitations to events. However, this database needs to be reviewed and updated regularly to remain useful.

There is a Local Implementation Group (LIG) for the project which includes public members from local communities. The LIG is responsible for leading implementation of the Community Health Nurse pilot locally, and evaluating the outcomes. The LIG which meets every 6 weeks, has a communications and engagement plan that is reviewed regularly and updated in light of experience and feedback.

Reports of the LIG actions are shared more widely in the form of update reports from the local project facilitator. These are designed to be interesting and informative for patients, carers, the public, and staff / other professional groups.

Feedback has generally been positive, and people seem satisfied with the project proposals and the processes of communication and engagement.

Any learning points for the future

- Through the many forms of dialogue we have been able to respond to and address some concerns which people raised about service provision.
- We wish to encourage engagement and comment from a wider audience, so need to review what information is being cascaded to service users, and how.
- We are planning to review and clarify the role of the public members on the LIG to ensure shared understanding of everyone's role in communication and feedback systems.
- Additional aids such as loop system may be needed for service users communication (hard of hearing, other languages, young carers)
- There is a need to look at a variety of ways of reaching stakeholders who have specific needs or lifestyles to promote inclusion - use of plain English, use of other languages and styles of communication.

For further information contact: Carena Macivor, Team Leader West Caithness/RONC Facilitator Tel: 01847 893442

Objective 5	NHS Highland identifies learning from complaints, and improves practice through supporting and training staff
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5a Implement revised complaints recording and analysis

During 2008/09, the complaints team have been working with Information Services Division (ISD) on the development of a new national complaints database. Early in August 2008, NHS Highland started using this new database. There have been significant delays in ISD providing monthly reports which has prevented detailed analysis of complaints and the identification of learning points.

How patients, carers, others were involved in the piece of work, what they did, how they contributed, what was the impact of their involvement/contributions?

This specific action was for staff to implement the new national recording system so patients were not involved in that implementation process. However, the Complaints policy and procedures will be updated during 2009/10, and we will involve patients, carers, the Scottish Health Council (SHC), and staff of the Independent Advice and Support Service (IASS) in this piece of work.

Any learning points for the future?

One example of local work which complements the national complaints recording and reporting is from the North Community Health Partnership which conducted an audit of informal complaints. The results of this initial audit have been shared with the Scottish Health Council, and the local team are now planning a re-audit which will be undertaken in November 2009. Support will be sought from patients, the public and Scottish Health Council to revise the methodology and include both informal complaints and compliments.

For further information contact: Mirian Morrison, Clinical Governance Manager
Tel: 01463 706808

5b Specific actions (eg changes in working systems or practice, staff training) follow the identification of learning points from analysis of complaints

How patients, carers, others contributed through complaints, and what was the impact of the associated learning?

Learning which arises from the investigation of complaints is managed through NHS Highland's Clinical Governance arrangements. Each of the five operational units has a Clinical Governance and Risk Management Group where key points of learning from complaints are raised, and agreed actions implemented. In addition, the NHS Highland wide Clinical Governance Committee has an overview of complaints and the findings from investigation of them. The Committee receives regular reports on complaints. These highlight common themes and identify areas where action is required to address the issues raised by patients.

In addition, any complaint which is referred to the Scottish Public Services Ombudsman is discussed at the five local Clinical Governance and Risk Management Groups, and at other key Highland wide forums, including the main joint Management Team Meeting (the Direct Health Services Management Team). This helps to ensure that any learning is shared, and actions implemented across all parts of NHS Highland.

People who have made a complaint give feedback about the way in which their complaint was handled. This feedback has been reported recently to the Clinical Governance Committee, along with recommendations about improving communication with the patient or family, and improvements in how the outcome of an investigation is fed back to the complainant.

The following brief summaries present two examples of learning from complaints, and how these changed working practice.

1. Dignity and respect:

Following a complaint about dignity and respect in a care environment, it became evident that some staff did not understand the specific, specialised needs associated with this patient's condition. Staff were provided with additional training to help them recognise and respond to patients with these specialised needs. While this complaint related to an individual hospital ward, it highlighted the importance of developing an NHS Highland policy on privacy and dignity for all patients. (See Objective 6).

2. Protocol, training and policy development:

A complaint was received about some aspects of care at one of our hospitals. As a result of this complaint, a meeting was held with the family and the following actions were agreed:

- There would be specific communication training for nursing staff

- The hospital would review its Bed Management Policy
- The admission protocol will be reviewed to include asking the patient if they would like their condition discussed with the next of kin.

All actions have been implemented.

For further information contact: Lesley-Anne-Smith, Head of Clinical Governance
Tel: 01463 706912

Objective 6	NHS Highland staff recognise and respect patients' need for privacy and dignity
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Develop a local Privacy and Dignity Policy, through the direct involvement of staff, patients, carers and others

This has been a major piece of work which affects all NHS Highland staff and all healthcare users'. The need for this policy was identified through patient narratives and observations of care as part of the "Leadership at the Point of Care" programme. This is a professional learning programme for senior healthcare professionals from all parts of NHS Highland. The Better Health, Better Care Action Plan, (2007, Scottish Government) and results from several surveys of patients state that Privacy, Dignity and Respect are high priorities for healthcare users, carers and healthcare providers. Privacy, Dignity and Respect are inextricably linked to satisfaction of care and therefore should be an integral part of the delivery of individualised care.

How patients, carers, others were involved in the piece of work, what they did, how they contributed, what was the impact of their involvement/contributions?

Patients, carers and a wide range of healthcare workers, helped to identify the need for this policy, mainly through patient narratives (patients telling stories of their experiences) and through observations of care (sitting observing in a ward area, actively watching, using all the senses to observe all that is going on). In addition, we were aware of a formal complaint and many other informal expressions of concern about aspects of privacy, dignity and respect. A small group from Cohort 6 of "Leadership at the Point of Care" were nominated by their colleagues, to lead further work, and the Privacy, Dignity and Respect Policy Working Group was set up. The senior hospital chaplain is part of this working group and a Scottish Health Council Local Officer attended some of the meetings.

The Policy is now written, has been equality and diversity impact assessed, and is now ready to go out to wide consultation with people affected by the policy. Once there is a final version, there will be a launch and briefing sessions for all NHS Highland staff and it will be promoted to healthcare users.

This policy was devised to ensure all healthcare users receiving care within NHS Highland will have their rights to Privacy, Dignity and Respect acknowledged.

What worked well or less well – methods, techniques, positive and/or negative feedback from participants?

The working group analysed a lot of taped conversations with healthcare users, carers and NHS Highland staff, so their comments and experiences were driving this from the start.

We divided the policy content into manageable units and used the internet to find out what others had done. Interestingly we found nothing from Scotland by this method.

Having a small working group from varying backgrounds allowed the work to move forward at a good pace and inviting specialists as and when required. The time and energy from the working group reflects the priority they attach to this topic and their commitment to it. NHS Highland will soon have an up to date Privacy, Dignity and Respect Policy (including Chaperone Guidelines), a first for Scotland.

Any learning points for the future?

- Having taped conversations and notes to refer to from healthcare users, carers and staff had a huge impact on the shape of this policy.
- Having the commitment and support of the Board Director of Nursing, NHS Highland Board and the ongoing support of staff managers was essential, and greatly valued.
- Working in small groups on specific themes kept everyone focussed.
- After much discussion, we decided to adopt a logo for this policy. This will start to appear on products and publications.



For further information contact: Jennifer Lobban, Project Manager/Clinical Facilitator Leading Better Care.
Tel: 01463 704715

Objective 7	The redesign of mental health services in Argyll & Bute is informed by patient, carer and public involvement at local level
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Implement the redesign process and associated communications and engagement actions

How patients, carers, others were involved in the piece of work, what they did, how they contributed, what was the impact of their involvement/contributions?

This has been a major piece of work to redesign mental health services across Argyll and Bute. Service users and carers have been heavily involved from the very earliest stages, and have been engaged through a wide range of activities. The work has progressed in three distinct phases – phase 1 gathering information, phase 2 options development and appraisal, and phase 3 public consultation on the final list of options. A few details of the engagement are summarised here as an indication of some of the extensive pre consultation work.

One of the very early aims was to develop an understanding of what was most important to people, so that this information was shaping the redesign from the start. Approximately 70 people participated in individual interviews and group meetings from which was developed a list of key aims for services. These aims were a key reference point during the development and appraisal of options for the future.

This information gathering stage was also promoted through a series of launch events and public drop-in events held during March 2008. These events were important in promoting wider awareness of the work going on, and were a useful means of encouraging many people to get involved as it progressed. Approximately 80 people participated in these events, and their comment and feedback was added to that gathered through other means.

Members of local mental health user and carer groups have been directly involved in the redesign Project Board and the Project Team, so that there has been a voice from users and carers at every level of activity. A Project Newsletter “*Improving Mental Health Services*” was first published in April 2008 and monthly thereafter. These provided information about the redesign project, progress to date, information about up and coming key events, information on how to get involved, who to contact for more information and a summary of key discussion points from recent events. Each edition was distributed very widely across the area through user and carer groups and contacts, Community Councils, other community groups and voluntary organisations, and the Argyll and Bute Public Partnership Forum (PPF).

Phase two began with a Service User and Carer event to help prepare people for their active involvement in the work of developing options for the future of local services. Users and carers then participated in workshops on specific service themes, (e.g. primary care, community support services, preventing admission, rehabilitation, recovery, dealing with crisis, supporting discharge). The outputs from these were written up into a number of options. Users and carers were then involved in the options appraisal process so that their

perspectives informed the final list of options for public consultation.

Phase three the public consultation is now in progress.

What worked well or less well – methods, techniques, positive and/or negative feedback from participants?

Many of the diverse methods and techniques used worked very well, based on the evidence of people's continuing involvement and the direct feedback gathered from those involved.

The experiences demonstrated the importance of offering people a range of ways to get involved. For example, not everyone is comfortable participating in group discussions, or other face to face methods, so early on service users and carers were able to contribute to the information gathering through a questionnaire as an alternative to interviews or group discussion. Feedback from service users and carers involved also highlighted that the time scale for this was too short, so it was extended to enable maximum participation. A total of 78 pre-consultation questionnaires were completed, and people also replied through emails and letters, providing additional comments.

Any learning points for the future?

The process of appraising the options is complex, demanding, and time consuming, but it was essential that users and carers and others were directly involved in this process. Users and carers were supported to participate by facilitators, but in the event, it was clear that extra time was required to complete the complex tasks involved. The learning points from this exercise have since helped to shape new guidance for the NHS on involving people in options development and appraisal.

For further information contact: Caroline Champion, Planning and Public Involvement Manager, A&B Community Health Partnership
Tel: 01546 605680

*The Scottish Health Council agrees that this self assessment represents a fair and accurate account of the progress made in the last year by NHS Highland in relation to Patient Focus and Public Involvement.
13th May 2008*