



NHS WESTERN ISLES

PFPI SELF ASSESSMENT

REPORT

2008-2009

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SCOTTISH HEALTH COUNCIL VERIFICATION

PATIENT FOCUS PUBLIC INVOLVEMENT ANNUAL REPORT 2008-09

SUMMARY

1. Governance Arrangements. The Designated Director for Patient Focus Public Involvement is the Nurse Director/Chief Operating Officer. There is a full time Patient Focus Public Involvement Development Officer based in the Health Board Offices. NHS Western Isles Health Board has established the Patient Focus Public Involvement Committee as a governance committee of the main Board to monitor and direct Patient Focus Public Involvement work across the broad spectrum of its healthcare activities. The Committee is composed of lay representatives and Health Board officers, chaired by a Non-Executive Director. Meetings are held every 2 months; the minutes are presented to inform the subsequent Board Meeting. The Patient Focus Public Involvement Committee oversees the compilation of the annual Patient Focus Public Involvement self assessment report for the Scottish Health Council and the Patient Focus Public Involvement section of the NHS Western Isles Annual Report. It produces an annual report of its own activities for the Health Board.

2. Public Partnership Forum. In NHS Western Isles the Public Partnership Forum has two main components; the People's Health Network and Locality Planning Groups.

a. The People's Health Network is a database of people who want to contribute to the work of NHS Western Isles by providing advice and comment on those aspects of healthcare in which they have a particular interest. The People's Health Network is a virtual network and communication with members is carried out principally by email and by post. On registration members are asked to indicate which health services they are interested in, for example children's health, diabetes, and how they would like to be involved, for example attending group discussions or meetings, reviewing documents and policies or completing written questionnaires. The People's Health Network is supported by a Steering Group. The Steering Group includes a member of the People's Health Network; it meets quarterly to monitor, assess and develop the membership and use of the network by colleagues managing and providing services. The Steering Group initiates action to promote the network amongst the public and service providers. Through the People's Health Network, an elected public representative should be nominated to sit as a full member of the Community Health and Social Care Partnership committee.

b. Locality Planning Groups have been set up to ensure the public have an active part to play in the planning of their services. They:

- Engage with the wider community to ensure views are properly representative.
- Ascertain, co-ordinate and express the views of the local community.
- Receive papers for comment from other Community Health and Social Care Partnership groups and committees.
- Receive information on new services at a planning stage where appropriate.
- Provide recommendations via Community Health and Social Care Partnership to local public authorities on local services.

The Locality Planning Groups are situated within the main centres of population, and meet quarterly. They receive support from the Community Health and Social Care Partnership but they are run by their own elected members. Each Locality Planning Group has a seat on the Community Health and Social Care Partnership committee for an elected representative of the Group.

3. What Has Worked Well in Progressing Patient Focus Public Involvement.

a. The recognition that our Public Partnership Forum has the two main pillars of the Locality Planning Groups and the People's Health Network has been a major conceptual step forward in promoting and enabling public engagement with our design and delivery of health services. The previous arrangement had a serious shortcoming in that there was little mutual interaction between members of the People's Health Network; the network had been established as a virtual network because of considerations of geography, and of the fact that many members expressly did not wish to attend meetings – it was difficult to find ways of increasing the networking activity required from a Public Partnership Forum. The inclusion of the Locality Planning Groups addresses that concern.

b. The intimate involvement of patients and the public has been beneficial to our development of a Clinical Strategy for the delivery of healthcare in the Western Isles as shown in case study 7. We tried involvement both by specific invitation for focus groups and by holding open public meetings. Both were successful in their own way, although there was some criticism of the language used in the information provided for the open meetings.

c. The success of the open X-ray clinics last year prompted a similar initiative in the Western Isles Hospital Physiotherapy Department which enabled patients to self-refer to the service for assessment and treatment, thus cutting waiting times and providing easier access.

d. For those who require an extended stay in hospital, keeping the mind active is positive for improved outcomes. The traditional books and magazines are always useful and welcome but many people now find pursuing their interests and hobbies online is a real advantage. In response to requests from patients we have found a way to provide access to the internet for patients in the Western Isles Hospital and hope to extend the service to the Uist and Barra Hospital in the near future.

4. Where Further Work is Required. The nature of the relationship and working agreements between the Community Health and Social Care Partnership, the People's Health Network and Locality Planning Groups needs to be revised and clarified in short order to reflect the change in emphasis. The inclusion of a brief introduction to Patient Focus and Public Involvement in induction training for all staff has raised awareness and will continue to do so – further training in communications for staff has been developed but not yet delivered in any significant quantity. Extending this raising of awareness amongst the community will be the priority for 2009-10.

5. How public/patients have been supported to be involved and the difference it has made. Our public/patient representatives have their travel and carer costs reimbursed to ensure that their willing investment of time and energy in involvement projects need not leave them out of pocket. Our public meetings are held in accessible venues, we have offered assistance with travel. Where practicable we offer local meetings in varied timeframes to allow the maximum attendance by different groups; a good example was the process used to share this report with the community – two meetings were held, one in the morning and one in the evening to facilitate wider attendance. Locality Planning Groups initially receive some admin and secretarial support from the Community Health and Social Care Partnership although the hope is for them to become self-supporting.

PROGRESS AGAINST ACTIONS FOR 2008-9

CASE STUDIES

6. This account of case studies was considered and approved at public meetings attended by members of the People's Health Network, Locality Planning Groups and by members of patient and community groups in a combination of face to face and email/postal response.

7. Case Study 1 - Diabetes Managed Clinical Network. The agreed action was “undertake a survey of the diabetes retinal screening (DRS) programme by targeting 15% of patients registered with each GP practice”. Whilst we believed we had designed a new and improved DRS Service we understand that it is the users who are the only ones qualified to comment on whether it met their needs. We wanted to hear from them exactly how they felt about it and so the DRS sub-group designed a survey which was approved by the MCN. This was distributed to 150 randomly selected service users from each of the 13 GP practices.

We were pleased to receive 84 out of the 150 surveys completed, a 56% return. The results were analysed and have been included in the DRS Annual Report 07/08 which can be found on www.diabetes-hebrides.org.

The results make very positive reading with the majority of those surveyed coming between the “very satisfied” and “satisfied” category. Individual comments have been looked at and have been very encouraging. The few “negative” ones will be discussed at the next MCN meeting in April 09. If any areas have been highlighted as unsatisfactory and there are ways to improve them, then we will seek resolutions and implement these as soon as possible.

The DRS Annual Report which includes the survey analysis has been sent to all MCN members and will be tabled at the next MCN meeting on the 14th April 09

8. Case Study 2 - Cancer Support. The Cancer Focus Group of Lewis and Harris (CFG) has met regularly with Gill Chadwick, Macmillan Lead Cancer Nurse NHSWI continuing to discuss work plans for the group. CFG membership comprises of people affected by cancer, not necessarily those who have had a cancer diagnosis. It encompasses family, friends and carers as well as current and past patients.

Discussions among the Cancer Focus Group about some of their own poor experiences led them to suggest the need for some training for clinicians in the breaking of bad news. The slides used

in the 'Breaking Bad News' teaching sessions were written by Gill but were amended by members of the group following its presentation to the group. Teaching sessions have been delivered in the Western Isles Hospital (WIH) and in Bethesda Hospice. Attendees at these sessions have included medical staff (all levels), nursing staff and Allied Health Professionals and some students. A further session is booked for June for the latest 'batch' of new doctors in WIH. Gill has adapted the teaching session for delivery to a public/patient audience as requested by members of the group. A date has yet to be set for this presentation.

Following discussion with the Head of the Dietetic Department, CFG members are considering the development of a leaflet to help signpost people with dietary concerns to areas of help. This would be in line with the previously published 'so now I know I have cancer', i.e. offering information on available resources rather than re-inventing the wheel. This booklet is featured on the Scottish Health Council's Evolving Practice website. Having seen another booklet on that website about guidance for patients who may be stranded at a mainland airport, CFG members are contributing to a local version - this is a topic close to several members' hearts as some have experienced this problem.

CFG members are enthusiastic about and very appreciative of the work of the Maggie's Cancer Care Centres on the mainland and are exploring ways of a similar development for all people of the Western Isles with a life-limiting and /or life-threatening condition.

9. Case Study 3 - British Heart Foundation Nursing Team. The Heart Failure Service has been steadily expanding with 10 new referrals each month. Correspondingly, the service provided has been expanded to meet the need. To help to provide evidence to support a continuation of this service a survey of patient satisfaction and another of clinical effectiveness was undertaken. The patient satisfaction survey questionnaire was designed with the patients in mind – it was circulated to users for approval and/or amendment to provide assurance that this aim was met. The response rate was very high at 90% with very high levels of satisfaction expressed by both patients and carers. The results of both surveys will inform the submission to NHS Western Isles in a bid to continue funding for this service.

10. Case Study 4 - People's Health Network. There were two agreed actions under this heading:

a. To promote networking activity among members. Much of the Public Partnership Forum work has already been reported on in earlier sections of this report and rather subsumed the first action – the networking event held in conjunction with the Scottish Health Council showed us that good networking opportunities already existed in the guise of Locality Planning Groups. The People's Health Network was established as a virtual network precisely because members preferred correspondence over attending meetings. Networking opportunities in the shape of the regular Locality Planning Group meetings will be signposted to members.

b. To ensure that a representative sits on the Community Health and Social Care Partnership committee. Following the resignation of the elected representative the seat has been filled by the deputy chair of the Community Health and Social Care Partnership,

who is a People's Health Network member. No election was held because of difficulties with administrative support. This shortcoming will be rectified at the earliest opportunity.

11. Case Study 5 - Mental Health Issues – Extracts from An Cliseam Project. An Cliseam Project is part of the National Leading Change Programme, Delivering for Mental health. The project aims to improve the mental health and wellbeing of older adults living in the Western Isles by developing and improving local services and facilities for them. The Project started in March 2008 and encompassed three separate, but interlinked strands. The project team consists of a multiagency group representing the Voluntary sector, the Health Board and Comhairle nan Eilean Siar.

a. There is the Evidence, Audit, Research strand which is looking into the impact of bilingualism on dementia – there is a possibility that being bilingual can delay the onset of dementia. The group are liaising with researchers in Edinburgh and the UHI about this.

b. The next strand is the Physical Environment and Technology group who are developing the existing garden space beside Clisham Ward in the Western Isles Hospital into a special sensory garden enriching the sensory experience for patients with dementia and other mental health problems. Local school children, whose ideas for the garden have helped inform the design, have now created a link with the staff and patients in Clisham ward, which will extend into the future, where they will be engaged with the project through bulb planting and helping the older people enjoy simple planting tasks in the garden. The plans have been finalised, a contractor appointed and a start date of June arranged, to allow the delivery of some of the special equipment for the garden.

c. The third area is around Service Improvement. The group are currently developing a Strategy for Older Adult Mental Health, and this document is to be signed off by the executive team in May 09 then to be added into the Clinical Strategy which will be sent out for wide consultation throughout the Islands before being finalised. This consultation process will include the Mental Health Partnership, which includes representation from every voluntary agency concerned with mental health who are able to feed back to and from their members and the in-patient forum sub group will also be party to this.

12. Case Study 6 – Support for People with Multiple Sclerosis.

a. The past year has largely involved undertaking research and scoping exercises to determine what the actual needs of individuals with MS living in the Western Isles are. Initially it was vital to meet with key stakeholders (patients, carers, health & social care professionals/practitioners etc) and discuss their thoughts and views about current service provision. They also expressed what they felt the current needs to be and what they would like to see. A patient survey was also sent to all individuals with a registered diagnosis of MS via the GP practices (the results of this can be viewed in the MS scope report). This identified where the service strengths and weaknesses were and compared against the evidence base and current clinical guidelines to determine ideally what

services for MS should provide. Process mapping with key stakeholders was also undertaken to articulate this clearly and an ideal patient pathway was devised from this.

b. The report was approved and circulated to key stakeholders and a draft action plan (currently awaiting approval) was created in response to the recommendations made in the scoping exercise. This was developed in conjunction with the steering group and modified accordingly. At present a number of these objectives have been implemented or are in the process of being implemented. Education for healthcare professionals was identified as a key priority and is in the process of being developed. Training has been delivered to all social carers with involvement with clients with MS. Local standards in terms of policy and protocol are also being created to ensure practice is benchmarked.

c. The local branch of the MS Society has also become involved in assisting some initiatives which were identified as being potentially beneficial for individuals whose lives are affected by MS. Initiatives which are currently being explored and implemented include an MS awareness day, website and chronic disease self management courses. The work for the coming year will seek to further build on these initiatives.

13. Case Study 7 - Clinical Strategy Engagement. The agreed action was “to demonstrate sound principles of patient/public information, consultation and involvement in designing service change”. Much public engagement had already been completed in the preparatory work for Se Ur Beatha, which was relaunched with a large scale public meeting held in the Town Hall in Stornoway in Feb 08. So that we could build on this previous work and provide an opportunity for geographic inclusion we held option development meetings in Lewis, Benbecula and Barra during the summer. The invited participants were articulate and enthusiastic – their input sparked further specialist consultation and was incorporated into the developing options. In parallel we tried the idea of using manned kiosks to engage with our staff at various healthcare locations – these kiosks were also used by members of the public and patients. We also used unmanned kiosks offering a supply of information leaflets but received no feedback on the effectiveness of this approach. We visited many community organisations to spread awareness of the Clinical Strategy and to listen to people’s ideas – our own Locality Planning Groups were keen and receptive but we also found interest from community councils, patient groups, liaison and support groups. Conscious that these meetings were by invitation we then held a series of open public meetings through the islands early in the New Year so that the general public could have their say and influence the design of the options. We paid particular attention to ensuring that venues were accessible and that explanatory material was available – although there were some comments that the language was a little technical and complex. These public meetings were well attended and offered some valuable lessons in the relative merits of different forms of publicity, in the use of feedback forms and in the presentation of information. Throughout the process we maintained a regular liaison with the local Scottish Health Council office to ensure close observation of our activities and to act on suggestions wherever practicable.

SCOTTISH HEALTH COUNCIL VERIFICATION

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 Western Isles in relation to Patient Focus and Public Involvement.