A VOICE FOR
CANCER PATIENTS AND CARERS
IN NORTH WALES

NORTH WALES CANCER NETWORK
PATIENT AND CARER LIAISON GROUP (PCLG)

ANNUAL REPORT
JULY 2010 – MAY 2011

Gillian Evans, Chair, North Wales Cancer Network Patient and Carer Liaison Group

Pat Evans, User Involvement Facilitator, North Wales Cancer Network
01745 445168  pat.evans@wales.nhs.uk
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INTRODUCTION

This report provides a summary of the projects and activities with which the North Wales Cancer Network Patient and Carer Liaison Group (PCLG) has been involved over the course of another busy year. The achievements are testimony to the commitment of PCLG members to improving the experience of people who are, and have been, affected by cancer. Amazing energy and enthusiasm has once again been shown by PCLG members, including those who have themselves been going through spells of ill health or who have been caring for others. The PCLG has been encouraged by the continuing support from the North Wales Cancer Network and the Cancer Clinical Programme Group. A number of key health and social care professionals have made time to attend meetings, listen to the views of members and support the active involvement of service users in the development of cancer services in North Wales.

The work of the PCLG has been guided by a number of priorities, agreed by members in September 2010:

- Continue to develop the PCLG ‘Locality Group’ Structure
- Secure PCLG funding
- Build upon partnerships with the Cancer Clinical Programme Group (CPG)
- Engage with current patients and carers
- Recruit new members

Additional activities and project work include:

- Continued involvement at a National level – responding to consultations etc
- Development of new partnerships with the Voluntary Sector
- Involvement in professional training
- Improvement of information and support for carers
- Feedback on patient information
DEVELOPMENT OF PCLG STRUCTURE

Since June 2010, the PCLG has continued to develop its structure in line with a strategy, agreed in 2009, to establish three locality user groups – North West Wales, North East Wales and Conwy & Denbighshire – with an overarching PCLG Executive.

The ‘locality groups’ will enable the PCLG to respond to local issues within one of the largest health organisations in Europe, recognising that patient experiences and priorities for improvement, whilst sharing many common themes, can vary across the region. The locality groups will hopefully encourage recruitment and increase participation amongst local health and social care professionals.

A North West Wales Locality Group was established back in 2008. In September 2010, a committed team of PCLG members – Sandra Hulland, Kath Fox and Roy Bedwell – planned a very successful launch day event for a North East Wales Cancer User Group. Since the launch, the Group has had three very successful meetings (page 12).

Planning is now underway for the launch of Conwy and Denbighshire Group in September 2011.
FUNDING

The decision of the Cancer CPG to allocate £6000 / year to support infrastructure costs of the PCLG reflects the commitment of North Wales’ cancer services to supporting user involvement and has provided a significant boost to the Group.

The PCLG has also been successful in two grant applications to Macmillan Cancer Support, providing an additional £3450 to support a number of specific projects falling in 2010/11 and 2011/12. These include:

- Focussed listening events, aimed at gathering the views of diverse patient/carer groups
- Involvement of service users in professional training
- Development of information and support for carers
- Development of the Central Locality Group
- User involvement in the North Wales Review of Haematology Services

The PCLG now has its own cost centre which will enable budgetary control in 2011/12 to be significantly improved. Monthly updates of expenditure will assist the PCLG in managing expenditure allocated to individual projects more effectively.

<table>
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<th>YEAR 2010/11 (excluding grant applications)</th>
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<tr>
<td>INCOME</td>
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<tr>
<td>Budget from CCPG</td>
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<tr>
<td>TOTAL EXPENDITURE</td>
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<td>UNDERSPEND</td>
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WORKING IN PARTNERSHIP WITH THE CANCER CPG

For over 10 years the Cancer Network, and more recently the Cancer CPG, has encouraged and supported the representation of service users on tumour specific and project groups. During the past 12 months, the PCLG has established nine new areas of representation within the Cancer CPG, in addition to building upon existing partnerships and carrying out additional projects. The chart overleaf summarises current areas of representation on Cancer CPG Groups:
<table>
<thead>
<tr>
<th>Cancer CPG Board</th>
<th>Gill Evans (Chair of PCLG) Facilitator</th>
<th>There is a vibrant line of communication between the Cancer CPG and PCLG, enabling the views of users to be taken directly to the ‘decision makers’.</th>
</tr>
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<tbody>
<tr>
<td>Cancer Network Advisory Board</td>
<td>Gill Evans Betty Foster(Vice Chair)</td>
<td>Historically the PCLG’s main partnership was with the Network Board, and although the Group is still supported by the Network the working relationship has lessened.</td>
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<tr>
<td><strong>CANCER CPG WORKING GROUPS</strong></td>
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<tr>
<td>User Experience and Information Group</td>
<td>Gill Evans Facilitator</td>
<td>The outcomes of PCLG listening events and patient experience surveys have played a central role in guiding the development of the working strategy for the User Experience and Information Group.</td>
</tr>
<tr>
<td>Cancer Trials Research Group</td>
<td>Sandra Hulland Diane Farmer</td>
<td>This is a new area of representation for the PCLG and not an easy Group for service users but the professional members have been very positive about the value of their involvement.</td>
</tr>
<tr>
<td>Cancer Charities Forum</td>
<td>Betty Foster</td>
<td>This is a new area of representation for the PCLG which will hopefully continue to develop.</td>
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<td><strong>PROJECT GROUPS</strong></td>
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<tr>
<td>Key Worker Policy</td>
<td>Karen Sinclair Sue Phillips</td>
<td>The development of the key worker policy is a ‘hot topic’ and has been the subject of numerous debates/focus groups for the PCLG and its locality groups. The working group will continue to seek the views of service users as it works toward implementing the policy in North Wales.</td>
</tr>
<tr>
<td>Complementary therapies</td>
<td>Sheila Smith</td>
<td>Sheila’s experience as a trained complementary therapist is making her a valuable member of this task and finish group which will be scoping complementary therapy services across the region.</td>
</tr>
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## Review of Haematology Services

Gill Evans, Karen Sinclair, Michael Sinclair, Kath Swale, Doreen Atkinson, Jeanette Chamber, Nick Ayrton

Gill Evans, is a member of the Project Team for this review. The PCLG has brought together a focus group of ‘expert patients’ who are working together to provide a user perspective to the review process.

## Macmillan Information Centres

Gill Evans, Betty Foster, Iona Jones, Roma Goffett

PCLG representatives have been working with the estates team to choose furnishings for the new Information Centre in Ysbyty Glan Clwyd. The PCLG has also facilitated a new and exciting partnership with the Art Department at Llandrillo College whose students will be creating art work for the Glan Clwyd Centre.

## Environments

Tony Hendry, Diane Farmer

Tony and Diane are working with Iona Davies, Housekeeper Manager, to refurbish the dining area and quiet room on Enfys Ward.

## North Wales Conference

Gill Evans

Gill is providing user input into the planning of the 2011 North Wales Cancer Conference.

## CLINICAL ADVISORY GROUPS

### Psychology

Sheila Smith

Sheila has become a very active member of this new Group, currently working with the team to scope sources of psychological and emotional support in North Wales.

### Breast Cancer

Iona Jones

Historically, one of the main roles of the PCLG has been to provide user representation on the tumour specific planning groups, ‘DONs’. The PCLG is now working toward re-establishing user representation on the newly emerging tumour specific ‘CAGs’.

### Palliative Care

Sandra Hulland, Kath Fox


### Upper Gastrointestinal

Hazel Meredith
A user involvement group cannot be truly representative, and the PCLG is becoming increasingly aware of the importance of its role in listening to the views of current and recently treated patients from diverse sections of society.

‘Together we can make a difference’: This PCLG event in June 2010 attracted more than 90 patients and carers to the Oriel Country Hotel in St Asaph. The main aim of the day was to provide information and signposting to local sources support for cancer patients and carers. More than 20 local support organisations brought information stands. The day was a great success and received very positive feedback from patients, carers and professionals.

A report of the event was presented to the Cancer CPG and included the results of a brief survey completed by those attending. The survey asked for views on priorities for improving the experience of cancer patients / carers. In summary the main issues were:

- Information and support for carers
- Communication between patients/carers and health professionals
- Care and support after treatment
- Communication between Hospitals and Primary Health Care Teams

‘Quality Rounds’: The PCLG and Locality Groups have welcomed an invitation from Yvonne Lush, Associate Chief of Staff (Nursing), for members to become involved in gathering patient views for the ‘Fundamentals of Care’ audit. Hopefully patients will be more willing to talk openly to members of the PCLG. It is anticipated that the project will also provide another opportunity for the PCLG to engage with current patients.

Surveys: The PCLG will be undertaking a number of patient surveys over the coming months. The Network User Involvement Facilitator will be taking a lead in carrying out tumour specific patient experience surveys. The survey programme will begin with colorectal, lung and breast cancer.

Members of the North West Wales Locality Group have contributed to the design of a survey for patients attending the Alaw Day Unit. Members of the Group will assist in distributing the survey.

RECRUITMENT OF NEW MEMBERS

Recruitment of new members is a problem for most user involvement groups and the PCLG is no exception. Ideally a Group should include experiences from a wide range of tumour types, communities and minority groups, without becoming too unwieldy. Over the past two years, the PCLG has perhaps become rather complacent about attracting ‘new faces’.
A new recruitment drive is underway. Leaflets and posters inviting people to ‘get involved’ or to simply share their views of local cancer services are being widely distributed to GP surgeries, outpatient clinics, libraries etc. There will be more emphasis on developing methods of ‘virtual’ involvement which do not necessitate attendance at meetings.

IN Volvement AT A NATIONAl LEvLeL

Cancer Services Coordinating Group: The PCLG has always maintained close links with the Cancer Services Coordinating Group (CSCG) through its representation on the CSCG Patient Forum. The membership of this forum included the Chairs of the regional Cancer Network User Groups and user representatives on All Wales Cancer Steering Groups. Hazel Meredith and Roy Bedwell, members of the PCLG, have been patient representative on the All Wales Drugs and Colorectal Groups respectively. Restructuring within the CSCG has prompted the patient forum to be disbanded and user representation on the All Wales Groups to be removed. Dr Jane Hanson is working with the Cancer Network User Involvement Coordinators to develop new ideas for involving users in a meaningful way at this strategic level of service development.


All Wales Palliative Care Implementation Group: Gill Evans continues to be a valued member of this National Group. In March 2011, Professor Baroness Finlay presented “One Wales: 3 years on”; which represented a summary of the work undertaken by the Group over the last three years. This was presented at the Pierhead Building, in Cardiff, to the Minister and representatives from across Wales.

PARTNERSHIPS WITH THE VOLUNTARY SECTOR

Macmillan Cancer Support: The PCLG has traditionally maintained close ties with Macmillan. Over the years the organisation has been very generous in funding both PCLG infrastructure costs and special events led by the Group.

The PCLG continues to be particularly appreciative of the support of Anne Mart, Macmillan Involvement Coordinator for Wales, who regularly attends PCLG and locality group meetings and provides both direct support and a valuable conduit of information. The PCLG is represented on the All Wales Macmillan User Involvement Steering Group which facilitates user input into the organisation’s strategy in Wales.

Gill Evans has devoted a great deal of time to her role as a patient representative on a Macmillan grant panel which reviews applications from Cancer Network User Groups across the UK. In November 2010, she also became part of the Macmillan Steering Group to develop the report on ‘Person-Centred Cancer Care’, which formed part of a document setting out Macmillan’s manifesto for 2011 and beyond.
Wales Cancer Alliance: Gill Evans has on many occasions proved to be an articulate and passionate advocate for patient-centred cancer care. The Welsh Cancer Alliance extended a personal invitation for Gill to present her views at the opening of a high profile event in the Senedd which gave the four main political parties in Wales an opportunity to set out their policies for cancer services over the next Assembly term (2011-2015). Gill’s presentation received coverage on National Television.

Tenovus: Over the past year the PCLG has begun to strengthen its links with Tenovus as this organisation embarks on some innovative projects in North Wales (see updates from the North East and North West Locality Groups, page 11).

Community Health Councils: The PCLG has always recognised the importance of links with the Community Health Councils. The Group values CHC representation provided by Vera Wilson for the North West Locality Group and Roma Goffett for the PCLG.

Health and Social Care Facilitators: The participation of Health and Social Care Facilitators, Julie Cooper (AVOW) and Sioned Larsen (Mantell Gwynedd) in PCLG and Locality Group meetings has been greatly appreciated. The PCLG recognises the importance of developing links with the regional voluntary organisations, particularly in terms of promoting equality of care for all and ensuring that we are hearing the views from all communities across North Wales.

IN INVOLVEMENT IN PROFESSIONAL TRAINING

Patient stories can be a powerful teaching tool when included as part of professional training. Over recent years several PCLG members have provided a patient perspective in various training courses for nurses and GPs.

Trish Bayles, Michael Summerson, Kath Fox and Diane Farmer presented their personal experiences of diagnostic and therapeutic radiology services to students at the Wrexham Medical Institute, at the request of lecturer Dr Sola Decker. Feedback from Dr Decker and from the students was very positive. Gill Evans and Kath Fox have become regular contributors to GP training sessions. Gill gave a presentation to 19 junior GPs, providing a patient view of good quality palliative care in the community setting.

A presentation by Gill was also very well received at a conference in November 2010, ‘Getting it right for palliative care patients in Wales’ which explored best practice in delivering end of life care. The conference was primarily for GPs and had been organised by the General Medical Council in response to new guidance for treatment and care towards the end of life.
PATIENT INFORMATION

Macmillan Information Centres: For several years the PCLG has lobbied for improved information resources for cancer patients and carers in North Wales. The development of two new Macmillan Information Centres - in Ysbyty Glan Clwyd and Ysbyty Gwynedd - has therefore been exciting news. The PCLG has been very appreciative of Pam Wedley’s continuing support. Pam, Information Manager for the Macmillan Shooting Star Information Centre, attends most meetings of the PCLG and the North East Locality Group, always keeping members informed and supporting the involvement of PCLG members in service improvements.

Information leaflets: Members have given their views on a wide range of patient information booklets and leaflets.

Macmillan All Wales Information Project: This project has developed tumour specific information pathways and aims to promote sharing of high quality patient information and promote standardisation of information pathways across Wales. Nick and Marion Ayrton have been valued members of the steering group for this All Wales project, often travelling from North West Wales to Llandrindod Wells to attend meetings. Sadly, Marion Ayrton passed away in December 2010. Marion gave a great deal of her time to voluntary work in Ysbyty Gwynedd and was a very active member of the North West Locality Group, always approaching tasks with a positive attitude and a passion to improve cancer care for others. Marion will be greatly missed.

INFORMATION AND SUPPORT FOR CARERS

One of the most powerful messages to come from the PCLG listening event, ‘Together we can make a difference’ was a call from carers for their needs to be acknowledged and for better ‘signposting’ to local sources of information and support.

The PCLG is currently working in partnership with the specialist social worker at the North Wales Cancer Treatment Centre to develop and pilot a very simple information pack for cancer carers. The Group is also working with Llandrillo College to organise free Health and Wellbeing workshops for Carers to coincide with Carers Week in June 2011. The workshops will be funded from a grant awarded to the PCLG by Macmillan Cancer Support.

The Group has also recognised a gap in bereavement support and will be working in partnership with the User Experience and Information Group to address this issue.

UPDATES FROM THE LOCALITY GROUPS

North West Wales Locality Group

The North West Wales Locality Group has met four times since June 2010. Meetings are always well attended and usually supported by at least one member of the Cancer CPG.
Local Health and Social Care professionals are invited to speak on particular topics.
Projects and activities are listed below:

Addressing Local Concerns:

- **Specialist Social Care and Benefits Advice**: The Group’s concerns about access to benefits advice for cancer patients in North West Wales were taken to the Cancer Clinical Programme Group (CCPG). Gaps in service provision have been acknowledged by the CCPG and are being addressed.

- **Concerns about closures**: Damian Heron, Cancer Network Director, was invited to the October meeting of the North West Group amidst media reports of closures within the Alaw Cancer Treatment Unit at Ysbyty Gwynedd. Damian was able to reassure members that whilst closure of the Alaw Inpatient Unit was one of a range of possibilities under consideration by the Cancer Clinical Programme Group for making efficiency savings, this option was no longer seen as feasible. Damian stated categorically that this was no longer being considered as a feasible option. The discussion provided members with an opportunity to ask questions about the future of the Alaw Unit.

Consultations:

- **Emotional Support**: Dr Alys Cole King, Consultant in adult mental health, visited the Group to seek their views on the development of information for cancer patients, friends and relatives on simple strategies for coping with stress and anxiety during the early stages of diagnosis and treatment.

- **Libraries Project**: Hywel James, Chair of the North Wales Library Service, visited the group in July 2010 to seek the views of members on a new partnership project between the Library Service and Macmillan Cancer Support which will be bringing cancer information resources to libraries in North Wales.

- **Tenovus Consultation**: Several members of the Group participated in a focus group facilitated by the Tenovus charity to discuss service user awareness and perception of cancer clinical guidelines.

- **Key Worker Role**: Members of the Group participated in a focus group, facilitated by the Long Term Conditions Alliance, to give a user view of the key worker role.

Gathering Patient Views:

- **Patient Survey for Alaw Day Unit**: The North West Group has developed a patient experience survey for patients attending the Alaw Day Unit. Members will soon be participating in distributing the questionnaire to patients.

- **Fundamentals of Care Audit**: At the invitation of Yvonne Lush Associate Chief of Staff (Nursing), members of the North West Group are getting involved in monitoring the views of patients on the NHS Wales Fundamentals of Care. Volunteers have attended a brief training session in preparation.

Peer Support:

- **‘Footsteps’**: Volunteers from the North West Group continue to work toward develop ‘Footsteps’, offering current patients and carers the opportunity to talk to trained volunteers who may have been through a similar experience.
North East Locality Group

Following a very successful launch in September 2010, the North East Wales Locality Group has had three meetings. The Group is small but very committed and members have already been ‘getting involved’:

Addressing Local Concerns

- **Holistic Assessment of Needs:** Karen Sinclair, on behalf of the Group, wrote to Citizens Advice Bureaux and Welfare Rights Units across NE Wales to gather their views on gaps that might exist in signposting cancer patients to sources of information and support. The responses reflected the importance of a ‘key worker’ to guide patients and carers to appropriate and timely sources of support.
- **Cross border services:** Cross border services are of particular interest to the NE Locality Group. What is the impact on patient experience of receiving treatment from cross border providers? How will restructuring within the English and Welsh NHS influence access to cross border services? Damian Heron, Associate Chief of Staff for the Cancer CPG attended the April 2011 meeting of the Group to hear the views of members and to discuss the future of these services.
- **Inpatient beds for oncology patients:** Members have expressed their concerns with regard the lack of dedicated inpatient beds for oncology patients in Wrexham Maelor Hospital.
- **Signposting to Macmillan Information Centre:** Members highlighted the need to improve signposting to the Macmillan Shooting Star Information Centre. Pam Wedley, Information Manager for Wrexham, heard these views and is responding!

Consultations

- **Key worker Policy:** Yvonne Lush, Associate Chief of Staff (Nursing), has sought the views of the group on the key worker policy. Karen Sinclair and Sue Phillips have been recruited as patient representatives to the team which is currently developing guidelines for the implementation of the key worker policy in North Wales.
- **Tenovus:** Jane Ballantyne attended the April meeting of the NE Group to discuss new support services for cancer patients which are being developed by the Charity in North Wales. Members highlighted a need for improved access to legal and employment advice for cancer patients and carers.

Professional Training

- Trish Bayles and Michael Summerson presented their perspective of therapeutic radiology services to 2nd year radiology students at the Wrexham Medical Institute and received excellent feedback from both lecturer and students.
User Involvement Training

In March 2011 members of the NE Group attended a one day training session designed to support service users and NHS staff to work in partnership to improve services. The day, facilitated by a trainer from Macmillan Cancer Support, was very successful. It provided members with a much clearer sense of what they can achieve as members of a user involvement group and offered useful guidelines on how to actively influence services.

PRIORITIES FOR 2011 / 2012

The PCLG has agreed a number of priorities which will guide its work programme for 2011 / 2012:

• Maintain engagement/ user involvement with current patients/carers
• Maintain membership of PCLG, NE and NW groups
• Create the Central locality group by December 2011
• Develop patterns of communication between the locality groups
• Secure funding from BCUHB for 2012/13
• Secure grant funding from Macmillan for 2011/12 and beyond
• Develop a PCLG interactive website
• Become pro-active in user involvement in BCUHB reviews of service
• Continue to review PCLG representation on NHS Groups
• Continue to develop user involvement in BCUHB training programmes for staff
• Promote systems of support for former patients/carers
• Develop partnerships with self help and support groups
• Plan an awareness raising event for young people affected by cancer