Southern Health and Social Care Trust
Quality Care - for you, with you

Have Your Say!

Issue 1—January 2012

The Staff Newsletter Highlighting User Involvement and Experience in the Southern Trust

In this first edition we are showcasing and providing feedback on some examples of different ways service users/carers and the public have been involved in the planning, development and delivery of Health and Social Care Services in the Southern Trust.

This is the first edition of the PPI Newsletter which we hope to publish annually to celebrate user involvement and partnership working within the Southern Trust.

The Personal & Public Involvement Panel

The Southern Trust has established a Personal and Public Involvement (PPI) Panel as a mechanism for service users and carers to feed into the Trusts PPI structures and processes.

The role of the Southern Trusts Personal and Public Involvement (PPI) Panel is to:

- Provide feedback on how the Southern Trust is progressing its service user, carer and stakeholder involvement agenda and comment on the Trust's PPI consultation scheme and action plan
- Work with the Trust to enhance personal and public involvement across all of its services
- Review the outcomes of the patient client experience
- Nominate members to sit on relevant fora and feedback to the PPI Panel
- Work with the Trust to identify local need, shape and design service development and delivery and participate in evaluation of services.

Members of the PPI Panel

So what is PPI?

PPI stands for Personal and Public Involvement. It is a term used to describe the people who use health and social care services, their carers, relatives, friends, neighbours, voluntary workers, members of community groups and employees of voluntary organisations. PPI is about giving local people a say in how services are planned, delivered and evaluated. Trust staff can do this by developing good communication with their service users, carers and other stakeholders, providing them with the information they need to make informed choices about their care and to work in partnership to make decisions about service development and improvement.

Daunted by the thought of user involvement?

PPI Training Available

Build your confidence to help you engage with your service users with our PPI Awareness Course. The PPI Officer can come to your team and deliver a short training session on PPI and how you can ensure that it is an integral part of your working practice.

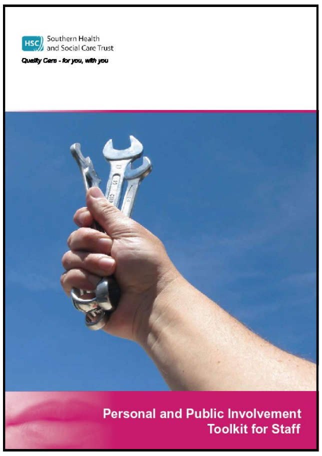
PPI Fact Sheets

The PPI Team have developed a range of fact sheets to support staff in enhancing personal and public involvement in their area of work. These will include more detailed information on individual methods of involvement. Fact sheets currently available to download from the Promoting Wellbeing website and the Trust Intranet include:

- Focus Groups
- How to set up a Service User Group
- Methods of Involvement
- What is PPI?
- Questionnaire Design
- Working with Hard to Reach Groups

If you require any further advice, guidance or assistance in relation to user involvement please contact the PPI Team.

PPI Staff Toolkit



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Personal and Public Involvement
Toolkit for Staff

We recently developed a PPI Toolkit to provide staff and managers with information and guidance to enhance personal and public involvement within their area of service and should be read in conjunction with the *Personal and Public Involvement (PPI) Strategic Plan 2010 - 2013, SHSCT (2010).* This resource is also available on the Trusts Intranet and Website. Many thanks to all who contributed to the development of the Toolkit- your support is very much appreciated. http://shsctintranet.hpss.n-i.nhs.uk/HTML/OP/documents/PersonalandPublicInvolvementToolkitforStaff.pdf

Examples of PPI Activity

OLDER PEOPLE & PRIMARY CARE SERVICES
Primary Care Division

The Lymphoedema service in the Trust continually engages with service users to explore their experiences of their Lymphoedema service and ask for suggestions for improvements. Also very importantly the service continues to investigate methods of providing support to allow them to live with and manage their long term condition. The service held two focus groups and key areas discussed and focused on were: accessing, advice and information, treatment, gaining meaningful patient focused outcomes of treatment, commenting on facilities that were available and how to access new and review services. At the end of the session opinion was sought around how they felt about the focus group process. It was reported as a positive event and a comment repeated several times was that the *"users would like to attend a local support group."*

As a follow up to the focus groups and the user /carer comments it was decided to hold a Stakeholder event in February 2010. The purpose of this event was to share with users the developments to date and future plans, provide feedback from the focus groups and to launch patient information leaflets. It was a very positive event with two way communication between service users, carers and the Lymphoedema practitioners. It also identified the level of interest in the development of a local support group. The **Local Lymphoedema Support Group** commenced in January 2011 and is continuing to run. A Trust wide programme of Lymphoedema awareness training is established and supported by a range of resources available on the Trust Intranet. Through the work of the "Lead Users" the support group has grown slowly for those with primary and secondary Lymphoedema, and Lipoedema. The "Lead Users" are working to further develop the group and increase membership through a press release placed in the local newspapers in the Trust area. In September 2011 a repeat survey of users on their experience of the services and their involvement in the planning and delivery will identify further areas for improvement and partnership working.

Engagement with service users has been, a valuable and effective method of informing and reforming service delivery and improving patient choice, focus future developments and ensure value for money. It has directed the Lymphoedema service on "patient-centred approaches" to meet the changing needs of users and their carer's.

For further information please
see our fact sheet on
'How to Set Up A Service User Group'
which is available on the User Involvement - PPI Section
of www.promotingwellbeing.info

CHILDREN & YOUNG PEOPLE SERVICES
Corporate Parenting Division

The 16 Plus Service User Group is a group of 12 young people aged 16 - 21 years who are preparing to leave care. The Service User group works closely with the 16 Plus Service to try to provide ideas and guidance to enhance support the care leavers get within the areas of education, employment and training, etc. Currently the 16+ Service User Group are **developing a DVD**, leaflet and information pack for young people leaving care by young people with experience of the care system to be available for all young people who transfer to the 16 Plus Service.

This is a service user led project and the DVD, leaflet and information pack will be produced and filmed by the 16+ Service User Group. The pack will form the basis of discussion by staff with young people on an individual and group basis about transition services like:

- **Education**
- **Employment and Training**
- **Accommodation**
- **Life skills Health**
- **Relationships /Personal Support**
- **Rights and Legal Issues**
- **Parenting**

For further information please see our fact sheet on 'Working with Hard to Reach Groups' which is available on the User Involvement Section / Resources of www.promotingwellbeing.info

Young people through their involvement in the Service User Group have also identified a number of training needs and through participation in the group they will receive training from the Trust, the Youth Service and other providers. The Service User Group has already been involved in a number of consultation exercises in relation to Looked After Children and their comments have been taken on board in that process. This work will continue and a number of H&SC staff have stated an interest in working with the group when drafting service proposals ensuring a clear Service User perspective in Agency developments.

The 16 Plus Service User Group

MENTAL HEALTH & DISBILITY SERVICES
Learning Disability Division

The **Woodlawn Parent and Carer Forum** was set up in early 2010. Woodlawn House is a purpose built respite unit for adults with a learning disability. Expression of interests for the parent/ carer forum were sought from all parents and carers in July 2009 following a recommendation from the RQIA that a forum/group would be established. An information session was held in February 2010 to gauge interest from parents and carers in becoming involved and following this the first formal meeting was held in April 2010. The Parent and Carer Forum is at early stages of development and it is a group of parents and carers who have dependants who avail of respite at Woodlawn House, who come together to discuss relevant issues about Woodlawn House. The forums main aim is to ensure the needs of adults with a learning disability are met. The parents and carers offer support to each other, exchange information, and have influenced Trust services e.g. Review of Respite. The group agreed to carry out a survey with parents and carers to try to attract more people to the group and also to find out what issues parents and carers feel are important for the forum to look at.

Staff in Woodlawn House supported the formation of the forum and currently support the forum by sending the minutes of meetings to all parents/carers regardless if they attended or not. A copy of the minutes are also held in Woodlawn and share with staff. Staff on occasion are asked to join the group to discuss queries parents/carers have in relation to areas such as clothing and admission/discharge times.

The group has been meeting every quarter for a coffee and a chat in various venues across the Southern Trust. At the last meeting Miceal Crilly the Assistant Director for Learning Disability came to update the group on the respite review and current thinking within the Trust. He explained that he was keen to work with parents and carers to develop services within current restraints and that working groups will be set up to involve parents and carers. The group appreciated his visit and found the meeting to be very informal with plenty lively discussion.

For further information please
see our fact sheet on
'Methods of Involvement'
which is available on the User Involvement - PPI Section
of www.promotingwellbeing.info

ACUTE SERVICES

Cancer and Clinical Services

The Head of Cancer Services wanted to gather feedback from people with an experience of cancer (service users, their family/carers and southern trust staff). Although evaluation in terms of questionnaires and surveys is core to cancer services, staff felt that if would be beneficial to the service to get more in-depth information from service users, their family and wider networks. A working group was established to see how this could be taken forward. Two service users were also asked to join the group to help plan the engagement activity.

Following meetings of the working group it was agreed to facilitate three **Focus Groups** in the Southern Trust Area. It was vital that a focus group was held in the three locality areas within the Trust area to ensure service users and their carers could attend. The three focus groups took place in September 2011.

In preparation for the focus groups the working group developed and circulated a flyer which gave details of three focus groups and a contact number if service users/carers wanted to gather further information. The flyer was circulated widely among:

- Southern Trust Staff via staff e brief
- Community/Voluntary sector
- GP Surgeries via practice managers
- Local newspapers
- Local Cancer Support Groups
- CAWT Social Inclusion Project (Co-operation and Working Together)

For further information please see our fact sheet on 'Focus Groups' which is available on the User Involvement - PPI Section of www.promotingwellbeing.info

Suggestions from the participants will help further develop cancer services and there was also good evidence of meeting the 5 Patient Client Experience Standards from participant feedback. The focus groups were also an opportunity for Cancer Services to ask the participants if they would be willing to get involved in the future. Participants were given a registration form to fill in if they wished to be contacted if further opportunities were available. This will assist Cancer Services to develop a database from which they can draw when they are making improvements whether to policies, procedures, facilities or services. A total of 16 participants expressed a wish to be involved in future work within Cancer Services and since have been commented on a leaflet currently being developed by the Mandeville Unit, CAH explaining the Volunteer service available.

Some quotes from participants:

"I felt that people were very interested in me and it gave me a chance to express my feelings"

"Excellent way of learning how we can improve our delivery of service to patients and their carers"

Volunteering

What is Volunteering?

"Volunteering is the commitment of time and energy for the benefit of society and the community, the environment, or individuals outside ones immediate family. It is undertaken freely and by choice without concern for financial gain".

The Southern Trust welcomes Volunteers from all walks of life and offers a host of opportunities to suit all skills and aspirations. Current volunteering opportunities include:

- Befriending
- Sighted Guides
- Arts & Crafts
- Outings Escort
- Bus Escort
- Crèche Support
- Entertainment
- Gardening

The **'Here to Help' Volunteering Service** is based in the hospital foyer of Craigavon Area Hospital and has been set up to provide information, directions and assistance to service users and visitors coming to the hospital. The trained volunteers are located at an information point and are easily identifiable in 'Here to Help' t-shirts and fleeces. The service continues to recruit and retain additional volunteers to extend the service throughout the day. The service is currently available Monday to Friday 8.45am-4.15pm. The volunteers also feed any issues received from service users to appropriate managers within the hospital and they receive warm appreciation from service users and visitors. They have also availed of PPI Awareness Training.

If you come across service users who have expressed an interest in volunteering please contact the **Volunteer Co-ordinators** in the Trust:

Gerardette McVeigh
Volunteer Co-ordinator
Brownlow H&SS Centre
Tel: 028 3831 1484

Imelda McPolin
Volunteer Co-ordinator
John Mitchel Place, Newry
Tel: 028 3083 4270

Reimbursing Service Users

Do You Know About the Southern Trusts Reimbursement Guidelines?

For effective involvement people need to feel supported and that their contribution is valued by both the organisation and its staff. The Southern Trust believes that where service users, carers and stakeholders are involved in supporting the ongoing development of services they should not be left "out of pocket" or financially worse off as a result. The Trust will reimburse legitimate out-of pocket expenses to service users who become involved e.g. travel, subsistence, administration or costs incurred for replacement care and individual support needs. It is crucial that you include the planning of reimbursement at the start of any PPI activity. Please refer to section 10 of the PPI Toolkit for more information on reimbursing service users or click http://shsctintranet.hpss.n-i.nhs.uk/HTML/PandP/documents/InterimSErviceUserReimbursementGUIDANCE.pdf

PPI Activity Forms
Its important to send them to the PPI Team!

Please remember to register any work you are doing to involve service users- however small. This could be a satisfaction survey / questionnaire, focus group, support group etc. *Share good practice - everyone benefits.*
http://shsctintranet.hpss.n-i.nhs.uk/HTML/OP/Information.html

"Community partners supporting PPI"

Peter Donnelly is a member of LARG (Lobbying Activism & Research Group) and a member of the Trusts PPI Service User /Carer Panel. Peter's involvement is underpinned by training and support provided by the BIG Lottery and delivered through the Community Integration Project at Willowbank.

"When Ann McGlone told me about the Lottery funding I thought this was going to be more of the same craic that we had been doing in the LARG . Through LARG we work on disability issues and finding out what local services are available and who the movers and shakers are. I didn't expect that by the early winter I would not have only have joined the local PPI Panel but I had volunteered to sit on at least two of the working groups. PPI means Personal Public Involvement and supposed to ensure that people who use services have some say in them.

The Community Integration funding means I have support and training to help me in this role. I was a bit out of my depth with some of the jargon but I feel I have learned a lot and have gained a good insight in to how Southern Trust delivers on PPI and the implementation plans they have drawn up.

Working with sub groups means I have had to learn about taking notes / minutes & giving feed back to the main PPI panel. Earlier this year I was able to do a Level One qualification on the UNCRPD (UN Convention on the Rights of People with Disabilities) I couldn't believe I would actually be able to do this but the Tutor took us through it Step by step and made a complicated subject much easier to understand."

The PPI Team

The role of the PPI Team is to work across Directorates and Programme's of Care to ensure service user, carer and public involvement and volunteering practice are integral to the development and delivery of their services. The Team is here to provide advice, information and training and will also support managers and staff to develop action plans to enhance user involvement. If you require any further advice, guidance or assistance in relation to user involvement please contact:

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Head of Service for User Involvement &
Professional Lead for Community Development
Tel: 028 3741 2519
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Sinead Hughes
User Involvement Officer
Tel: 028 37412523
Sinead.hughes@southerntrust.hscni.net

Kate Johnston, ***Personal Secretary,***
Tel: 028 3741 2468 **kate.johnston@southerntrust.hscni.net**

Also check out the PPI Section of the Promoting Wellbeing Website www.promotingwellbeing.info, the intranet & Trust website **'Involving You'** section.