



**Service User, Patient and Carer Involvement
Notes from meeting on 14th June 2005**

1. Development of PMS strategy

- Service users/carers/patients need to be involved in drawing on everything said at this meeting to help design/write the strategy
- Strategy needs to be part of an ongoing process

2. Reasons for involving service users – the potential benefits

Group began to elaborate on ‘why’ there should be this involvement

- Ensure that education was grounded in *real experience*, to make sure that doctors listened to the whole story and to ensure that doctors realised that people needed to be treated as ‘wholes’ and not just the presenting condition
- Involvement would help to change attitudes of doctors and to challenge their preconceived notions of people. For example mental health service users, people with impairments, older people.
- Involvement could also challenge the medical model of treatment and care
- Involvement could help medical students to see people as partners (equals) in their own care
- Involvement should also help medical students/doctors to consider the wider context of the person, ie: the support that family members require and that for some people support will come from outside of the family and they should have the same consideration as family members
- Develop real empathy “walk in someone’s shoes”
- Could have a true benefit for service users, raising self esteem
- Too many years of doctors knowing best
- The whole feeling of being a doctor needs to change (power)

3. Good practice elsewhere

- PMS could learn from other good practice eg: Plymouth University, CQSW
- Listen to other experiences eg: Plymouth University
- To draw on good practice which already exists in social work education. Service user and carer involvement in social services and the NHS to link with inter-professional learning.
- We need commitment at the highest level.
- The fear of the group was that messages contributed today may get lost

4. Dangers/threats

- User Involvement can be tokenistic
- Patients can be just as humiliated as students
- As barriers break down doctors will feel less threatened

5. Principles/good practice

- Unanimous agreement that there should be service user and carer involvement in all aspects of medical education and there from the beginning.
- Service users and carer stories should be actively driving the learning experience of PMS
- Has to be an organic process
- Safe environment to share experiences/knowledge
- Allow those involved to chat and relax. Feel that their time is worthwhile
- Methods of disseminating information/material needs to be appropriate (contacting people)
- Information needs to be presented in an appropriate manner eg: pictures, less words, symbols, font

6. Actual process of user involvement – how to do it

How could people be involved?

- Felt important for people's stories to be heard but also important to hear the stories outside of the consultation – suggestion that medical students could attend 'outreach' services eg work with a help-line, as this would help them hear different narratives
- Service users, carers and patients could act as mentors for medical students
- PMS should come into the community and not just hold meetings in the PMS

Other messages

- Don't over-use people – tendency for people to be involved to be asked to be involved in lots of activities – should continually seek to engage and encourage other service users, patients and carers to be involved
- Respect people's boundaries
- Consider people's needs (and any limitations)
- Don't establish mechanisms in a bubble-research what else is out there and use existing mechanisms where possible
 - NB where using existing mechanisms these need to be funded properly
- Involvement cannot be done in isolation it needs to be part of any ongoing process
- Realisation that some service users, patients and carers might also want to be involved in research as well as training
- Assessment of communication could be an area – planning, partners and assessor.
- Listening to people telling their story
- Service Users and carers actively directing the learning experience
- Use real people
- Knowing what questions to ask from real experience of people's lives
- Both service users and carers
- A sign that there will be commitment from the top. Service users and carers at board level

- When and where should be negotiated – meet needs of service users and carers
- There should be active service user and carer involvement with all stages of the medical education eg: selection of medical students, teaching, assessing etc
- Introduce idea of involvement alongside traditional methods of treatment eg: during scenario based learning or workshop, which isn't marked or assessed
- However, not all people are able or at the same
- Understanding that people are at different levels eg: literacy, articulation
- Maybe after a teaching session with students have time to chat informally and bounce ideas
- We need to be creative
- Scope for both formal involvement eg: presentation and informal (creative) involvement
- Treat people as equal partners (training & support, attitude)

7. Doctors' characteristics good and bad

- Doctor can have a real effect on a whole family not just the service user also carer/family
- Being sensitive and aware
- Tomorrows doctors need to be:
 - approachable
 - needs to be a partnership
 - aware of differences
 - not pigeonholing people
 - Not stereotyping patients
 - respecting the uniqueness of each individual
 - understand that they don't know everything
 - autonomous medical survivor (empowering; for self management)
 - knowledge and expertise which meets the knowledge and expertise of patient
 - two-way communication
 - make you better
 - be aware that some patients/carers know more than you (they are the real asset)

- Doctor is part of a team of people to care and not to be threatened by others (eg: service users) in the team.
- Doctors need to enable patients
- Doctors need a sense of community and method of support
- Look at patients more holistically

8. **Support and training for users and carers and staff**

What support should be provided to service users, carers and patients to facilitate their involvement?

- Appropriate training should be offered to all – people should be asked what they need to feel confident, to be able to articulate their thoughts, to be able to contribute as fully as they wish
- Training / support should be bespoke and not uniform
- Service providers, academics, managers etc also require training about service user, patient and carer involvement
- Training should also encompass self –directed ways of learning and not necessarily concerned with the specific role which people are being asked to play
- Clarity of decision making – where does the power lie?
- Although involvement is everyone's responsibility it was felt to be important that within the Peninsula Medical School there was someone who had overall responsibility. This would send a message of how important the School felt involvement was and would also provide dedicated time to make it happen

Practical support

- Finances (time and travel)
- Arranging transport where required
- Accessible venue
- Meets costs – travel and time
- Train PMS staff in how to get best out of service users and carers.
- Mentor
- Training in presentations, preparation
- Respite for carers to enable them to participate

- Support or Buddy
- Empower learning for patients and carers.
- People who want to be involved need support and training

9. **Miscellaneous**

- Compare the experiences of families/patients/carer in involvement at PMS with another university.