

GOOD PRACTICE REVIEW ON USER INVOLVEMENT

PROPOSED GUIDELINES

Following the Good Practice Review in the Western Area on User Involvement, the following draft guidelines have been proposed for use within Health and Social Services organisations.

The guidelines are applicable when pursuing User Involvement with each of the Section 75 groups of people, and are categorised under the following headings.

- Management Board Level Issues
- Guidelines Relating to User Panels
- Guidelines Relating to Information and Communication
- Guidelines Relating to the Accessibility of Meetings which Users will attend
- Guidelines Relating to Advocacy
- Guidelines Relating to Capacity Building
- Guidelines Relating to Staff Awareness and Training

In addition to these overarching guidelines, some issues should particularly be considered when involving users from specific groups of people. These guidelines are listed at the end of this document. These guidelines were developed through the research process, and as a result of the consultation exercise.

PROPOSED USER INVOLVEMENT GUIDELINES	
Management Board Levels Issues	
1	Chief Executives of HPSS organisations should be accountable to ensure that User Involvement Guidelines are being effectively implemented.
2	HPSS organisations should develop a clear policy on User Involvement, in collaboration with service users and carers. These policies should be regularly monitored and evaluated.
3	Partnerships should be established with other organisations such as community and voluntary organisations, and other HPSS projects to prevent duplication of effort. HPSS organisations should relate to Community and Voluntary structures that are already in place and are seen to successfully involve users.
4	In recognition of the resource implications of taking forward a user involvement approach, the HPSS should review arrangements for provision of funding to facilitate user/carer involvement, including issues such as payment for user/carer expertise, expenses, travel, and other practical support such as child care arrangements.
5	Achievements on User Involvement should be reported by HPSS organisations on an annual basis, either through a specific section included in the organisation's Annual Report, or through a separate reporting mechanism. Such reports should be made available to the public, and to users who have been consulted.
Guidelines Relating to User Panels	
6	User panels should be used to ensure user involvement from each of the section 75 categories in decision making, and to share information and good and poor practice examples. The following issues should be carefully considered and agreed with users when developing such panels:- representation/membership; appointment mechanisms; openness; accountability and structures.
7	When users are asked to sit as members of other groups to inform decisions about services, at least 2 members should be users or carers.
8	In some instances, it may be necessary to form a specific user group, which will represent the views of one section 75 category only.
9	The extent of involvement and participation (length of time etc) should be agreed with user panel members.
10	Service users and carers should be consulted in two ways. Both as a group with needs which are common, and as individuals with specific needs.

Guidelines Relating to Information and Communication

11	A wide variety of information formats should be used in order to ensure that the wide range of user communication needs are met. Examples of such formats include: - audio, Braille, large print, videos, ethnic minority languages, lip readable language, sign language, electronic formats.
12	Information about services should be readily available to the wider public. Mechanisms which can be used include:- leaflets in waiting areas, media campaigns, posters on notice boards.
13	Information should be in keeping with the principles of the Plain English campaign, in a jargon free style, which is applicable to all groups. Where possible materials should be piloted in advance.
14	A multi-method approach to information gathering is recommended. Useful tools include surveys, questionnaires, open days, discussions, focus groups, one to one contacts, feedback cards, direct contact, complaints forms and electronic information exchange (which is particularly useful for users with sight disabilities).
15	Greater user of qualitative approaches to information gathering should be used, ensuring that all client groups can contribute.
16	Acknowledgements should be sent to all consultation participants
17	Feedback should be provided to consultees on what they have said, and what changes have been made as a result, using appropriate channels.
18	An open door policy for HPSS organisations is a good way to encourage community involvement.

Guidelines Relating to the Accessibility of Meetings which Users will attend

19	When planning meetings, consideration should be given to the needs of specific user groups, e.g. Location, venue, time, accessibility. For example young people and children attend school during the day, and do not drive; users with disabilities need appropriate access to venues; many users from ethnic communities have evening working commitments and are unable to attend meetings at this time; carers have commitments to the people they care for.
20	Consideration should be given to covering travelling expenses for users attending meetings.
21	Clear instructions, minutes, agendas and any papers should be given to those attending meetings in advance, in order to ensure that everyone can meaningfully be involved in discussions. The timescales and methods for sharing this information should be agreed with the users.
22	Protection and safety of children and young people travelling to attend meetings is of paramount importance. One method of reducing risk is to ensure PECs screening of taxi drivers.

Guidelines Relating to Advocacy	
23	Advocacy is important to enable the views of those who cannot participate to be heard. As far as possible, advocacy should be provided as a method of user involvement. Such advocacy must be seen to be independent.
24	Where possible people from the same section 75 category should be used as advocates.
Guidelines Relating to Capacity Building	
25	Capacity building programmes should be provided to ensure that users can fully participate. Such capacity building should include training on confidence building, how to chair and accept positions of responsibility at meetings, negotiating skills, how to contribute to consultation.
26	Users should be involved in gauging user needs and developing such capacity building programmes.
Guidelines Relating to Staff Awareness Training	
27	Cultural awareness training relating to each of the section 75 categories of people, should be provided to HPSS staff.
<i>In addition to the above guidelines, which apply to each of the section 75 categories, some additional guidelines have been developed, which apply to User Involvement with the specific categories of people listed below.</i>	
Young People/Children	
28	Youth Councils, Youth Forums and Peer Led Focus Groups can be a good way to involve users.
29	Young researchers should be used to help formulate specific questions, to ask the questions and validate the results when dealing with children and young people, when possible.
30	Workshops and conferences are preferred methods of involving young people.
31	When it is ethically appropriate, information should be given directly to young people and not channelled through parents or guardians.
Learning Disabled Service Users	
32	Involving people with learning disability in the decision making process is important. To do this effectively, a greater degree of preparation is required, considering the specific needs of this group of people. Specific approaches which are recognised as helpful include face to face interviews and small group discussions.

<i>Service Users from Ethnic Minorities</i>	
33	Health care professionals should receive guidance from local Trusts on the availability and accessibility of interpreters.
<i>Gay, Lesbian, Bisexual Community</i>	
34	Voluntary questionnaires can be used in health centres and clinics to gather views and opinions on services from people from the gay lesbian, bisexual community
35	Gay, lesbian and bisexual communities have different needs and aspirations in relation to user involvement. It is important to recognise these differences.
<i>Transsexual Community</i>	
36	The distinction between the gay and transsexual community should be recognised. Representatives of the transsexual community should be utilised to support the involvement of this community.