Service user involvement

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What is service user involvement?
User involvement in general
Four key elements of user involvement

• **Objective / purpose of involvement**
  – Why are users involved? E.g. Gain new ideas, to improve user relations

• **Stages of involvement**
  – 10 stages

• **Intensity of involvement**
  – Continuum: passive listening to extremely intense

• **Modes of involvement**
  – E.g. face to face interviews, brain storming, focus group,
10 stages where users are involved

Alam 2002

- Strategic planning
- Ideas generation
- Ideas screening
- Business analysis
- Formation of functional teams
- Service and process design
- Personnel training
- Service testing & pilot run
- Test marketing
- Commercialisation
Four key elements of user involvement

• **Objective / purpose of involvement**
  – Why are users involved? E.g. Gain new ideas, to improve user relations

• **Stages of involvement**
  – 10 stages

• **Intensity of involvement**
  – Continuum: passive listening to extremely intense

• **Modes of involvement**
  – E.g. face to face interviews, brain storming, focus group,
Service Idea Assessment in the Three Dimensions of Originality, User Value, and Producibility

Chi-Square Residuals of the Higher Quartile

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Groups</th>
<th>Observed</th>
<th>Expected</th>
<th>Residual</th>
<th>R</th>
</tr>
</thead>
<tbody>
<tr>
<td>Originality</td>
<td>Professionals</td>
<td>10</td>
<td>18.1</td>
<td>-8.1</td>
<td>-1.91</td>
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<tr>
<td></td>
<td>Ordinary users</td>
<td>42</td>
<td>28.7</td>
<td>13.3</td>
<td>2.49*</td>
</tr>
<tr>
<td></td>
<td>Consulting users</td>
<td>25</td>
<td>30.2</td>
<td>-5.2</td>
<td>-0.95</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>77</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>User Value</td>
<td>Professionals</td>
<td>9</td>
<td>18.4</td>
<td>-9.4</td>
<td>-2.19*</td>
</tr>
<tr>
<td></td>
<td>Ordinary users</td>
<td>41</td>
<td>29.1</td>
<td>11.9</td>
<td>2.21*</td>
</tr>
<tr>
<td></td>
<td>Consulting users</td>
<td>28</td>
<td>30.6</td>
<td>-2.6</td>
<td>-0.47</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>78</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Producibility</td>
<td>Professionals</td>
<td>16</td>
<td>18.8</td>
<td>-2.8</td>
<td>-0.65</td>
</tr>
<tr>
<td></td>
<td>Ordinary users</td>
<td>29</td>
<td>29.8</td>
<td>-0.8</td>
<td>-0.15</td>
</tr>
<tr>
<td></td>
<td>Consulting users</td>
<td>35</td>
<td>31.4</td>
<td>3.6</td>
<td>0.64</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>80</td>
<td></td>
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</tbody>
</table>

NOTE: $R$ = standardized residual.
*Significant contribution because absolute value of $R$ is greater than 2.00.
Policy context of user involvement

• Community health councils 1973
• NHS & Community care act 1990
• Patient charter 1991
• Local voices 1992
• Working in partnership 1994
• Building bridges 1995
• NHS plan 2000
• Health & social care act 2001
• Commission for patient & public involvement 2002
• Patient Tsar 2003
Creating a Patient-led NHS
Delivering the NHS Improvement Plan
A patient-led NHS

Better quality, and more capacity, stimulated by financial incentives

More insight into local communities, to improve how effectively we help them

Applying learning from around the world in a new institute for skills and innovation

A patient-led NHS – builds on the best from the past

Locally driven service, operating to a national framework and standards

People offered services to maintain health, not just to treat sickness

A joined-up service which enables integrated care for patients

A choice for patients of when and where they are treated
<table>
<thead>
<tr>
<th>Good Practice Principles for Involving Mental Health Service Users and Carers MARD (2007a)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Making a Real Difference (MARD)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Clarity</th>
<th>Inclusiveness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Equality of treatment</td>
<td>Positive attitudes</td>
</tr>
<tr>
<td>Good communication</td>
<td>Helpful information</td>
</tr>
<tr>
<td>Physical accessibility</td>
<td>Robust procedures + systems</td>
</tr>
<tr>
<td>Give support</td>
<td>Provide resources</td>
</tr>
<tr>
<td>Meaningful involvement</td>
<td>Consider practical issues</td>
</tr>
</tbody>
</table>
# How to Create a Written Involvement Plan (MARD 2007b)

<table>
<thead>
<tr>
<th>Name of service user/carer</th>
<th>Name of organisational mentor</th>
</tr>
</thead>
<tbody>
<tr>
<td>All relevant contact details</td>
<td>Sign off by both parties</td>
</tr>
<tr>
<td>Project name</td>
<td>Dated completed document</td>
</tr>
<tr>
<td>Proposed and actual start date of involvement</td>
<td>Proposed and actual date of completion of involvement</td>
</tr>
<tr>
<td>Contact for complaint/compliment</td>
<td>Support needs of user/carer</td>
</tr>
<tr>
<td>Personal expectations of involvement</td>
<td>Organisational expectations</td>
</tr>
</tbody>
</table>
2012

• Patient should be at the heart of everything we do
• Genuine shared decision making
• All along pathways
• All aspect of care
# User’s influence on health services

**User led**

- **Consumerism**
  - Users have a choice of services
  - Can influence service provision
- **Political activism**
- **Self help**
  - Provide part of the service

**Service led**

- **Consultation**
- **Active partner in**
  - Planning of service
  - Delivering of service
  - Evaluating services
- **Formally integrated.**
Why get service users involved?
Examples of user involvement in England

<table>
<thead>
<tr>
<th>Levels of interaction</th>
<th>Recipient of communication</th>
<th>Subject of consultation</th>
<th>Agent in control</th>
</tr>
</thead>
<tbody>
<tr>
<td>Between service users</td>
<td>Newsletters</td>
<td>Advocacy schemes</td>
<td>Hearing voices</td>
</tr>
<tr>
<td></td>
<td>Periodicals</td>
<td></td>
<td>Newsletters</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Periodicals</td>
</tr>
<tr>
<td>Between users and professionals</td>
<td>Receiving care plans</td>
<td>Agreeing care plans</td>
<td>Direct payments</td>
</tr>
<tr>
<td>Management of local services</td>
<td>Receiving information services</td>
<td>Patient councils</td>
<td>User-run crisis houses</td>
</tr>
<tr>
<td></td>
<td></td>
<td>User surveys</td>
<td>Social firms</td>
</tr>
<tr>
<td></td>
<td></td>
<td>User-focused monitoring</td>
<td></td>
</tr>
<tr>
<td>Planning of overall services</td>
<td>Community care plans</td>
<td>Mental health taskforce membership</td>
<td></td>
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<td></td>
<td></td>
<td>Stakeholder conferences</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Users on local implementation teams</td>
<td></td>
</tr>
</tbody>
</table>
SERVICE USER INVOLVEMENT: RELEVANCE AND IMPORTANCE

For service users and staff
- service users experience greater dignity and self-worth
- improved morale among service users and staff

For the services
- better understanding and acceptance of service users’ perspectives;
- service improvement resulting from the expert knowledge brought by service users to a partnership with providers and other stakeholders;
- better decision making and better health outcomes;
- increased acceptability of changes;
- more likelihood of new initiatives succeeding;
- better understanding of the context of people’s lives in the community;
- helps make service providers more accountable to the communities they serve.
<table>
<thead>
<tr>
<th>Barriers</th>
<th>Possible solutions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Questioning whether users or carers involved are representative</td>
<td>Accept unrepresentativeness if any relevant experience is needed; or accept partial representativeness by careful selection of only particular stakeholders (users and carers do not make good proxies for each other, as they may have different agendas); or appoint participants to be accountable to other stakeholders</td>
</tr>
<tr>
<td>Lack of interest from users and carers</td>
<td>Widen sources of recruitment, for instance by contacting voluntary organisations. Target difficult-to-reach groups by advertising in a range of languages or formats</td>
</tr>
<tr>
<td>Tokenism – few users and carers involved, or involvement in only trivial tasks</td>
<td>Alleviate providers’ doubts about the usefulness of user and carer involvement, by having a clear, reachable aim, and monitoring the project. Set-up agreed procedures for incorporating user and carer views into decision-making processes of organisation</td>
</tr>
<tr>
<td>Concern about users’ ability to make rational contributions</td>
<td>Some disorders may preclude participation, if they impair cognitive or communication skills, but the users’ involvement could be achieved (for example) through advocacy</td>
</tr>
<tr>
<td>Stress of involvement may damage users’ mental health</td>
<td>Provide clinical support</td>
</tr>
<tr>
<td>User and carer stakeholders’ lack of experience</td>
<td>Provide training and information to enable participation</td>
</tr>
<tr>
<td>Communication barriers</td>
<td>Limit use of jargon. Long-term discussion groups can ease communication</td>
</tr>
<tr>
<td>Role strain (difficulty relinquishing patient or healer role)</td>
<td>User and professional training</td>
</tr>
</tbody>
</table>

BRITISH JOURNAL OF PSYCHIATRY (2003), 183, 89–91
Ladder of Participation

FULL CONTROL: Service users control decision making at the highest level.

SHARING POWER: Service users share decisions and responsibility, influencing and determining outcomes.

PARTICIPATION: Service users can make suggestions and influence outcomes.

CONSULTATION: Service users are asked what they think but have limited influence.

INFORMATION: Services users are told what is happening but have no influence.

NO CONTROL: Service users are passive consumers.
Supporting People User Involvement Survey  Nov 2007

Benefits to participants
- Increased Participation 90%
- Increased self Confidence 74%
- Gaining Employment 28%
- Taking up voluntary Work 30%
- Presentation skills 37%
- Interviewing Skills 37%

Figure 3: Client groups consulted
- Older people 95%
- People with learning difficulties 91%
- People with mental health problems 87%
- Single homeless people 86%
- Young people at risk 83%
- Offenders and those at risk of offending 83%
- People with drug problems 83%

Figure 4: Methods of Involvement
- Focus groups 84%
- Postal questionnaires 79%
- Face to face surveys 70%
- In depth interviews 62%
- Service users panels 43%
- Service user advocates 35%
- Telephone or text 35%

http://www.serviceuserinvolvement.co.uk/default.asp
Assessing the promise of user involvement in health service development: ethnographic study

Nina Fudge, research associate,1 Charles D A Wolfe, professor of public health,1,2 Christopher McKeivitt, senior research fellow1

<table>
<thead>
<tr>
<th>WHAT IS ALREADY KNOWN ON THIS TOPIC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Involving patients and the public in health service development is said to lead to better services and improved outcomes</td>
</tr>
<tr>
<td>Evidence showing the effects of this on the quality and effectiveness of services is limited</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>WHAT THIS STUDY ADDS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professionals determine how service users will be involved in service development and this may limit change that can be achieved</td>
</tr>
<tr>
<td>Small numbers of service users were “involved,” with personal gains for them</td>
</tr>
<tr>
<td>Service users’ experiential knowledge is valued because it seems to provide information that will improve delivery of care</td>
</tr>
</tbody>
</table>
Model for Evaluating Service User Involvement
PPPI model (Faulkner, 2010)

• **Purpose**
  Understand their role, avoiding tokenism and involvement for its own sake.

• **Presence**
  Number of service users and carers involved, their characteristics in relation to the project or programme.

• **Process**
  At what level are service users and carers involved? Are good practice guidelines being applied?

• **Impact**
  What impact if any are service users or carers having on the project or programme?
NICE: 15 quality standards
College

- Service User Recovery Forum (SURF) and Carers' Forum
- Viewpoint: Devoted to the views of people who have experienced mental health problems.
Involving carers and service users in the training of psychiatrists

Service user involvement in psychiatric training: a practical perspective

Owen Haeney, Rajesh Moholkar, Nicholas Taylor and Thomas Harrison


Access the most recent version at DOI: 10.1192/pb.bp.106.013714
Service user in research

An evaluation of service user involvement in studies adopted by the Mental Health Research Network

Kristina Staley
TwoCan Associates

January 2012
User involvement in Neuropsychiatry

• We have a user representative – linked up with college service user group
• Involvement with Curriculum application to GMC
• JCP-MH – commissioning guidelines
• Close links with neurological alliance and a number of patient charities
• Service user feedback
Service user involvement in Neuropsychiatry

• How should Neuropsychiatry embrace user involvement further?
• What can Section of Neuropsychiatry do?
• What about conditions where we do not have an existing service user groups?
• Can service users be an advocate for neuropsychiatry service development?