

Better Services for People Who Self-Harm

Service User Handbook

WELCOME!

It's great that you are getting involved in the 'Better Services for People who Self-Harm' Programme.

This handbook offers information and resources which we hope you will find helpful. You will also have a copy of the Project Management Pack which gives more detailed information about the project.

We'd like to improve this handbook as time goes on, and would welcome your ideas and feedback, which can be incorporated as the project progresses.

Please fill in the contact form on page 42 and return it to us to let us know how you would like us to contact you.

Looking forward to working with you.

Compiled by Helen Blackwell and Lucy Palmer, October 2005
Revised May 2007

Available online at: www.rcpsych.ac.uk/cru/auditselfharm.htm

To request further copies, or to suggest changes to this document,
please contact selfharmproject@cru.rcpsych.ac.uk, Telephone 020 7977
6643

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'Better Services for People who Self-Harm' Introduction to the project

The issue

Self-harm is one of the top five causes of admissions to emergency departments in the UK (68,716 admissions in 2001/2002). The quality of care that people receive varies enormously between different hospitals, and often between different practitioners in the same hospital.

Although there are, of course, areas of good practice, many people who attend an emergency department as a result of self-harm find the experience negative. In 2004 the National Institute of Clinical Excellence published a guideline to treatment in the first 48 hours after an incident of self-harm . (available at www.nice.org.uk). The guideline concluded that improving staff knowledge and attitudes is the key to better services, reducing levels of self-harm, levels of distress to service users, and deaths resulting from self-harm. The 'Better Services' project has taken the NICE guideline and added some more recommendations from staff and service users and created a manual of standards, which can be found in the publications section of our website: www.rcpsych.ac.uk/cru/auditselfharm.htm

The 'Better Services' project aims to improve services by identifying standards of good practice, inviting local teams to audit their services against these standards and develop action plans to bring about change.

Some of the improvements identified through the quality improvement processes will relate to the behaviour of individual practitioners, others to the structure of the services within which they practice. Teams may be able to act on some of the findings immediately e.g. by introducing a new risk assessment tool. Others will require more time, e.g. increasing access to liaison psychiatry services.

What is the 'Better Services for People who Self-Harm' Programme?

So far, over 40 local teams have been established throughout the UK. Each team includes service users, as well as staff from emergency departments, their associated mental health services, and local ambulance services. Local teams will work together and with other teams to review their services against good practice standards, and then make changes aimed at improving the services. The programme of work runs for 12-18 months and will take teams through a number of stages.

As a service user expert, your views are vital to the project. We want you and your team mates to get the most of this programme. If you wish to contact us at any time to discuss your role in the project, or to feed back your views, please get in touch; we would love to hear from you!

Programme of activity

The first phase of the programme begins in 2007, and will have the following stages:

**April –May
2007**

Team leads will establish their **local project team** (LPT), to work on the programme.

**June/July
2007**

Your team will be invited to attend a one-day **introductory workshop**, to learn about the programme and start planning your work as a team. Data collection methodology will also be explained. Teams choose to attend on one of the following dates:

- Wednesday 27th June (London)
- Thursday 5th July (Manchester)

**July –
October
2007**

Data collection (between July–Oct 07)

Data collection is the term used for gathering information and views about services from staff and service users. Tried and tested data collection methods are used and all tools and guidance notes will be sent to teams beforehand. Your team will collect data around the following:

Service user views: a survey designed by users and staff will be available online and also in paper format (with freepost envelopes for easy return to us). No teams have to input this data locally.

Staff views will be gained via one simple online survey. Team leads will be asked to forward a link to the online staff survey to all of their colleagues.

One policy checklist will be completed by each local project team.

Teams that opt to complete the case flow audit will record basic activity data for 50 people who attend the emergency department (ED) following self-harm.

**November –
December
2007**

All teams will then each receive an individualised **local report**, including:

- All data and comments from staff and service users
- A summary of the policy checklist and case flow data
- Reference to the quality standards (including the Healthcare Commission's standards and the NICE guideline).

**December
2007**

An **aggregated report** will also be provided, allowing each team to compare their scores to national averages (note: services will not be named unless to highlight good practice).

**January
2008**

A **peer-review and change management training event** will be delivered to all team leads, enabling them to:

- Lead a peer-review
- Learn more about applying the principles of change management
- Talk to other members and consider which team they might wish to visit for the peer-review

Refreshments, relevant materials and a certificate of attendance will be provided.

**January –
February
2008**

Local project teams will go on **peer-review visits** to explore key themes and support local action planning. Discussion will be based on the local report of the team being visited, which all parties will have read beforehand. This is an excellent opportunity to learn about practice taking place elsewhere and avoid 'reinventing the wheel'. Guidance notes are provided by the central project team to ensure that reviews are easy to organise and straightforward to follow on the day.

The vast majority of teams that have taken part in the programme described the peer-reviews as '*very instrumental*' in helping them make improvements.

**April
2008**

Teams will attend a **feedback event** to share their expertise and describe what action they are taking to improve their local service. This is an excellent opportunity to hear from other teams and discuss key issues relevant to the field.

July 2008

The re-audit. Teams will repeat the main data collection activities, one year on from the original audit. This will help see what change has taken place. Teams will receive final local and aggregated follow-up reports.

Throughout

Teams are encouraged to start **making changes** as early on in the programme as they wish. Some teams may have already made plans or started activity before they collect data. Others will wait and act specifically on findings from their local report. During the peer-reviews, teams will be asked to draw up action plans with input from their colleagues, and this can be a key factor in improving services. Finally, the learning events and networking opportunities can also inspire change.

Teams will also be offered a range of **change interventions**, including training material, information for service users, checklists and tools.

For more details, please refer to the Project Management Pack (issued at launch events and available from the local team lead, or the central project team).

Networking and Communication Opportunities



To join the email discussion group, allowing you to talk about the project and share best practice ideas email sh-discuss@cru.rcpsych.ac.uk



If you (or any member of your team) would like to write a piece for the newsletter, or would like the newsletter editor to interview you about positive practice taking place at your service, please contact Philippa Strevens on 020 7977 6643, Email pstrevens@cru.rcpsych.ac.uk

Who's who in the central project team (CPT)?

Philippa Strevens Quality Improvement Administrator
Helen Blackwell Service User Adviser
Lucy Palmer Programme Manager

General enquires about the project:



Better Services for People who Self-Harm
Royal College of Psychiatrists' Centre for Quality Improvement,
4th Floor Standon House, 21 Mansell Street, London, E1 8AA



020 7977 6642/6643



020 7481 4831



selfharmproject@cru.rcpsych.ac.uk



www.rcpsych.ac.uk/cru/auditselfharm.htm

To contact Helen Blackwell, the project's service user adviser:



07817 217 390



hblackwell@cru.rcpsych.ac.uk

Service user members of the national steering group

Kayleigh Caesar
Satveer Nijjar
George Haworth

Your local project team (LPT) members

You might wish to use this to help you keep in touch with other team members

Team Lead	Name Job Title /Role Address Contact Telephone Fax Email
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Representative(s) from Mental Health Service	Name Job Title /Role Address Contact Telephone Fax Email	Name Job Title /Role Address Contact Telephone Fax Email
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Representative(s) from Ambulance Service	Name Job Title /Role Address Contact Telephone Fax Email	Name Job Title /Role Address Contact Telephone Fax Email
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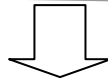
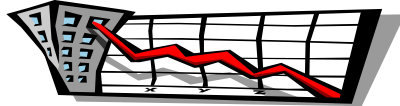
Service User Representatives	Name Job Title /Role Address Contact Telephone Fax Email	Name Job Title /Role Address Contact Telephone Fax Email
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Other Team Members	Name Job Title /Role Address Contact Telephone Fax Email	Name Job Title /Role Address Contact Telephone Fax Email
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Your role as a service user representative

Your role is to contribute to the team. The team's role is to work together to:

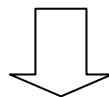
*Collect information about services
Via data collection*



*Interpret the information
By discussing the results as a team and then hosting and visiting a review
to discuss the findings with others*



*Plan actions to improve services
Drawing up realistic action plans that address the issues brought up in
the data collection*



*Make changes and communicate results
Taking the ideas forward and improving services*



You will be involved in all aspects of the project. This is likely to include:

Attending local project team (LPT) meetings

- These will be held locally - frequency of meetings will depend on how often your LPT chooses to meet
- During the meetings, you will work with another service user and local staff from ambulance, emergency department and mental health services. You will be involved in discussions around how to improve services.

Workshops and events run by the central project team (CPT). There are 3 main events:

- An **introductory workshop** - you and your team-mates will be invited to attend an introductory workshop, which encourages teams to start working together and plan the project
- Once data collection has been completed, **peer-reviews** will take place and your team will visit and receive a visit from, another LPT to discuss progress
- Later on in the programme, each team will be invited to attend a **feedback and action planning workshop**, to discuss what changes your team is making

Other tasks

- You will be involved in helping to decide how best to collect data from other service users
- You will probably be involved in contacting or visiting local groups or services to gather views from service users in your area and keep them informed as the project progresses. You will be supported by other team mates in doing this
- Preparing for events (by reading)

As a service user member of the LPT you will have a key role in consulting other service users and contributing views and ideas based on experience of using services, but your other skills are valuable too. You might for example, be good at analysing information, or facilitating groups, or bring knowledge of the local area, and numerous other things.

The table overleaf gives a possible outline of how service user time might be allocated, ***but this is really a starting point for discussion*** – it is open to negotiation.

Guide to time commitment for service user members of local project teams

Many local teams have asked us for advice about how much input we expect from service user representatives on the LPT. This guide adheres to some of the key elements of 'good practice' indicated in the project management pack, i.e.:

- Service user representatives can share some aspects of the role between them, but should not be expected to serve as sole representative in any professional forum/meeting/event
- To minimise the risk of this happening, three service users should *ideally* be recruited to the local project team. If a team has only two service users, it is a good idea to recruit a deputy who can stand in for you if you are unable to attend a meeting. (This will not cost the project any extra money because they would only pay for the person who attends).
- It is essential that service users are **fully involved** in every stage. You will play a vital role and should be invited to all meetings and events connected to the project and have an equal say in all aspects of decision making.

Activity	Estimated no of days per user
Attend introductory workshop (June/July 07)	1 day
Contact with local user groups and services to encourage responses to the service user survey (between July - Oct 07) by telephone, email, writing or in person. <i>Please note: posters, surveys and information sheets will be provided.</i>	2 days
Meet with project team to discuss results of audit and prepare for peer-reviews (Jan/Feb 08)	½ day
Attend a peer-review, with team mates (Jan/Feb 08)	1 day
Receive a peer-review visit, with team mates (Jan/Feb 07)	1 day
Attend a feedback workshop (April 08)	1 day
Attend additional project team meetings	1.5 days
Extra reading or preparation	1 day
Total	9 days

This is for guidance only and is up for negotiation between you and your local team. As there will be two (or even three) service users on the team, you can split some of the tasks between you. Overleaf is the role description that we have given to team leads, to summarise your potential involvement in the programme:

BETTER SERVICES FOR PEOPLE WHO SELF-HARM

Service User Member of local project team (LPT) Job Description and Person Specification

The role of the service user representative is to help improve services by:

- Joining a local project team of 5-10 people, alongside another service user and staff from ambulance, emergency department and mental health
- Attending local project team meetings and contributing as an equal partner
- Helping to raise awareness of the programme with other service users, including contacting local user groups and voluntary organisations
- Encouraging service users to complete a survey of their views on self-harm services
- Visiting another team (with members of your LPT) to discuss how their service could be improved and receiving a visit from another team
- Attending a number of workshops with your LPT

Essential criteria

Recent experience of using mental health services

Recent experience of using emergency services for treatment of self-harm**.

Understanding of user empowerment and user involvement

Ability to work in groups

Willingness to consult people with experience of self-harm and represent their views

Available to devote 6 to 9 days to the project over the course of the project, including meetings held during the day

Confidence in communicating with a range of people including service users, carers, mental health professionals, medical staff and service managers

A bonus!

Experience of quality improvement work, research or service evaluation

Experience of working in committees or working groups

Understanding of issues facing service users from diverse communities

**** Note**

At least one of the service user representatives should have personal experience of self-harm and use of emergency services. However, it is recognised that other service users may have particular expertise to bring, for example, experience of group advocacy, user consultation etc, and one user representative could be someone with this experience.

Data collection

Data collection is the term used for gathering information and views about services from staff and service users. Good response rates to the staff and service user surveys are vital to the success of the project – the more views that each team can gather, the more information they will have about what needs to be improved.

A strategy

As a service user member of the local project team (LPT), you will have a significant role to play in:

- Helping inform local service users about the project
- Inviting service users to complete the questionnaire

Please note!

Although your contribution to data collection will be invaluable, the responsibility should be **shared by the whole of the LPT**, and it will be important for the team to develop a strategy together. If your team would like further advice on this from the central project team, please let us know.

The service user survey

Teams will be provided with a questionnaire to be distributed to service users, asking their views about their care and treatment. The questionnaire can be filled in online, or on paper. It will be returned directly to the central project team, so that local staff members do not know what individual service users have said. The information on the questionnaires will be collated and fed back to local teams in a report, alongside information gathered from staff members.

Timetable for data collection

June - July 2007	Start to contact local organisations to let them know about the project (see section on networking with local organisations)
July – October 2007	Teams will distribute questionnaires and continue publicity

Publicising the project and questionnaire

The central project team will produce questionnaires for staff to give to people who attend emergency departments after self-harming. The questionnaire will come with an addressed, freepost envelope, allowing people to return them easily at no cost.

People attending emergency departments may not feel up to completing a questionnaire whilst they are going through a difficult time, and it is crucial to make

contact with a wider group of people who may have been to the emergency department in the past. Anyone who has used emergency services after self-harming in the last 18 months is welcome to complete the questionnaire. We are also interested in the views of people who have self-harmed but have chosen not to use emergency services. It will be possible to contact service users through local services, user groups and voluntary organisations. However, many people who use emergency services after self-harm, including overdosing, may not be in contact with mental health services. They may have attended the emergency department just once. We want to hear the views of this group of people, and this means publicising the project outside mental health organisations. In addition to the paper version of the questionnaire, an electronic version will be available for completion online at www.rcpsych.ac.uk/selfharm

Your strategy could include

1. Offering questionnaires to people attending emergency departments (essential).
2. Posters in emergency departments, provided by the central project team (essential)
3. Distributing leaflets/posters/cards to local mental health organisations, including:
 - Mental health housing projects
 - Inpatient wards, day centres and day hospitals
 - Community mental health teams
 - Crisis houses
 - User groups
 - Advocacy projects
 - Counselling services
 - Mental health charities
4. Asking for information about the project to be included in newsletters produced by any of these organisations. (Remember to do this early in the data collection period, as organisations may only produce one newsletter during this time).
5. Asking if you can visit mental health groups and centres to talk about the project
6. Contacting other organisations in your area, e.g:
 - Community centres
 - Organisations for deaf people, disability projects
 - Cultural centres
 - Women's refuges/homelessness projects
 - Prisons
 - Drug and alcohol projects
7. Wider publicity. e.g.
 - In libraries
 - Article in local newspaper
 - Local radio or television

Contact the central project team if you would like a sample press release or text for leaflets or newsletters.

Tips for user consultation and networking

What is consultation and networking about?

Making contact with local service users, organisations and other local people is important for four reasons:

- To let people know the project is happening – an opportunity to raise awareness about self-harm
- To learn from groups that already have expertise in self-harm and user involvement
- To gather the views of people who have used emergency services after self-harming
- To give feedback to interested organisations and individuals about the progress of the project.

Which groups?

User groups • Mind • Patients' Council • Day Centres • Advocacy Groups • Community Mental Health Teams • Rethink • Inpatient Units • Emergency Departments (A&E) • Disability Groups • Black and ethnic specific mental health projects • Specialist Self-harm Services • Community or Religious groups • Self-harm Support Groups • Lesbian, Gay, Bisexual and Transgender groups • Refugee Groups • Patient and Public Involvement Forum • Supported Housing • Other Local Mental Health Charities •

How do we make contact?

Local directory of mental health services

Sometimes there is a directory produced by Mind, statutory mental health services, or a local user group. This could be online &/or in booklet form. Contact your local Mind association or PALS (Patient Advice and Liaison Service) in the NHS Mental Health Trust, or the communications department of the Primary Care Trust. They should know if there is a directory and how to access it. (To find your local Mind Association or PALS see the 'Useful Contacts' on page 25)

Voluntary Service Council

Most areas have a Voluntary Service Council which offers support to local voluntary sector organisations. They will have details of mental health charities and projects in the area, as well as disability, cultural and community groups. Check in your local phone book for [Name of place] Voluntary Service Council or [Name of place] Council for Voluntary Service. Or phone the NCVO (National Council for Voluntary Organisations) Helpdesk on 0800 2 798 798.

Mind

For details of the local Mind association contact the Mind Information Line on 0845 766 0163 or do a search on the Mind website – www.mind.org.uk. The local Mind association may also be able to help with a mailing list of other mental health organisations in the area.

Action 4 Advocacy (A4A)

A4A is building up a database of advocacy services nationwide. This includes projects offering individual advocacy and group advocacy organisations. Contact A4A on 020 7820 7868 or use the directory of projects on their website – www.advocacyacrosslondon.org.uk.

Statutory mental health services

The NHS mental health trust will have details of day centres, day hospitals, community mental health teams and other settings which may be a point of contact with people who self-harm. To find contact details of your local mental health trust ask the trust representative in your local project team or do a search on the NHS website – www.nhs.uk.

Self-harm support groups

There are a number of self-harm support groups in the country, and you may have one in your area. The national self-harm network website is a good place to check this out – www.nshn.co.uk.

Specialist self-harm services

There are some specialist projects around the country. Look on the national self-harm network website for details – www.nshn.co.uk.

Not sure about how best to go about it?

If *at any stage* you feel unclear about any aspect of your role, or would like some advice on how best to contribute, you can speak to your project lead, or contact the central project team, who will be more than happy to advise.



Useful contacts

National Self-Harm Network

PO Box 7264
Nottingham NG1 6WJ
info@nshn.co.uk
www.nshn.co.uk

The National Self-harm network is a survivor led organisation campaigning for the rights and understanding of people who self-harm . Their website gives extensive information and links to other organisations and offers an online discussion forum.

Bristol Crisis Service for Women

PO Box 654
Bristol
BS99 1XH
www.users.zetnet.co.uk/bcsw

Office: 0117 927 9600

National Helpline: 0117 925 1119 (Friday and Saturday 9pm - 12.30 am, Sunday 6 – 9 pm)

Bristol Crisis Service for Women supports women in distress, particularly women who have harmed themselves. They run and support self help groups and have produced a wide range of publications for people who self-harm , their family and friends, and workers. They also publish a magazine, SHOUT, for women who self-harm . The helpline is staffed by women with understanding of self-harm .

The Basement Project

PO Box 5
Abergavenny
NP7 5XW
basement.project@virgin.net
01873 856524

The Basement Project runs support groups for people who have been abused as children and people who self-harm . The project also offers training, consultation and supervision for workers in community and mental health services. They publish a quarterly newsletter – Self Injury Forum. Some resources are published in Welsh as well as English.

42ND Street

Second Floor
Swan Buildings
20 Swan Street
Manchester
M4 5JW
0161 832 0169

42nd Street works with young people aged 15 – 25 in Manchester who are at risk of suicide and self-harm. The project offers one day training workshops to other organisations

Mind

15 – 19 Broadway
London
E15 4BQ
020 8519 2122
InfoLine 0845 766 0163 (9.15 – 5.15 Monday to Friday)

Mind Cymru

3rd Floor, Quebec House, Castlebridge
5 – 19 Cambridge Road East
Cardiff CF11 9AB
029 2039 5123

Mind is a national mental health charity, with local associations in most parts of England and Wales. National Mind campaigns on mental health issues, produces a wide range of mental health resources, and runs training events and conferences. Local associations are independent organisations, affiliated to National Mind. They often provide services such as advocacy, counselling, day services, employment projects, and housing, and also often have a role in campaigning and education.

The Scottish Association for Mental Health

Cumbræ House
15 Carlton Court
Glasgow
G5 9JP
0141 568 7000
www.samh.org.uk

The Scottish association provides a range of services across Scotland for people with mental health problems and works to influence public policy as it affects people with mental health problems

The Northern Ireland Association for Mental Health

80 University Street
Belfast
Co Antrim
BT7 1HE
028 9032 8474
www.niamh.co.uk

The Northern Ireland association offers a wide range of services including housing, home support, advocacy and information. It also undertakes research and works to raise awareness of mental health issues

Mental Health Foundation

9th Floor, Sea Container House
20 Upper Ground
London
SE1 9QB
020 7803 1100
www.mentalhealth.org.uk

The Mental Health Foundation is a national charity working in the area of mental health and learning disability. It conducts research, raises public awareness and influences policy, publishes resources and has grant programmes to fund innovative mental health projects.

Action 4 Advocacy

020 7820 7868
www.advocacyacrosslondon.org.uk

Action 4 Advocacy is London based, but is building up a database of advocacy services nationwide. They cover advocacy for all groups of people, including people with mental health issues. The database holds details of projects offering individual advocacy and group advocacy, including user groups. A4A publishes a magazine, Planet Advocacy, and regular e-newsletters.

Rethink

Head Office - 0845 456 0455
National Advice Service – 020 8974 6814 (10am – 3pm, Monday to Friday)
www.rethink.org.uk

Rethink is a national charity working to help people affected by severe mental illness recover a better quality of life. It offers information, research and publications and a wide range of local mental health services'

US Network

Baglan Suite, Llys Kearns, Jersey Marine, Swansea. SA1 8QL
E-mail: jeff@walesnetwork.freemove.co.uk
Web: www.usnetwork.co.uk
Tel: 01792 470246
Fax: 01792 470254

US Network is the All Wales User and Survivor Network for people who use or have used mental health services and their allies. US aims to provide an effective voice for survivors and users, to increase awareness of mental health issues and work for better mental health services in Wales. US Network campaigns on mental health issues, publishes a number of newsletters and booklets and encourages sharing of information amongst users in Wales.

INVOLVE

02380 651088

Textphone 02380 626239

www.invo.org.uk

INVOLVE exists to promote patient and public involvement in NHS research. Their publications can be downloaded from their website – they have extremely useful guidelines for service user involvement in research.

PALS (patient advice and liaison service)

PALS is an NHS service which gives people information on local health services, helps them to find the best service for them and deals with any queries and concerns. The Dept of Health website gives more information - www.dh.gov.uk (search for PALS).

To find details of the local PALS service the website suggests phoning the local hospital switchboard or phoning NHS Direct on 0845 46 47

Young people and self-harm – a national inquiry

www.selfharmuk.org

020 7828 6085

Inquiry co-ordinated by the Mental Health Foundation and Camelot Foundation into the experience of young people who self-harm. The report, 'Truth Hurts', was published in 2006

Involving service users – a checklist

This is a copy of the checklist we included in the project management pack, for your reference. This checklist was written for local team leads, to help them involve service users effectively.

Working collaboratively

- Make the purpose and remit of the local project team clear
- Be prepared to relinquish some power and adapt ways of working, but be honest about any areas of decision making which users cannot influence
- Be prepared for the work to take longer, e.g. because of the need for greater discussion and information sharing
- Be clear to staff and service users that no-one will be treated differently in their use of services for taking part in consultation and representation: this fear can sometimes prevent users taking part or saying what they think
- Let individuals and groups know that you appreciate their input

Access

- Ask service users (and other members of the team) about access needs – don't wait for them to raise the issue. Examples might be:
 - Use of a personal assistant or support worker
 - Access to taxis or other forms of transport
 - Wheelchair accessible venues
 - Hearing induction loop
 - British Sign Language interpreters
 - Community language interpreters
 - Written material in large print, in Braille or on audiotape
 - Reminders before meetings
 - Specific dietary requirements
 - Provision of childcare
- Hold meetings in user-friendly and public transport accessible places: ask people about this
- Hold some meetings on users' 'home territory', e.g. at the premises of a user or voluntary sector organisation
- Ask about the best time of day for meetings. Early mornings may be difficult for some service users because of the effects of medication

Organising meetings

- Ask service users if they have items to be included on the agenda; don't place them near the end
- Allow enough time between meetings for service users to consult user networks. Plan ahead to allow for use of existing communication networks e.g. monthly newsletters, regular user forum meetings
- Consult service users on the structure of the meeting, e.g. length of meeting, number of breaks; check if comfort breaks are needed.
- Consider different formats for meetings to facilitate participation, e.g. small group discussion with feedback
- Provide plenty of drinks – some psychotropic medication dries your mouth

At the meeting

- It is the Chair's role to ensure that all members of the group have the chance to participate
- Ask team members for suggestions for ground rules for meetings
- Establish a ground rule that any personal information or experience shared is confidential to the group
- Be clear which elements of the agenda can be discussed outside the meeting and which cannot
- Use specialist language only where necessary. Consider asking members of the group to prepare 'front sheets' summarising academic papers, if academic papers are being discussed
- Encourage all members of the team to ask for clarification when terms are not understood
- Be prepared for strong emotions at times – most service users will bring some painful experiences of services. Anger and hurt are normal responses!

Study related support

- If required, facilitate access to training, e.g. in committee skills, understanding audit and evaluation etc
- Ask service users if they would like a mentor, e.g. an experienced member of the LPT chosen by the service user

Practical support

- Produce papers, including the agenda, soon after the meeting so that representatives can consult other people.
- Find out what practical support the service users need to feed back issues from the meeting to other users, and to consult with service users locally
- Ensure that user representatives have access to necessary facilities such as phone, email, photocopier etc, if required.

Emotional support

- Facilitate time and space for service user representatives to get together after meetings for mutual support and debriefing, either with or without a member of the LPT, whichever the service users prefer
- Ensure that service users have access to someone outside the local project team to talk through personal issues raised by involvement in the project - discussions about services can trigger difficult memories and feelings.

With acknowledgements to:

Changing Practice: Mental Health Nursing and User Empowerment. Peter Campbell and Vivien Lindow, 1997, Royal College of Nursing and Mind Publications

Involving Marginalised and Vulnerable People in Research: A Consultation Document, Roger Steele, 2004, INVOLVE

Guidance for Good Practice: Service User Involvement in the UK Mental Health Research Network, Alison Faulkner, 2005, SURGE

'A guide to reimbursing and paying members of the public who are actively involved in research: INVOLVE, 2006 http://www.invo.org.uk/pdfs/Payment_Guidefinal240806.pdf

Appendix 1: Guidance for paying service users and example fees – taken from INVOLVE

The text below is taken directly from the INVOLVE publication 'A guide to reimbursing and paying members of the public who are actively involved in research: for researchers and research commissioners, who may also be people who use services).

INVOLVE is a national advisory Group, funded by the National Institute for Health Research, which aims to promote and support active public involvement in NHS, public health and social care research.

The full document can be found at
www.invo.org.uk/pdfs/Payment_Guidefinal240806.pdf

Reimbursement of expenses

All out of pocket expenses should be reimbursed. Reimbursement of expenses facilitates equal opportunities for participation, and people who use services should not end up financially worse off for providing what is, in effect, a public service. The following expenses should be carefully considered:

Travel (public transport, taxi fares, or an agreed private car mileage rate which includes wear and tear)

Overnight accommodation, etc.

Subsistence (food etc. whilst on 'business' or bought due to having to be at a certain place at a certain time)

Childcare

Telephone/internet access/fax costs

Stationery/equipment

Carer costs

Costs of a Personal Assistant of the individual's choice

Conference fees

Participation in training

Reimbursement for expenses, needs to be made promptly, or in some cases even in advance. This will be very important to people on low incomes.

Payment for time, skills and expertise

People who use services should be paid for their time and expertise to a level consistent with other members of the research team. This will depend on a variety of factors and circumstances. For example, it's unfair to expect people who are unpaid to sit alongside paid non-executive members of research advisory groups or committees, or to ask them to give their time for free when others are paid for their time as part of their day job, or through locum fees. On the other hand, where a committee/group is entirely voluntary, payment for time cannot reasonably be expected.

Setting a rate for payments

Rates paid will depend on a number of variables, as each situation is different. It may be helpful to ask the following questions:

How does the principle of equity apply in this situation?

What level of skills, expertise, and experience are we seeking/expecting from the people who use services on the project?

What are the time commitments involved in the role they are playing in the project (including preparation, reading, travel, communication, meetings etc.)?

What are the comparative levels of pay and responsibility of participating professionals?

What level of responsibility are we expecting the person to shoulder in respect of the project?

What are the local and national pay conditions for the equivalent role?

What is the current national minimum wage?

Choice regarding payment

When offering payment for the involvement of people who use services, the importance of choice cannot be over-estimated:

Where possible, it can be mutually beneficial to negotiate rates of payment, conditions, and 'job descriptions' with local or national service user groups as appropriate.

There may be reasons why some people might choose not to be paid. This may be because of altruism, financial circumstances, or because of the potential impact on social security benefits, or tax. These are a matter of individual choice, and not reasons for avoiding the offer of payment in the first place.

It is important to make clear from the outset *when* and *what* payment can be expected, as this informs people's choices about whether or not to get involved.

Acknowledgements and other forms of reward

Specifically thanking and acknowledging individuals for their time and contributions should not be overlooked whether they are paid or not. Consideration should be given to enhancing the experiential benefits for individuals who get involved. These might include training and learning, attending conferences, confidence building, help with ongoing learning, CV development, and future employment, for example.

Examples of payments from the INVOLVE paper

There is a range of different ways in which the public and people who use services have been paid. The following examples show the year to which they were relevant in brackets. Some organisations may have changed their rates and processes. Please note that the National Minimum Wage changes over time and this can be checked at www.direct.gov.uk

Guidance has been agreed with the Department of Health in 2006 for the **National Institute of Health Research** programmes on payment rates to members of the public for attendance at committee meetings and carrying out peer review. It says that people who are asked to be members of a committee, or review proposals or reports, should be paid a fee if they are not in receipt of a full time salary from public funds and they meet both of the following criteria:

- They are members of the public or people who use services (as defined by INVOLVE)
- They are being asked to provide a public perspective at the meeting or to the review

Payment rates are:

Committee fee - for attendance at and preparation for a committee meeting a daily rate of **£150.00**

Peer review fee

Lower level £50 - for reviews of short documents such as research briefs and vignettes or lay summaries of reports.

Middle level £100 - for reviews of larger amounts of information. For example reviewing several grant applications, or medium length reports (50 - 200 pages).

Higher level £200 - for reviews of large reports or documents. For example reviewing long reports (over 200 pages).

The NIMHE West Midlands Mental Health Development Centre pays service users for training on the following scale (2005):

Short presentation (up to 30 minutes) £40.00

Presentation / workshop/ seminar (up to 60 minutes) £75.00

Half day workshop/ training event £125.00

Whole day training event £250.00

Consultancy/other substantive work - to be negotiated locally

The National Institute for Health and Clinical Excellence (NICE) pay patient and carer members of NICE guideline development groups and public health programme development groups £200 per day long meeting. This fee covers attendance as well as a considerable amount of background reading needed between meetings. Members of the public who sit on the NICE Citizens Council receive £150 per day for their attendance. A member of a NICE independent advisory committee (technology appraisal committee, guideline review panels, interventional procedures advisory committee, public health interventions advisory committee, research and development committee) will receive expenses only. (2005).

Appendix 2: Ten ways for mental health workers to impede user participation in planning and managing mental health services

This has been included in the project management pack to help teams think about the barriers to user involvement.

By Vivien Lindow

Introduction

I am introducing this subject in a contrary way. I am going to tell workers how to stop us from getting involved in service planning and management. All these things have happened to me in trying to take part in psychiatric service planning, as someone who has used the services. At the same time, I must acknowledge the very great help that professional people have given to me and other service users in helping us to be involved in trying to improve services.

1. Do not give resources

If you want to prevent user involvement, never give service users the money they need to meet and discuss policy matters. Do not offer money for training in committee skills. After all, you do not want them to get the hang of how the power system works.

2. Take charge

Secondly, take charge. When asked to be treasurer or chairperson by a user group where the members lack confidence, feel flattered, accept the job and wonder why the users will not take responsibility.

3. Sow doubts

The third way you can prevent user participation is to express doubt about the group's ability to be autonomous. Ask: "What if the chairperson becomes manic"? What happens when any chairperson is unable to fulfil that function? User groups are no different.

4. Not representative

Suggest to colleagues that the service users who are making representations are not representative because they are articulate. "Real" psychiatric patients are not articulate. If they were, they would have been given drugs to stop them speaking out. How representative are you?

5. Choose someone compliant

Invite a service user of your choice on to your committee rather than inviting a user group to send representatives. Then you can be sure to hear what you want to hear, not what psychiatric patients have to say.

6. Tokenism: outnumber them

My next two points are about tokenism. Invite just one service user representative on to a committee comprised of professionals. The user will probably not be confident enough to present other users' views unsupported. If the person is confident, he or she will be so heavily outnumbered that you will not have to change anything.

7. Tokenism: ignore them

The next form of tokenism is to consult widely, but exclude service users from the decision-making structures of your organisation. Then you can say that you have asked the service users, but will not have to act on what they have told you.

8. Embarrass them

The eighth idea to exclude service users is to embarrass them. For example, if a service user representative starts by making remarks that do not conform to your agenda, ensure that an awkward silence is followed by ignoring the content of what is said.

9. Exploit them

Never pay service users. Expect them to attend regularly as the only unpaid people in the roomful of salaried people. Then they will stop embarrassing you with their presence, and you'll have satisfied your conscience by inviting them.

10. Suggest that you are as powerless as service users

The tenth way to exclude psychiatric patients is to suggest that you are as powerless as they are. Mental health workers have the power to recommend children being taken away, to order compulsory admission to hospital, to remove access to desired services, to release grants of money and give access to housing of various sorts. You have a salary and probably a secure home. You do not carry a diagnosis that invalidates what you say.

The ideas in this paper have been published in "Just Lip-Service" by Viv Lindow in the Nursing Times (UK), 2 December, 1992.

Appendix 3: Managing your own health as a user/survivor worker

Be clear what you are taking on

It's important to have a clear idea of what you are committing yourself to, both in terms of time and what is involved. The section 'Service User Role Description' (page 12) gives an outline and the project management pack gives more information, but please feel free to ask about anything which is not clear. The role is not set in stone: there is room for negotiation.

Make use of support systems

We are suggesting that each service user has a mentor within the LPT and you have a say in who that is. It's up to you how you use time with them, but a few examples spring to mind. If you're not familiar with structures in NHS services, the mentor could help with explaining this and giving you further information. If you want talk about the way the LPT is working, the mentor might be a good person to talk it through with first of all. If there are ideas you'd like to test out before broaching them with the team, this could be a place to do it. If you need access to resources to carry out your role effectively, the mentor could negotiate this for you.

We're also suggesting that you have access to someone outside the LPT, perhaps for emotional support. This could be someone in a user group or Mind or other organisation you are involved with. Or it could be someone within the NHS trust who has skills to offer. This is something to negotiate with the LPT lead or your mentor in the LPT.

Another useful approach is for the service user team members to meet with the LPT chair for half an hour before LPT meetings to clarify anything which is not clear about the agenda, and to make sure the Chair allows time for things you want to raise in the meeting. It's helpful to debrief after the meeting or event as well – which could be with the other service users involved, or with your mentor, whatever you find most useful.

You should also feel free to contact the central project team at any time throughout the project for advice or further information on the project.

Plan ahead

A lot of people say that they get a buzz during events, but crash afterwards. It might be useful to think in advance about what you need in that case – whether it's being with a friend or having an easy day the following day.

Let the team know what you need

It is the team's responsibility as a whole to make sure the team works in a way which takes on board the needs of all its members, but please do voice your needs. This could be access needs such as written material in large print, or a lift to meetings. It could be that one time of day is better than another for meetings, or that you need to bring a support worker to meetings – whatever is necessary to enable you to be fully involved.

Think about how much of your own experience you want to disclose

Some people want to give examples of situations they have experienced, other don't. There's no right and wrong in this. What is most important is that your views and ideas are *informed by* your experience and that of other people. It's often helpful to negotiate with the team at the beginning whether you'd be happy for them to refer to your personal stories outside the meetings, for example when explaining to staff what the issues are, or whether examples you give are confidential to the LPT. Also would you want examples to be attributed to you or referred to anonymously?

Using A & E services

If you need to use emergency services during the time the project is running, do you feel OK about using the Emergency Department where the project is based, or would you prefer to go elsewhere? This is something you could talk through with your mentor in the team.

Getting other people involved

You'll probably be consulting service users in local organisations. Can people in those organisations help you organise things?

You might want to think about having someone who can deputise for you at meetings and events if you're going through a difficult time. It's important though that anyone standing in for you is well briefed.

Setting limits

This is the sort of project in which one could probably do an infinite amount, and it's tempting as we're all involved because of a commitment to improve services. But do set realistic limits.

Your own welfare is paramount and your personal needs must take priority over your role on the project team. If you feel at any stage that your role as a project team member is compromising your own wellbeing, you should inform your local project lead, mentor, or a member of the central project team as soon as possible. This is so that arrangements can be made to offer you more support, or give you a break from involvement if that would help. If you do take a break, you will, of course, be welcome to rejoin the project as soon as you are ready. Please be reassured, too, that you are free to withdraw from the project at any stage without damaging your prospects of taking part in future projects.

Please let us have your suggestions!

USER/SURVIVOR WORKER TOOLKIT



Think about how much you want to reveal about yourself



Put safety nets in place e.g. someone to take over if you are ill



Be realistic—don't take on too much

Ask for information e.g. about your role, NHS structures etc



Take time out if you need to



Make use of training opportunities



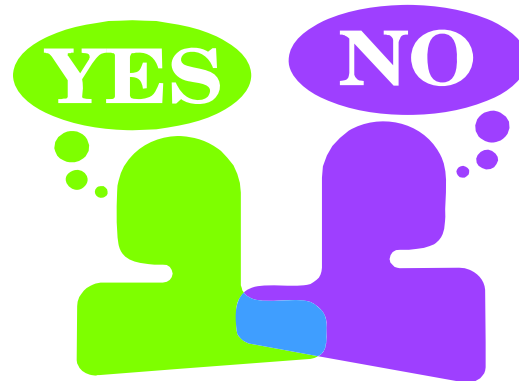
Make sure you are clear about your role (e.g. job description)



Make use of support and supervision



Ask yourself if you feel valued – if not, say what you need

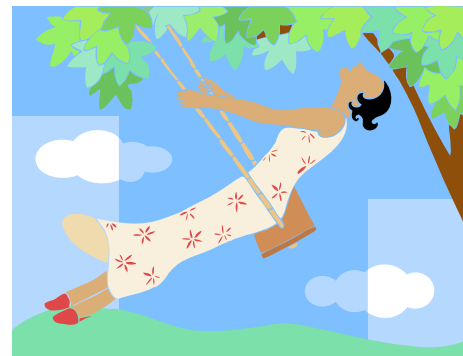


Say no if you need to

Spend time doing things which are nothing to do with mental health



Make contact with others who share your aims



Glossary

Action Research

Research designed to explore a practical situation or service, with the aim of implementing findings as they are discovered and bringing about positive change. Typically the research will follow a cycle of investigation – findings – action (implementation) – investigation – findings and so on. (See PDSA)

Audit

An investigation to measure the range and quality of a service against agreed standards.

Collaborative

In the 'Better Services for People Who Self-harm Project': a group of Local Project Teams which meet to share learning, good practice and action planning. In the 'Better Services' project there are six collaboratives in the UK, each with five or six Local Project Teams.

Collaborative research

The term 'collaborative research' is also used to describe an active partnership between researchers and service users to carry out a research project. Collaborative research can also refer to any partnership to carry out research, such as that between researchers and health service practitioners.

Commissioning research

This is the process of selecting someone to undertake a particular research project. It will typically involve advertising the research topic, selecting a shortlist of the best proposals from those submitted, and reaching a decision about which one to fund. The final decision may be informed by peer review, i.e. engaging other independent researchers and experts to read and comment on the shortlisted proposals.

Consumer

The term 'consumer' refers to anyone who is a consumer of the service, including patients, carers, long-term users of services, organisations that represent consumers' interests and members of the public who are the potential recipients of health promotion programmes. The intention is to distinguish between consumers and health or research professionals.

CRTU

The College Research and Training Unit of the Royal College of Psychiatrists

Data

Information collected as part of the research project

Dissemination

The process of ensuring that the results or findings of a research project reach a wide and relevant audience. This might involve giving talks at conferences, speaking on the radio, writing articles in newsletters or journals and giving talks at events arranged for people for whom the project is relevant.

Empowerment

Empowerment is what happens when someone gains a greater voice in situations where they have little power or say over what happens to them; or when someone gains greater control over their life through learning the skills or finding the opportunities in which to express themselves.

Epistemology

The theory or science of the method or grounds of knowledge.

Ethics (see also RECs below)

In research terms, ethics are the principles underlying the practice of research that will ensure, as a minimum, that no harm or abuse will be done to research participants. Examples include informed consent and maintaining confidentiality. Ethics can also include other values held dear to researchers and service users, such as the importance of respect, clarity and transparency, diversity and accessibility. (Note: 'Better Services for people who Self-harm is an audit project, rather than a research project, and does not need approval from Research Ethics Committees).

Evaluation

An evaluation seeks to assess how well a service or project is doing against its aims and objectives, and against some specified standards or level of quality. It is likely to use both qualitative and quantitative methods and to gain the views of service users, staff and other 'stakeholders' of the service.

Focus group

A focus group - or group discussion - is a small group of people brought together to discuss and respond to research questions. It is a good method to use when a researcher needs to gain people's views about a service or ideas about a new or ideal service.

Implementation

The process of acting on the findings of research to bring about positive change.

Informed consent

Ethically, a researcher needs to gain 'informed consent' from a research participant before they can proceed to include them in the research. It means that the participant must be fully informed and understand about the research and what involvement will entail before they agree to take part.

INVOLVE

(formerly Consumers in NHS Research) The Involve Support Unit provides advice and information on public involvement in research. There is a website and they produce a range of useful publications. www.invo.org.uk

Local project team(LPT)

In the 'Better Services for People Who Self-harm Project': The team co-ordinating the project in the local area. Each LPT is made up of representatives from the Ambulance Service, A & E Services, the Mental Health Trust and service users.

Methodology

A system of methods or ways of going about undertaking research.

NCCMH

National Collaborating Centre for Mental Health. One of seven collaborating centres established and funded by NICE to develop clinical guidelines on their behalf. The NCCMH develops the majority of the guidelines relating to mental health. It is a joint partnership between the Royal College of Psychiatrists and the British Psychological Society.

NICE

National Institute of Health and Clinical Excellence. NICE is the independent organisation responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health. (NB Since the production of the NICE Self-harm guideline NICE has become the National Institute for Health and Clinical Excellence.)

NICE Guidelines

NICE guidelines are recommendations for good practice for the treatment and management of specific health conditions. They are developed by a group of health workers, people who have the health condition themselves, carers and scientists. The recommendations are based on research evidence or, where no research evidence is available, on agreed recommendations of the guideline development group.

NICE Self-harm Guideline

Good practice recommendations developed by NICE for the physical and psychological management of self-harm in the first 48 hours after a person self-harms.

NIMHE

National Institute of Mental Health, England

Outcome/outcome measure

An outcome may be the result or effect of a treatment on a patient, e.g. a change in the level of depression caused by the use of anti-depressant medication. The outcome measure is what is used to measure the effect of the treatment on the patient. In this case, a questionnaire may be used before and after the use of the medication to assess whether it has brought about any change.

Peer review

The process by which a team of likeminded peers visit another team to review the service. For the self-harm project, a group made up of healthcare professionals and service user experts will spend a day visiting a local team, to find out about their service and help them make plans to improve. Unlike some 'inspections' by outside bodies, peer-reviews build on the fact that reviewers have a real understanding of the issues because they either work in, or are users of, similar services. The peers can therefore be supportive, encouraging and offer ideas for improvement based on their own experience.

PDSA

The Plan–Do–Study–Act cycle

The PDSA is an approach to quality improvement that encourages teams to plan changes, test their effectiveness over time, and then continue to make improvements on an ongoing basis. For the Self-Harm project, once initial data has been collected, teams will look at the findings and decide where improvements are needed. Teams then attempt to make the changes and then re-evaluate some time later to see if improvements have been made, and if the changes were lasting. Teams are encouraged to work on small changes first, and then build on their success over time.

Qualitative research

This is research that endeavours to gain understanding about personal experience and the meanings behind actions or beliefs. It is usually obtained through in-depth interview and seeks themes and issues rather than facts and figures. As it produces rich and detailed information, there will be few participants and analysis may not be applicable to the general population.

Quantitative research

This is research that aims to understand the world through measurement, facts and figures: data that can be readily analysed through statistical methods and widely generalisable.

REC

Research Ethics Committee. Local RECs have the responsibility of giving approval for research projects to go ahead. They are concerned with good practice in relation to the treatment of patients and clients in research as well as with high quality standards in research.

Research Governance

Research Governance refers to the process by which broad principles are set for good and ethical practice in research; it seeks to promote high quality scientific and ethical standards, encourage innovative research, and prevent poor performance and adverse incidents. The Research Governance Framework for health and social care was published in April 2001.

Self-harm

The NICE guideline defines self-harm as 'self-poisoning or self injury, irrespective of the apparent purpose of the act'. The guideline recognises that there are many culturally acceptable actions which result in self-inflicted physical or psychological harm, such as smoking, excessive drinking, over-eating or dieting, or that self-harm may form part of an accepted religious practice, social protest or be done as body enhancement. However, the NICE guideline and the 'Better Services for People Who Self-harm Project', focus on acts of self-harm which are an expression of personal distress and where the person directly intends to injure her/himself. (Note 1)

Self-injury

The term 'self-injury' is used to describe a wide range of actions including cutting, burning, hanging, stabbing, swallowing objects, inserting objects into the body, shooting, and jumping from a height or in front of vehicles

Self-poisoning

'Self-poisoning' includes overdosing on prescribed or over-the-counter medication. It could also include poisoning oneself in some other way, such as taking a dangerous amount of a street drug or drinking a harmful substance.

Self-harm Support Group

A group, open to people who self-harm, which meets to offer mutual support. It may be facilitated by service users or by mental health workers.

'Service user' and 'Survivor'

These terms can be used rather differently by different people. The term 'service user' is usually used where the people to be involved in a project are using or have used services, i.e. they are or have been patients or clients. Very often, in the context of research, this means they have used the service being explored within the research project.

The term 'survivor' is often intended as a more broad term to include people who have experienced mental or emotional distress, whether or not they have used mental health services. However, 'survivor' is also used politically to refer to people who have survived mental health services and/or treatments; in this sense it is shorthand for 'psychiatric system survivor'.

Stakeholders

These are people or organisations who have a recognisable 'stake' or interest in the service or project in question.

TOXBASE

The National Information Poison Service's computerised database, which is available via the internet to healthcare professionals. This database is the primary toxicology information source in the UK for the management of poisoning

User controlled / user-led research

This is research where service users lead or control the research: design, undertake and disseminate the results of a research project. There may be a distinction between the two: user controlled research may be more comprehensively under the control of service users, whereas user-led research may be funded from within an organisation where some control is retained but is led by service users. There is a project currently funded by Involve to scope this area, and to arrive at agreed definitions.

User group

A group or organisation made up entirely of users or ex-users of services. The term 'user group' often refers to a local group of people who have used mental health services. Groups are involved in a range of activities, which may include: mutual support, representing user views on statutory committees, consulting on and auditing local services, campaigning on local and national issues, running Patients' Councils and user forums, providing user-led mental health services etc.

Voluntary sector organisation

A charity or not-for-profit organisation. In the field of mental health some leading voluntary sector organisations are Mind, Rethink, Sane, and Richmond Fellowship - plus many other national and local charities.

Note 1

NICE Guideline page 16: 'It is important also to acknowledge that for some people, especially for those who have been abused as children, acts of self-harm occur seemingly out of the person's control or even awareness, during 'trance-like' or disassociative states. The guideline therefore uses the term 'self-harm' rather than 'deliberate self-harm'.'

With thanks to

SURGE: 'Guidance for Good Practice: Service User Involvement in the UK Mental Health Research Network', Faulkner, A.,2005.

INVOLVE 'A guide to reimbursing and paying members of the public who are actively involved in research:

☺ 16 ways to maintain a healthy level of insanity ☺

- At lunch time sit in your parked car with sunglasses on and point your hair dryer at passing cars. See if they slow down.
- Page yourself over the intercom. Don't disguise your voice.
- Every time someone asks you to do something ask them if they want fries with that.
- Put your rubbish bin on your desk and label it 'in-tray'.
- Put decaf in the coffee maker for three weeks. Once everyone has got over their caffeine addictions switch to espresso.
- don't use any punctuation
- As often as possible skip rather than walk.
- Specify that your Drive-Through order is 'to take away'
- Sing along at the opera.
- Go to a poetry recital and ask why the poems don't rhyme.
- Put mosquito netting around your work area and play tropical sounds all day.
- Five days in advance tell your friends that you are not in the mood to go to their party.
- When the money comes out of the ATM, scream, 'I won, I won!'
- When leaving the zoo start running towards the car park screaming, 'run for your lives, they're loose.'
- Tell your children over dinner, 'I'm sorry but due to the economy we are going to have to let you go.'
- And the final way to keep a healthy level of insanity.....Send this to someone to make them smileit is called therapy...

Contact form for user members of local project teams

We would like to be able to contact service user team members direct, for example to send you newsletters, let you know of training opportunities, ask for your feedback etc. However, if you prefer to be contacted through the local project team lead, that is fine as well. Please could you complete this form and return to:

Philippa Strevens

'Better Services for People who Self-Harm'
Royal College of Psychiatrists' Centre for Quality Improvement
4th Floor Standon House
21 Mansell Street
London E1 8AA

Email: pstrevens@cru.rcpsych.ac.uk

If there is any information you would rather not give, please leave blank

Your name
Name of Project Team
Contact address
Phone
Email
I am happy to be contacted by (please tick all that apply): <input type="checkbox"/> letter <input type="checkbox"/> phone <input type="checkbox"/> email or <input type="checkbox"/> I prefer to be contacted through the local project team lead