better services for people who self-harm

NATIONAL QUALITY IMPROVEMENT PROGRAMME

# Wave 3

# Project Management Pack

Charity reg. no. 228636

College of Emergency Medicine

## Contents                                                                                    Page

**Chapter 1: Introduction**
1.1 What is the Better Services for People who Self-Harm Programme?.............. 2
1.2 Programme of activity........................................................................ 3
1.3 The partners..................................................................................... 5
1.4 Funding............................................................................................ 6

**Chapter 2: Setting up the local project team (LPT)**
2.1 Who needs to be involved?.................................................................. 6
2.2 Choosing team members...................................................................... 6
Role description..................................................................................... 7
2.3 Leading the team and managing change................................................ 8
2.4 Methods of working............................................................................ 9

**Chapter 3: Developing a communication strategy**
3.1 Communication methods..................................................................... 10
3.2 Communication content...................................................................... 11
3.3 Communication with the wider organisation.......................................... 11
3.4 Communication with user groups and voluntary sector organisations.......... 12
Information sheet.................................................................................. 13

**Chapter 4: Recruiting and working with service users**
4.1 Recruiting service users..................................................................... 14
Service user role description ................................................................... 15
4.2 Payment and time commitment............................................................ 16
4.3 Working with service users.................................................................. 18
4.4 Involving service users: a checklist....................................................... 20

**Appendix 1**: Guidance from INVOLVE for paying service users......................... 23

**Appendix 2**: Tips for service user consultation and networking......................... 26

**Appendix 3**: Ten ways for mental health workers to impede user participation planning and managing mental health services............................... 28

**Appendix 4**: Frequently asked questions: ethics and information sharing......... 30

**N.B. The information contained within this pack may be freely photocopied for all those involved in the programme of work**

© 2007 The Royal College of Psychiatrists
For further information contact Enquiries@cru.rcpsych.ac.uk

# Welcome!

Welcome to the Better Services for People who Self-Harm quality improvement programme. We have put this pack together to provide you with:

1. Information about what the programme involves, including timescales
2. Support in forming a local project team (LPT), made up of the relevant staff and service users
3. Advice on how to get as much out of participation as possible

The guidance in this pack is neither exhaustive nor definitive, but it has been drawn from our experience of running national multi-centre audits and quality improvement programmes, which we hope will be of use.

We, the **Central Project Team (CPT)**, are committed to making this process as straightforward as possible. We are available to offer you full support at all stages of the programme and we hope that you will contact us any time you feel the need. We very much look forward to working with you.

Best wishes,

*The Central Project Team*

Philippa Strevens (Quality Improvement Administrator)
Helen Blackwell (Project Worker/National Service User Advisor)
Lucy Palmer (Programme Manager)


Better Services for People who Self-Harm, Central Project Team:

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

# 1: Introduction

Self-harm is one of the top five causes of acute medical admission in the UK, accounting for up to 170,000 emergency admissions per year. The quality of care for those who self-harm depends on the quality of joint working between emergency departments and mental health services, and this currently varies across the UK.

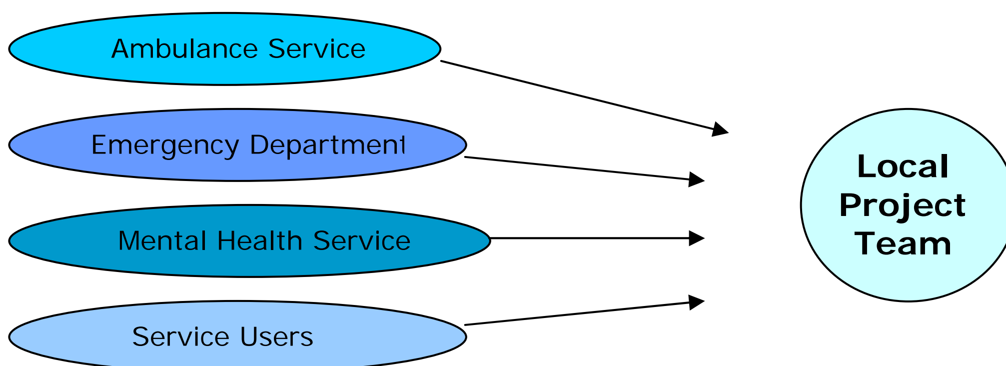
Although there are, of course, areas of good practice, many people who attend an emergency department as a result of self-harm have a negative experience. This finding greatly influenced the 2004 NICE guideline which concluded that improving staff knowledge and attitudes is the key to better services and reduction in the substantial morbidity and mortality associated with self-harm.

Through auditing local practices, you may be able to confirm commonly held assumptions about 'what is happening'. You may, however, be surprised by some of the things that are revealed. Some of the improvements identified through the audit processes will relate to the behaviour of individual practitioners, others to the structure of the services within which they practice.

You may be able to act on some of the findings immediately, e.g. by providing information to staff. Others will require medium-term solutions, e.g. increasing access to liaison psychiatry services during evenings and weekends. Others still may need long-term plans. Clearly, not all changes will be welcomed and some may be resisted. The central project team will help you to make the changes that you decide are best for your service.

## 1.1 What is the 'Better Services for People who Self-Harm' programme?

Local project teams (LPTs) are established throughout the UK, comprising of practitioners from emergency departments, their associated mental health services and local ambulance services. Local project teams are also expected to fully involve service users and we will help you with this.



## 1.2 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. There is advice in this pack about how best to do this and you should contact us if you are experiencing difficulties.

**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:

- Friday 15th June (London)
- Wednesday 27th June (London)
- Thursday 5th July (Manchester)

If you have not received a booking form please contact the central project team.

**July – October 2007**

**Data collection (between July – Oct 07)**

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. Older teams that have already taken part in the 'Better Services' programme will also complete a self-review document, measuring their long-term progress.

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 you to compare your 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:<br>• Lead a peer-review<br>• Learn more about applying the principles of change management<br>• Talk to other members and consider which team they might wish to visit for the peer-review<br><br>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 in 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.<br><br>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 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 have 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. |
| **Throughout** | Teams will be also be offered a range of **change interventions**, including training material, information for service users, checklists and tools. |

## Networking and Communication Opportunities

To join the email discussion group, allowing you to ask others for advice, share documents and 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**

### 1.3 The partners and the wider collaboration

The 'Better Services for People who Self-Harm' programme is being led by the Royal College of Psychiatrists' Centre for Quality Improvement, in partnership with the following organisations who represent key professionals in the care and support of people who self-harm.

- The Faculty of Accident and Emergency Medicine and the College of Emergency Medicine
- The Royal College of Nursing
- Mind
- The NICE National Collaborating Centre for Mental Health

The Central Project is advised by a steering group made up of representatives from the above organisations, as well as service users, and carers.

### 1.4 Funding

This programme is partly funded by the Health Foundation, which means that teams are able to take part at a reduced rate. The Health Foundation is an independent charity. This is one of several programmes that form the Health Foundation's 'Engaging with Quality' initiative, which aims to address the gap between 'current' and 'best' practice within various healthcare settings. See www.health.org for more details.

Other costs you need to be aware of are those stipulated in the 'Declaration of Understanding'. For example, service user representatives on your LPT should be reimbursed (session fees and reasonable expenses) and staff on your team will need a small amount of time and travel funds to be able to attend events. We estimate that the following number of days will be required **over the 18 month period**:

- Service users: between 6-8 days each
- Team lead: between 8-12 days
- Other members of the team 4-6 days each

A minimum of five people should form your local project team. Members can be rotated if necessary, but all parties (ambulance, emergency department, service users, mental health) should be represented.

# 2: Setting up the local project team (LPT)

## 2.1. Who needs to be involved?

The process will need to be 'owned' by the local project team itself and others being affected by the work. It is therefore vital that the people are involved and informed from the outset and throughout the course of the work.

## 2.2. Choosing team members

The composition of the project team is extremely important.

Include service users on the team (see section 4 for more details)

Invite some senior people from within the organisation, to demonstrate that there is commitment to the work. It may not be possible for the most senior staff to play an active role in running the LPT, but they should be aware of it and at least one member of the LPT should have a high level of seniority.

Involve individuals who are respected by their colleagues, for greater credibility

Are there people in the organisation who are unconvinced of the value of such initiatives? If so, it might be better to get them actively involved from the start.

Are there people in the organisation who are generally very supportive of initiatives of this kind? If so, it would be good to have them on the team too.

Stability of membership will increase the productivity of the team

Try to choose people who are able to influence their own colleagues (for example by encouraging colleagues to complete the online survey and read through training material). Key members should include the following:

- A member of your local ambulance trust
- At least 1 member of emergency department staff
- At least 1 member of your liaison psychiatry service / mental health trust
- Between 2–3 service user representatives
- (Optional) - Clinical audit/governance staff, representatives from specialist self-harm services in the local area and/or local voluntary sector organisations

**See the role description overleaf – this may be worth circulating to potential LPT members to ensure that they are clear about their role. Feel free to amend.**

**The role of the team will be to:**

- Ensure the programme of work is integrated within existing quality/audit structures
- Highlight the benefits of the work
- Enthuse and motivate by example
- Monitor adherence to local, regional and national time-scales
- Link with the central project team at the CQI
- Foster networking with other participating teams
- Devise and oversee a communications strategy

**Better Services for People who Self-Harm**

**Staff Member of local project team (LPT)**
**Suggested Role Description and Person Specification**

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

- Joining a local project team of 5-10 people, alongside trust colleagues from ambulance, emergency department and mental health, as well as 2-3 local service users
- Attending local project team meetings and contributing to discussions
- Helping to raise awareness of the programme with colleagues from your speciality
- Encouraging colleagues to complete a survey of their views on self-harm services
- Helping to collect other data, if necessary
- Visiting another team (with members of your LPT) for 1 day to discuss how their service could be improved and receiving a visit from another team
- Attending a number of workshops with your local project team

## Essential criteria

Interest in and enthusiasm towards improving services

Experience of working with people who have self-harmed

An appreciation of the importance of service user involvement

Ability to work in groups

Available to devote between 3 to 5 days over the course of the project (18 months)

## A bonus!

Experience of quality improvement or service evaluation.

Ability to influence others, including a possible 'cultural' shift

Understanding of issues facing people who self-harm

### Incentives for staff representatives

- The opportunity to directly influence change
- A chance to further develop your own skills
- The opporunity to work in partnership with service users on a quality improvement programme
- A certificate of participation
- Establishing better links with colleagues from other services within the trust, as well as user groups and voluntary sector organisations

## 2.3. Leading the team and managing change

You may be reading this because you are already the team lead. However, if you are not, and you need to assign the task to someone, you may find the following points useful:

- **Champion:** the lead needs to have an infectious sense of enthusiasm towards improving services for people who self-harm
- **Seniority**: this person will need to have the authority to 'make things happen', both in relation to getting the audit data collected, and in driving forward service improvements in the future
- **Respect, credibility and 'breadth':** the work programme necessitates the involvement of a wide section of people from different organisations. The lead will need to work effectively with all of these groups and individuals.
- **Time:** each component of the programme will have dates and deadlines for completion. The team lead needs to co-ordinate input across the team and to ensure that deadlines are met.

**What exactly is a leader?**

Some examples of leadership qualities commonly cited are:

- The ability to 'see what's going on' from different points of view
- Good communication and articulation
- The ability to think on your feet
- Humour and empathy
- Flexibility
- Integrity
- Compelling presence and the ability to make change happen:

**You may find the following change management principles useful:**

1. Thought processes and relationship dynamics are fundamental if change is to be successful
2. Change only happens when each person makes a decision to implement the change
3. People fear change if it "happens" to them
4. Given the freedom to do so, most people will build quality into their work as a matter of personal pride
5. Traditional organisational systems treat people like children and expect them to act like adults
6. "Truth" is more important during periods of change and uncertainty than "good news"
7. Trust is earned by those who demonstrate consistent behaviour and clearly defined values
8. People who work are capable of doing much more than they are doing
9. The intrinsic rewards of a project are often more important than the material rewards and recognition
10. A clearly defined vision of the end result enables all the people to define the most efficient path for accomplishing the results
11. The more input people have into defining the changes that will affect their work, the more they will take ownership for the results
12. To change the individual, change the system

## 2.4. Methods of working

**Creating a structure**

At the earliest point, the 'ground rules' for your LPT should be established. The sooner that team members know what is expected of them the more likely it is that they will work together effectively. You may wish to consider the following in defining your working arrangements.

- How often will you meet?
- When and where will you meet? (NB: providing food enhances attendance at meetings!)
- Can some meetings be held via telephone or video link if members are geographically diverse?
- How long will meetings last?
- Will the meetings be formal or informal?
- How will action points from the meeting be recorded and circulated?
- Think about structures which enable participation from *all* groups involved (see chapter 4 for more information on service user involvement

You may find it useful to complete the information on the back page of this document to include contact details for each member of your LPT and copy to your colleagues.

**Reviewing membership**

It is important to monitor the membership of your Local Project Team. If a person finds it impossible to attend consecutive meetings it may be appropriate to consider a replacement. By regularly ensuring the team membership is appropriate you can avoid:

- Resistance from groups of people who feel their views have not been adequately represented in setting up the audit locally;
- A small group of people feeling overwhelmed trying to manage the local data collection
- Loss of momentum

# 3: Developing a communication strategy

More people in your organisation will need to know about the work of the programme than could be accommodated on a working group. You will therefore need a communication strategy.

The involvement of the many people in your organisation whose work will relate to the work of 'Better Services' may be very active (e.g. collecting data or taking part in LPT meetings) or more passive (e.g. being consulted or receiving regular updates). Groups to consider include: ambulance professionals; service users; psychiatrists; nurses; clinical audit staff and senior management. You will need a communication strategy that defines the ways that you will keep these groups involved with, or informed about, the programme's progress. Consider:

- How will we make sure that trust staff have heard of the programme?
- How will we get across the benefit and importance of the programme?
- How will we ensure a good response rate to the staff and service user surveys?
- How will we disseminate the findings and key messages?
- Who will be responsible for establishing and maintaining this link?

A communication strategy will help you to understand and be clear about who will carry information and feedback about the project to the various 'stakeholder' groups.

## 3.1. Communication methods

Try to avoid re-inventing any wheels. Find out what systems are already in place and then 'hijack' them. Some examples are:

- Local newsletters
- Open meetings with senior management
- Bulletin boards in various clinical settings
- Existing meetings e.g. management committees, professional development sessions
- Intranet systems

In addition, you may wish to use one or more of the following approaches:

- Plan early meetings with key stakeholders to discuss how you are going to involve them
- Nominate 'link people' from your LPT to keep specified groups informed of progress

## 3.2. Communication content

**The details of the 'Better Services' programme**

The information sheet on page 13 can be circulated trust-wide. You can also copy and distribute sections of this document to your team mates to help them understand the programme in more depth. As the programme progresses, you may also want to inform people about key events and dates.

Later you will want to communicate major findings from the work and planned changes and interventions resulting from the findings.

**Hopes and fears**

People may have all sorts of concerns about the impact of the project on them. It is advisable to provide a forum where these can be discussed openly. For example, you could encourage discussion of concerns within an internal email discussion group if you have one already in existence. Or you could make this an agenda item for an existing multidisciplinary meeting or ward meeting.

**Benefits of involvement**

Try to stress the potential benefits of supporting the project. Staff are more likely be supportive if they can see clearly the link between the project and a positive impact on their working lives, and the lives of the people who use the services they provide.

## 3.3. Communication with the wider organisation

Change does not occur in a vacuum; changes in one area may produce knock-on effects for other processes within your organisation. Informing related groups within your organisation will help ensure that activities will be supported. On the contrary, if people hear about the work indirectly, they may feel that their contribution or involvement is not important and therefore feel less committed to implementing changes suggested as a result of the project.

Quality improvement activities are often perceived as cost-cutting exercises. Keeping people well informed can help dispel unwarranted fears. Similarly, this type of initiative can be seen as something 'imposed' by management, rather than as a response to a real issue. Telling people what is happening from the start can stop this from happening.

## 3.4. Communication with management

The programme will generate information. As staff and service users will all be invited to comment on the state of current practice, potential areas for improvement might be diverse. To be a catalyst for change, your LPT must have direct access to senior decision makers. You should be able to expect the following from senior managers:

- Support in carrying out the programme's work
- Interest in hearing regular updates on findings
- Commitment to agreeing areas for quality improvement
- Support in identifying and monitoring appropriate action plans
- Communication of findings and resource needs to the trust board

As well as providing practical support, visible management endorsement will lend credibility to change activities and these may stand a better chance of being accepted and implemented into clinical practice.

## 3.5. Communication with user groups and voluntary organisations

It is important that people with personal experience of self-harm in your locality get to know about the programme and receive information about it. This will help you:

1. Recruit service users to the LPT
2. Secure a high response rate to the service user survey
3. Feed back local findings and discuss action plans

There are guidelines in networking with local groups and organisations in Appendix 1 and in the service user handbook. Of course it will be important to publicise the findings to people using the full range of statutory mental health services.

It will be more difficult to make contact with those people who have used emergency services for treatment for self-harm just once or twice, but do not have ongoing contact with mental health services. It may be important here to think about ways of raising awareness of the project amongst the local community generally (for example through local media). Think also about contacting organisations outside the mental health sphere whose users may have experience of self-harm, e.g. women's refuges, support groups for people who have experienced abuse.

The whole team should be involved in developing a publicity and communications strategy for contacting people in the area who have experience of self-harm. Service user representatives will have a key role in implementing the strategy, but will need the support, involvement and resources of other team members as well.

**You may wish to copy the information sheet on the next page and circulate to Trust staff to make them aware of the project.**

**To download a copy of this leaflet, please go to the Wave 3 Member's Area of the project website: www.rcpsych.ac.uk/cru/auditselfharm.htm**

better services for people who self-harm

NATIONAL QUALITY IMPROVEMENT PROGRAMME

# Information Leaflet

**What is the 'Better Services for People who Self-Harm' Programme?**
This national quality improvement programme helps teams improve services for people who self-harm. Staff and service users are asked what they think about the treatment people receive during the first 48 hours after self-harm. In some cases, key activity data is audited. Your trust is one of over 50 in the UK that have signed up to this programme, which aims to ensure that:

- Staff feel more comfortable and confident working with people who self-harm
- Service users will report a better experience of care and treatment

Your local team lead, responsible for coordinating your Trust's involvement in the programme is:
____________________who can be contacted on____________________

**What do I need to do?**
Because your work involves contact with people who self-harm, you will be invited to complete a survey within the next few months, asking you what you think about:

- Is the training that staff receive around mental health and self-harm adequate?
- How do you find working with people who self-harm? Stressful? Rewarding?
- Is the ED an appropriate place for people who self-harm?
- How could handover be improved? And so on.

The survey will be available online, and your team lead will send you the relevant link – completing it should take no longer than 15 minutes.

**What happens to be responses?**
Your responses will go directly to the central project team who will summarise them anonymously in a report, along with the views of other staff, as well as people who have recently used your service. The findings will then be discussed in a peer-review, where other staff and service users will visit your ED for the day to help plan future improvements. A local project team, steered by your local team lead, will then work to bring about positive change for staff and patients, with support from the national project team.

**Who is running the project?**
The Royal College of Psychiatrists' Centre for Quality Improvement, in partnership with Mind, the Faculty of Accident and Emergency Medicine/College of Emergency Medicine the Royal College of Nursing, the Royal College of Physicians and the NICE National Collaborating Centre for Mental Health. It is funded by the Healthcare Foundation, an independent charity.
This project is classified as quality improvement, not research. Participation in the audit surveys is voluntary.

**For more information on the project please contact Philippa Strevens or Lucy Palmer at the Royal College of Psychiatrists' Centre for Quality Improvement:**
**Tel: 020 7977 6643  Email: selfharmproject@cru.rcpsych.ac.uk**
**Web: www.rcpsych.ac.uk/cru/auditselfharm.htm**

# 4. Recruiting and working with service users

Teams that have already taken part in the 'Better Services' programme cite user involvement as one of the most instrumental factors in helping them achieve positive change. Service users bring a wealth of experience to the team and can provide invaluable insight that cannot be obtained from other sources (in the same way that professionals from different disciplines will each bring knowledge and experience that is unique to their sphere of involvement). Service users can be highly influential within the team, and as ambassadors for the project within the wider service user community. The process of engaging and working with service users is one that has to be undertaken with care, however, and we hope that you will find the following guidance helpful.

## 4.1. Recruiting service users into your LPT

**Who to recruit?**

People with personal experience of using mental health services, and at least one service user who has experience of self-harm (see description below for more detail)

Service users who have experience of working on committees or groups, or are interested in learning to do so

Consider the implications of including workers and users who are or have been in an ongoing clinical relationship. If this situation occurs, discuss carefully with both parties whether this working relationship will be appropriate or whether one party should re-consider their involvement

**How to recruit?**

Consult with **voluntary organisations**, such as the ones below. Though they are not themselves user groups, these organisations may be in touch with many service users and be well placed to help you recruit (Mind should already be aware of the programme).

Mind: to find your nearest branch, visit mind.org.uk or call 0845 766 0163
Rethink: to find your nearest service, visit rethink.org.uk or call 0845 456 0455
Ethnic specific organisations, mental health advocacy projects, supported housing projects

Consult with **user groups** by asking your local Mind group for contacts or looking on the web. The leaders of local user groups may themselves be an excellent candidate to recruit, or they may suggest/nominate others. As well as being an excellent source of candidates, recruiting through a user group will ensure that the people who take on the role will have links with a network of other users for reference and support.

Make links with more than one user group. Even if all the service user members of the team are eventually recruited from the same organisation it will be necessary at various stages of the project to consult with wide networks of users and making these links early will help with this process. You might also consider **hosting a meeting** at which information about the project and the role of the team is presented to a number of service users and invite participants to nominate themselves once they are fully informed.

## 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 8 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.

**Incentives for potential service user representatves**
You might want to point out the following benefits:

- The opportunity to directly influence change
- A chance to further develop their own skills
- Involvement can make positive use of their own mental health expereinces
- The trust will pay them for their time
- A certificate of participation

**Paying service users for their time and expenses**
The need to pay service users for any work they undertake cannot be emphasised enough; it is likely that everyone else in the team is being paid for their time and skills. Service users should be offered a fair rate of payment that covers the time they spend on any aspect of their role, including: attending meetings or other events; reading papers; collecting data; consulting with other service users; liaison with other members of the team etc.

Please don't assume that service users are receiving social security benefits and therefore set artificially low rates of pay for this reason. However, do inform people that if they are receiving benefits it is their responsibility to take advice on the way in which payment may affect their social security status.

The rate of pay for service users on your team is for you/your trust to negotiate. Provision should be made to reimburse service user members for expenses incurred as a result of their participation in the team. This could include travel costs of attending meetings, subsistence, or other out of pocket expenses. Some examples of payment and further best practice guidance can be found in appendix 1.

**Guide to time commitment for service user members of local project team**

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 a user if they 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. They 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.

## Guide to time commitment of service users

| Activity | Estimated no of days per user |
|---|---|
| Attend introductory workshop (June/July 07) | 1 day |
| Contact with a local user group or service to encourage responses to the service user survey (between July - Oct 07) by telephone, email, writing or in person. *Please note: posters, surveys and information sheets will be provided.* | 1 day |
| 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 | 8 days |

This is for guidance only and is up for negotiation between each local team. As there will be two (or even three) service users on the team, you can split some of the tasks between them.

**Who should oversee the recruitment process?**
Someone with enough time! Make sure the recruitment of service user members is undertaken with as much care and thought as for any kind of personnel recruitment. The service user members of the team are equal partners rather than "token" representatives so it is not the case that just "any one will do"; it may take some time to recruit people with the right skills and experience.

Consider delegating responsibility for the recruitment process to one or more of: a) the lead/chair of a local user group; b) the person within your service whose responsibility it is to ensure service users are involved in service improvement initiatives (if such a person exists); an external service user consultant if you already have a relationship with one.

**How many service users should we recruit?**
Ideally, 3 service users, but a minimum of 2. It is not good practice to include only 1 service user on a professional working group, as a real or perceived power imbalance could make it difficult for that person to contribute effectively. Consider the balance between the number of service users and professionals on the team, to ensure that users have peer support. Recruiting 2 or 3 users also allows for the fact that individual users may be absent at times due to fluctuating health.

**When to recruit?**
Involve service users right from the start. It can be very difficult for anyone to act effectively in a team, or influence the direction of the project if key decisions have already been made by everyone else.

**What information do prospective service user members need?**

- The aims and objectives of the project
- The person specification and job description (page 15)
- A list of the other team members, as well as contact details of person within the team who will act as the contact for the service users
- Information about how service users can specify what support needs they may have
- Time-scales of meetings, what will be involved, and the venues, duration etc
- Information provided should be clear, concise and jargon-free
- Once initial information has been imparted there should be opportunities for interested people to talk about the project one-on-one with the local lead before deciding whether to join

All of the above is described in more detail in the **service user handbook** which should be distributed as early as possible to service user representatives.

**Having problems recruiting?**
Call the central project team on 0207 977 6643 if you would like advice on this, or email Helen Blackwell, National Service User Advisor on hblackwell@cru.rcpsych.ac.uk

Helen will advise you on the best course of action.

## 4.3. Working with service users in a professional team

Having successfully recruited service users into the LPT you may want advice on working together in such a way that everyone on the team contributes effectively and the team is best placed to achieve its goals. The following guidance has been drawn from several sources including professional service user consultants and the published documents listed at the end of this section.

Adopting a 'service user friendly' method of working such as this may require some new ways of thinking and working that at times could be challenging. The outcomes should be rewarding however and the service improvements you hope to produce should be all the more relevant and rooted in 'real life' for it.

**The service user's role in the team**
Service users will bring valuable personal experience to the team; however there is rarely one 'user view' and so it is unrealistic to expect the few users on your team to 'represent' the wider user community. Key aspects of the user role should be to:

Access the opinions and experiences of a range of other service users (e.g. via their existing user group links) when 'user views' are needed
Help to achieve a high response rate to the service user surveys
Inform the wider service user community about the project and specific interventions the team is involved in implementing

These tasks should be assisted by other team members.
Whilst service users are uniquely able to bring first hand experiences of using mental health services to the team, this does not mean that other members do not need to also consider this perspective and raise issues relating to it. Furthermore, service users' thoughts about other matters are equally valuable and should be encouraged. As individuals on the team, the service user members have an important role in developing the project locally, making decisions about how to carry out the project work, interpretation of results, implementing interventions to improve services and so on.

Crucial to effective team work is each member being clear and confident about their role and responsibilities. Whatever the details are that you negotiate as a team, it is most important that all members are fully informed of these details and given the opportunity to judge whether they are able to fulfil that role. Initiatives such as this one often risk failure because expectations of service users are either unclear or unrealistic.

Everyone wishes to be treated with dignity and respect whether they are service users or professionals and it is the responsibility of all members of the team to ensure that this takes place. Any discourtesy should be challenged and resolved and any antagonistic attitudes (towards any member of the team) should not be tolerated.

## Further reading:

Reward and recognition: The principles and practice of service user payment and reimbursement in health and social care. Department of Health, http://www.dh.gov.uk

'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

## 4.4 Involving Service Users – A checklist

### 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

Involving the public in NHS, public health, and social research: Briefing notes for researchers, Hanley B et al, 2003, INVOLVE

## Contact us

**We hope that this information pack answers some of your questions but please feel free to contact the Central Project Team at any stage of the programme:**

'Better Services for People who Self-Harm' Central Project Team

Royal College of Psychiatrists' Research and Training Unit,
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

This project management pack and other documents can be downloaded from the Wave 3 Member's Area of the Project Website:
**www.rcpsych.ac.uk/cru/auditselfharm.htm**

## 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
http://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 yourself the following questions:

**How does the principle of equity apply in this situation?**

- What level of skills, expertise, and experience am I 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 am I 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 for people who use services about 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: Tips for service 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-harmand 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) • Black and ethnic specific mental health projects • Disability groups • 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.

**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.

## Appendix 3: Ten ways for mental health workers to impede user participation in planning and managing mental health services - 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 of 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 then 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 4 – Frequently asked questions – ethics and information sharing

**What about research ethics governance?**

This project is classified as audit and not research, and does not require approval from a research ethics committee. That said, the Royal College of Psychiatrists' Centre for Quality Improvement (CQI) is committed to applying the highest ethical standards to its audit work.

In February 2006, the 'Better Services for People who Self-Harm' Programme submitted a full description of the project to the Central Office of Research Ethics Committees (COREC), detailing the audit methods used for the programme, including staff and patient surveys and consultations, the auditing of case notes and conducting peer-reviews. This included a list of the questions being put to service users and staff. The CQI also reiterated the safeguards it has put in place to protect the dignity, wellbeing and safety of participants throughout the audit process and gave examples of information sheets and guidance notes. The following reply was received from COREC:

"*Thank you for your query. We have read the documents you attached and would deem your work to be audit. We agree entirely that audit should be conducted to accepted ethical standards and your document clearly outlines this*".

(COREC February 2006).

For further information, please see www.rcpsych.ac.uk/ccqi

**Who owns the data?**

Any data collected by a local project team as part of a clinical audit or quality improvement exercise will belong to that team's trust/service. 'Better Services' will make available to each trust/service their raw data in an electronic (and often paper) format for the team to use in any way they wish. 'Better Services' would not seek to use data belonging to an individual Trust/service in any way other than to provide feedback to that trust.

Ownership of collated data sets that 'Better Services' creates from amalgamating data submitted by all members will be retained centrally. 'Better Services' may also publish data from collated data sets in publications or on our website. Any use of collated data sets would not identify individual trusts, unless to highlight good practice.

# Local Project Team (LPT) Members

| Role | Member | Member |
| --- | --- | --- |
| Team Lead | Name<br>Job Title /Role<br>Address<br><br><br><br>Contact Telephone<br>Fax<br>Email | |
| Representative(s) from Mental Health Service | Name<br>Job Title /Role<br>Address<br><br><br><br>Contact Telephone<br>Fax<br>Email | Name<br>Job Title /Role<br>Address<br><br><br><br>Contact Telephone<br>Fax<br>Email |
| Representative(s) from Ambulance Service | Name<br>Job Title /Role<br>Address<br><br><br><br>Contact Telephone<br>Fax<br>Email | Name<br>Job Title /Role<br>Address<br><br><br><br>Contact Telephone<br>Fax<br>Email |
| Service User Representatives | Name<br>Job Title /Role<br>Address<br><br><br><br>Contact Telephone<br>Fax<br>Email | Name<br>Job Title /Role<br>Address<br><br><br><br>Contact Telephone<br>Fax<br>Email |
| | Name<br>Job Title /Role<br>Address<br><br><br><br>Contact Telephone<br>Fax<br>Email | Name<br>Job Title /Role<br>Address<br><br><br><br>Contact Telephone<br>Fax<br>Email |
| Other Team Members | Name<br>Job Title /Role<br>Address<br><br><br><br>Contact Telephone<br>Fax<br>Email | Name<br>Job Title /Role<br>Address<br><br><br><br>Contact Telephone<br>Fax<br>Email |