Service User Research Group for England (SURGE)
UK Mental Health Research Network

Brief Guide to Involving

Mental Health Service Users

in Research

By

Louise Morgan
Research Worker
Service User Research Group for England

Brief Guide to Involving
Mental Health Service Users in Research

This guide has been produced to support SURGE's *Guidance for Good Practice* as a tool for researchers, hub personnel and lay service users who wish to develop collaborative research projects and programmes involving service users within the Mental Health Research Network.

The *Brief Guide* is intended to supplement rather than replace the *Guidance for Good Practice*, and we recommend readers refer to the full publication for further details (available from www.mhrn.info/surge).

What is SURGE?

SURGE is the Service User Research Group for England and is the service user arm of the UK Mental Health Research Network (MHRN). We have been set up to support mental health service users and people from universities and NHS trusts as they work together on mental health research.

SURGE contact details:

SURGE, Sainsbury Centre for Mental Health,
134-138 Borough High Street, London SE1 1LB.

Email: info@surge.scmh.org.uk
Phone: 020 7716 6778.

INDEX

What is service user involvement?

Service user involvement refers to the active engagement of individuals who have experience of using mental health services and/or mental health difficulties in planning, undertaking and disseminating research and national research structures. This is distinct from participating in research as a subject and instead refers to service users having a genuine input as partners at each stage of the research process.

Importance of involvement of service users in research

Meaningful service user involvement in the whole research process, from the development of research questions through to the dissemination of findings, is invaluable in bringing a different perspective to the research process. This generates important questions which are highly relevant to clinical practice and help to improve the evidence base used to inform how services are provided.

Three Key Principles

1) Clarity and Transparency

Anyone wishing to engage service users in research needs to be clear about why they are seeking user involvement. Service users also need to think about why they wish to become involved in a piece of work. Both parties need to be open and consider their expectations and what they hope to gain. It is useful for both parties to put their reasons down in writing and/or have a frank discussion at the start of a project.
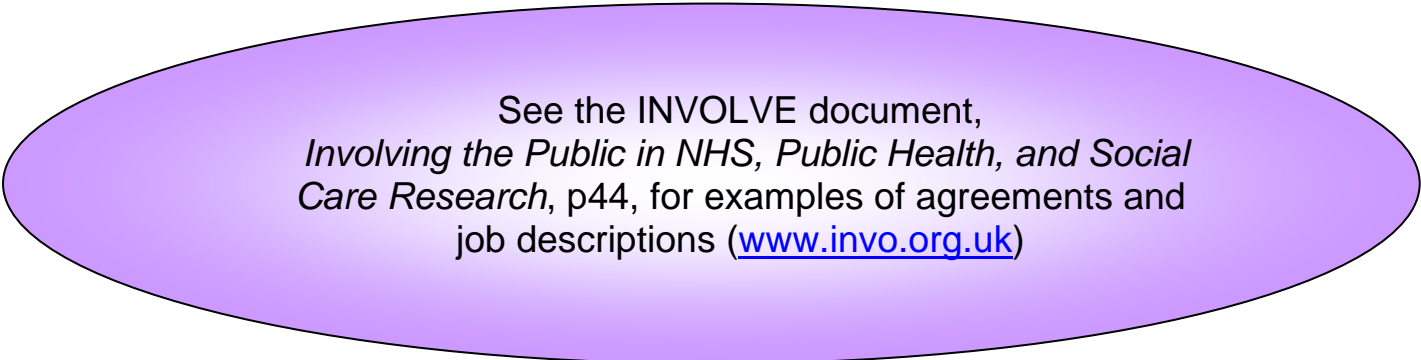
Clarity is needed from the start about:
- The nature and aims of a project, and the roles, responsibilities and time commitment of all parties
- Any limits to service users' involvement that cannot be avoided or overcome, for example, limits to the aspects of a project that can be influenced or participated in
- Incentives available for involvement (e.g. payment, training)
- What support and supervision is to be provided

Writing a role description and specifying what skills are needed can help people think through these issues and ensure clarity. Try not to see this as a formal or off-putting process: it is simply intended to make sure all parties have thought about, communicated and agreed the details of what involvement will mean.

It may be helpful to establish a written agreement which outlines rights and responsibilities on each side (for example, see Trivedi and Wykes, 2002).

http://bjp.rcpsych.org/cgi/reprint/181/6/468.pdf

See the INVOLVE document,
Involving the Public in NHS, Public Health, and Social Care Research, p44, for examples of agreements and job descriptions (www.invo.org.uk)

2) Accessibility

- It is essential to discuss any access needs at the start of a project: is there anything you or others need to enable all to participate fully? For example, hearing induction loop, British sign language interpreter, large print documents, specific seating or lighting, regular breaks, etc.
- It is important for everyone to use plain language, avoid unnecessary jargon and explain jargon clearly where its use is unavoidable.
- Accessible formats for the presentation of research materials may be helpful for research collaborators as well as participants.

<div align="center">

3) <u>Diversity</u>

</div>

- Think about the diversity of the population served: include people from minority ethnic communities and people with different mental health diagnoses; take into account issues relating to gender, sexuality, religion and physical disabilities/sensory impairments.
- Ensure the diversity of the service users to be involved in a piece of work reflects the nature of the project itself.
- Taking diversity on board may require additional outreach and capacity-building work: be prepared to go out to community groups; identify the difficulties and issues around involvement; be flexible in your approach; and build and maintain relationships over time.
- Be clear whether you are asking a service user to represent a broader 'community' or their own perspective. If you/they are to be a representative, be sure that connections with broader groups are in place and that enough time is provided to discuss issues with these groups.
- Take into account the diversity of views among service users. Like anybody else, not all service users feel the same way about specific issues or research projects.

Two Essential Factors for Successful Collaboration

<div align="center">

1) <u>Support</u>

</div>

<u>Adequate support</u> for service users is vital. It is important not to assume what (if any) support an individual may need, so open dialogue is essential.

You will need to consider the following areas of support:
- ➢ **Practical** (e.g. administrative, financial, travel arrangements, communications)
- ➢ **Emotional** (e.g. peer support, external supervision, mentoring, time and space to talk through difficulties – but be aware of boundaries: individuals providing support should not be acting as a clinician)
- ➢ **Research/Role related** (e.g. supervision, debriefing)

- Be flexible and <u>**negotiate**</u> the research/involvement process with sensitivity (build mutual respect and consider issues of power and disempowerment).
- Continuously assess training and support needs.

---

2) <u>Training</u>

<u>**Training in relevant knowledge and skills**</u> is essential for all parties. It is important that *everyone* is prepared to offer and accept relevant training that will help to build the capacity for successful collaborations (consult SURGE for information on available training).
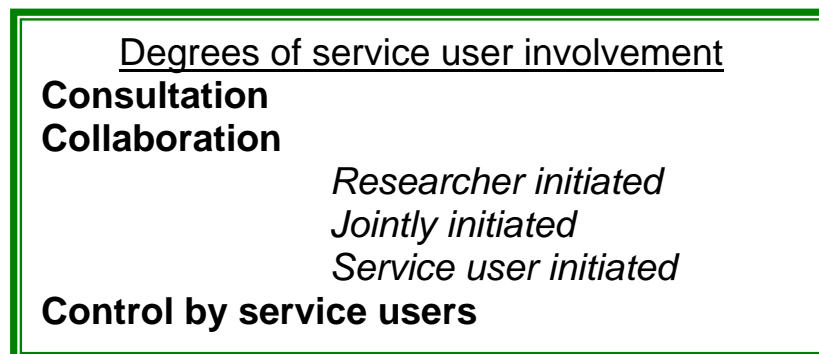
- Training ought to be built around locally identified needs and should be inclusive of people with differing academic and personal abilities and experience. It should not be limited to those who are committed to involvement in the MHRN or have attained a certain level of experience.
- Service users have expressed the importance of being able to participate in training at the level they feel able on the day. This can be vital in engaging people who may have lost confidence in their skills and abilities.

Suggested Themes

- Service user involvement awareness for researchers, hub personnel, project steering group members and clinicians
- Basic skills for committee members, e.g. running an accessible committee, participation in a committee
- Team skills, identification of skills, confidence, assertiveness, negotiation and communication
- Training to be a representative: accountability, consultation, reporting, transparency, time management, prioritisation, peer support
- Research awareness for lay service users
- Research infrastructure, including MHRN and R&D structures
- Research skills for specific roles/projects
- Proposal writing for survivor researchers

Degree of User Involvement

It is important to think through the type and level of involvement, as this helps to maintain clarity and awareness of where decision making power lies. It is suggested that any research project be categorised according to the degree of service user involvement, as below. This model is a useful tool for considering these issues and, as such, we would recommend all involvement opportunities are considered in a similar way.

<u>Degrees of service user involvement</u>
Consultation
Collaboration
> *Researcher initiated*
> *Jointly initiated*
> *Service user initiated*

Control by service users

Consultation: service users' views and advice are sought without any sharing of power in the decision-making process. For advice on how to consult service users or what you can expect from a consultation event, please see below.

Collaboration: this involves an active, ongoing partnership with service users/survivors in the research process, including genuine sharing of power and cooperative working. This may include the ***employment of service user researchers.***

> *In these cases, serious consideration needs to be given to the role of the employed service user and the ways in which their views are to contribute to the research process.*

Control: service users design and undertake a research project, and disseminate its results.

> ***User-controlled research*** *plays an important role in exploring topics of specific concern to service users, challenging the validity of traditional knowledge standpoints and the meaning and status of sources of 'evidence' in an ostensibly evidence-based NHS. The promotion and encouragement of user-controlled research is part of the range of research adopted and supported by the Mental Health Research Network.*

For a full exploration of user-controlled research,
see Turner and Beresford:
http://www.spn.org.uk/fileadmin/SPN_uploads/Documents/Papers/invo_user_controlled_research.pdf

Tips for Consultation Events

❖ There should always be more than one service user in a consultation.
❖ Ideally, service users in meetings/advisory groups should have access to (or be members of) a larger group which provides them with support and accountability.
❖ Adequate and accessible information must be provided well in advance.
❖ Refreshments and regular breaks should be available in any meeting.
❖ Payment of fees and travel expenses should be made on the day of the consultation.
❖ Consult with people with integrity: be clear and open about how you will be taking views on board.
❖ Consider and discuss how to run accessible meetings/committees.
❖ The chair needs to be well briefed to enable the group to hear from service user members.
❖ Developing a group agreement can help the group function thoughtfully and respectfully (contact SURGE for further advice).
❖ Support must be offered but no one should assume what, if any, support is appropriate. It important to discuss this individually. You might like to consider, for example, buddying, agenda pre-briefing, debriefing, mentoring, out-of-meeting contact, multi-member peer support, etc.

- ❖ All parties must be prepared to offer and accept relevant training that will help to build everyone's skills for working in partnership (contact SURGE for information on training available).
- ❖ Remember to apply the three key principles outlined earlier.
- ❖ It is essential that feedback is provided on the impact of involvement and any changes that arise.

SURGE is here to help: contact us for advice on what works or with any questions or difficulties.

For further advice, see Shaping Our Lives'
Guidelines for Making Events Accessible,
available at
http://www.shapingourlives.org.uk/publications.htm

Payment
- Ensure that service users are offered realistic payment for work carried out. Do not set rates based on the assumption that all service users are in receipt of benefits. Flexibility to enable individuals to accept payment appropriate to their personal circumstances is key.

- Travel and child/family care expenses need to be considered.

- All payments should be made promptly, ideally on the day of the event.

Complex benefit regulations make it impossible to make a universal statement on payments. Please refer to Department of Health guidelines *Reward and Recognition:*

http://www.csip.org.uk/index.cfm?fuseaction=main.viewItem&intItemID=83649

Step-by-Step Guide to User Involvement in Research Projects

Aim: to ensure service user involvement is embedded in each stage of the research process with appropriate planning and allocation of resources.

STEP ONE: Planning and Starting a Project

Key issues to consider: creating opportunities, allocating resources

Service users should be involved from the start of a project

- Identify opportunities for involvement: consider each stage of the research process – e.g. study design, identifying relevant outcome measures, writing proposals, data collection, data analysis, reporting and dissemination – and think about how service users can be constructively involved in these processes.

- Resources should be planned in advance to take into account the time and money required to involve people fully.

- Ensure that an adequate budget for user involvement is written into the proposal. Money to pay people's expenses and for preliminary training and support can be vital.

- Plan for:
  - Flexibility is essential. Consider issues of additional support and capacity to reschedule the timetable or scope of research, and anticipate the need for extra time at the end of the project to facilitate a flexible approach throughout.
  - Support needs will vary and should be discussed fully. Mechanisms for dealing with distress should be considered. This may include external and/or peer support and supervision, nominating a mentor/contact, and strategies enabling service users to maintain control of the process.
  - Training (see page 4).
  - Possible periods of absence.

- Communicate well in advance with finance departments, human resources departments and occupational health about any intention to involve or employ mental health service users in research in order to facilitate the process and pre-empt any difficulties that may arise. We would recommend beginning this process as early as possible, perhaps at the same time as submitting proposals to Research Ethics Committees.

- Ethics: consult service users on the ethical issues of a proposed research project.

STEP TWO: Undertaking Research

Key issues to consider: support and training

- Please refer to P3 and P4 in the introduction for further information.

STEP THREE: Dissemination and Implementation

Key issues to consider: accessibility, learning from experience

- Write up: the nature and effect of user involvement should be written up as part of the research methods and results.

- Dissemination to service user audiences in accessible formats must form part of a dissemination strategy. Service users must be informed about any publications that arise from the research.

- Implementation is a priority for many service users. It can be built in from the start of a project through adequate budgeting and the involvement of local stakeholders. If this is not likely, this must be clearly communicated to those involved.

- Consider endings: find a way to mark the ending of a project and a way to enable service users and other researchers to reflect upon their experience and the learning they have gained through collaborating.

- Evaluation: consider evaluating service user input into the research process from the perspective of all involved. This information can be fed into SURGE and facilitates the development of knowledge in this area.

How SURGE and the MHRN will Help

❖ UK MHRN hubs, in consultation with SURGE, will identify local service user groups and gather the knowledge and experience of user involvement held by individual hub partners.

❖ UK MHRN hubs, in consultation with SURGE, will build up collaborative relationships with service user groups, survivor researchers and other interested individuals over time in order to build up trust as well as expertise.

❖ UK MHRN hubs, in consultation with SURGE, will maintain a register of individuals with experience and expertise whom those new to involvement can consult for local advice. This will include service user groups and consultants, survivor researchers, service user involvement coordinators and others within the hub consortium with relevant experience.

❖ UK MHRN hubs, in consultation with SURGE, will aim to ensure that outcomes and experiences of MHRN-adopted research projects are shared with local SU groups.

❖ SURGE will keep in touch with all involved in the research study to evaluate service user input throughout the research process from the perspective of all involved, so that knowledge in this area can be evaluated and is furthered.

❖ UK MHRN hubs, in consultation with SURGE, will stay in touch with service users and researchers who have completed collaborative projects, as this can help in the process of building and maintaining relationships.

**Research Projects' Responsibility for User Involvement
in UK MHRN Adopted Projects**

❖ To consult SURGE and UK MHRN as early in the research process as possible for guidance and advice on comprehensive service user involvement

❖ To keep SURGE and the UK MHRN hubs informed of service user involvement in the research study

❖ To work with SURGE and UK MHRN hubs to support and develop service user involvement in the research study

Step-by-Step Guide to User Involvement in MHRN Hubs

Aim: to ensure meaningful service user involvement throughout the hub itself and to support and encourage user involvement in projects running in the hub.

STEP ONE: Capacity Building

Key issues to consider: communication, developing relationships

- Get to know your community: identify local service user groups (the mental health voluntary sector can often help signpost this information); gather the knowledge and experience of user involvement held by hub partners in local Trusts and academic institutions (e.g. Public and Patient Involvement Leads and user involvement projects/development consultants, working together groups/Trust user forums); and consult with local experts, e.g. the National Institute for Mental Health in England regional development centre user involvement leads.

- It is important to develop collaborative relationships over time in order to build up trust as well as expertise. Consider ways to maintain relationships with local service user groups and the service user research community by maintaining awareness of how they can contribute to and benefit from hub activity, e.g. through hub member visits to service user groups, and service user group representatives' visits to hub committees to share research interests and priorities. Consider how networking opportunities (e.g. roadshow events in conjunction with SURGE) can be provided.

- Identify opportunities for involvement within the hub: consider the structures and remit of the hub and think about how service users can be constructively involved in these processes. Consult local service users on how this can best be achieved and consider working together to draw up a user involvement strategy for the hub.

- Contact others for advice on what works, including those identified in the *Guidance for Good Practice* and INVOLVE (admin@invo.org.uk).

STEP TWO: Identifying Research Priorities

- Consult with local service users/user groups about their priorities for research and seek to find some areas of common interest with current Trust or MHRN research priorities.

- Inform service users about your priorities and about research currently being carried out within your hub and across the MHRN.

STEP THREE: Supporting and Maintaining Involvement

Key issues to consider: build and sustain relationships

- **Keep a record and maintain a register of:**
  - ➢ People within your organisation who have relevant experience and expertise in this field so that this can be built on
  - ➢ Service user consultants or service user involvement coordinators/professional collaborators with experience of research whom those new to service user involvement can consult for local advice on development
  - ➢ Service users who have the expertise and willingness to act as mentors for those new to involvement
  - ➢ Service users, service user groups and survivor researchers with an interest in involvement in research
  - ➢ Training opportunities locally and nationally that will help to build everyone's capacity for successful collaborative research

- **Create links** with finance departments, human resources departments and occupational health to increase understanding of user involvement and pre-empt any difficulties that may arise. It is often useful to negotiate a point of contact in these departments and take the time to explain what involvement means and entails.

- **Communicate well in advance** with these departments about any intention to involve or employ mental health service users in both research projects and hub activity in order to facilitate these processes. We would recommend beginning this process as early as possible, perhaps at the same time as submitting proposals to Research Ethics Committees.

- **Publicise change:** it is vital that the local service user community is given feedback about the impact of involvement initiatives and any changes that have arisen as a result of service user involvement. This helps to challenge disillusionment, maintain motivation and encourage involvement. It is important that information about involvement is honest and transparent.

- **Stay in touch** with service users and researchers who have completed collaborative projects, as this can help in the process of building and maintaining relationships.

STEP FOUR: Communication and Dissemination

Key issues to consider: accessibility, learning from experience

- **Dissemination** to service user audiences in accessible formats must form part of a project dissemination strategy. Service users must be informed about any publications that arise from the research. In consultation with SURGE, ensure outcomes and experiences of MHRN-adopted research projects are shared with local SU groups.
- **Implementation** is a priority for many service users. It can be built in from the start of a project through the involvement of local stakeholders. If this is not likely, this must be clearly communicated to those involved.
- **Consider endings:** find a way to mark the ending of a particular piece of work or project and a way to enable everyone involved to reflect upon their experience and the learning they have gained through collaborating.
- **Evaluation:** consider evaluating service user input into hub activity from the perspective of all involved so that knowledge in this area is furthered.

How SURGE will Help

❖ SURGE will actively support the development of user involvement initiatives in hubs, working in partnership with hubs and providing guidance and advice where required.

❖ SURGE will act as a central repository for information and for the sharing of knowledge about best practice and effective user involvement across the network.

❖ SURGE will work jointly with hubs to help build and sustain collaborative relationships and facilitate networking opportunities with service user groups, survivor researchers and other interested individuals.

❖ SURGE will work with hubs to ensure outcomes and experiences of MHRN-adopted research projects are shared with service user groups.

❖ SURGE can provide direct support and opportunities for peer support for service users involved in UK MHRN activity.

❖ SURGE will keep in touch with all involved in hub activity to evaluate service user involvement from the perspective of all involved, so that knowledge in this area can be furthered.

Hub Responsibilities for User Involvement in UK MHRN Activity

❖ To work, in conjunction with SURGE, towards embedding service user involvement in all hub activity

❖ To encourage, support and facilitate the involvement of service users in projects running on the network

❖ To build and maintain links with service user groups in the locality

❖ To keep SURGE informed of user involvement in hub activity to enable joint learning and the sharing of good practice across the network

Step-by-Step Guide to User Involvement
in Clinical Research Groups

Aim: to facilitate meaningful service user input into the activity of the research group and ensure plans for user involvement are integrated into the project proposals that are generated.

STEP ONE: Establishing a Research Group

- Get to know key groups and individuals linked to your topic/specialist subject area

- It is important to develop collaborative relationships over time in order to build up trust as well as expertise. Consider ways to maintain relationships with local and national service user groups and the service user research community by maintaining awareness of how they can contribute to and benefit from research group activity, e.g. through group member visits to service user groups and service user group representatives' visits to research group committees to share research interests and priorities. Stay in touch with service users and researchers who have completed collaborative projects, as this can help in the process of building and maintaining relationships.

- Identify opportunities for involvement: consider each stage of the process – e.g. developing ideas, study design, identifying relevant research outcomes, writing protocols – and think about how service users can be constructively involved in these processes.

- Consider how best to engage service users: think about what method is most suitable for each part of the process e.g. developing a service user reference group, encouraging service user membership of group meetings.

- Ensure that a budget to develop collaborative relationships can be identified. Money to pay people's expenses and for preliminary training and support can be vital.

- Contact others for advice on what works, including those identified in the *Guidance for Good Practice* and INVOLVE (admin@invo.org.uk).

STEP TWO: Identifying Research Priorities

- Consult with local and appropriate national service users/user groups about their priorities for research and seek to find areas of common interest.

- Inform service users about your priorities and about research ideas currently being formulated.

STEP THREE: Developing Project Proposals

Planning a Project

Ensure service users will be involved from the start of the project.

- Identify opportunities for involvement in the project: consider each stage of the process – e.g. study design, identifying relevant research outcomes, writing proposals, data collection, data analysis, reporting and dissemination – and think about how service users can be constructively involved in these processes.

- Be prepared to consult service users and discuss with SURGE about how best to integrate user involvement into the research project being proposed.

- Resources should be planned in advance to take into account the time and money required to involve people fully.

- Ensure that an adequate budget for user involvement is written into the proposal.

- Ethics: consult service users on the ethical issues of a proposed research project.

- Plan for:
  - Flexibility is essential. Consider issues of additional support and capacity to reschedule the timetable or scope of research, and anticipate the need for extra time at the end of the project to facilitate a flexible approach throughout.
  - Support needs will vary and should be discussed fully. Mechanisms for dealing with distress should be considered. These may include external and/or peer support and supervision, nominating a mentor/contact, and strategies enabling service users to maintain control of the process.
  - Training (see page 4).
  - Possible periods of absence.

Consider Outcomes of Proposed Project

- Dissemination to service user audiences in accessible formats must form part of a dissemination strategy. Service users must be informed about any publications that arise from the research. SURGE and MHRN hubs can assist with this.

- Implementation is a priority for many service users. It can be built in from the start of a project through adequate budgeting and the involvement of local stakeholders. If this is not likely, this must be clearly communicated to those involved.

STEP FOUR: Completion

- Consider endings: find a way to mark the ending of a project and a way to enable service users and others to reflect upon their experience and the learning they have gained through collaborating.

- Evaluation: consider evaluating service user input into the research process from the perspective of all involved. This information can be fed into SURGE and facilitates the development of knowledge in this area.
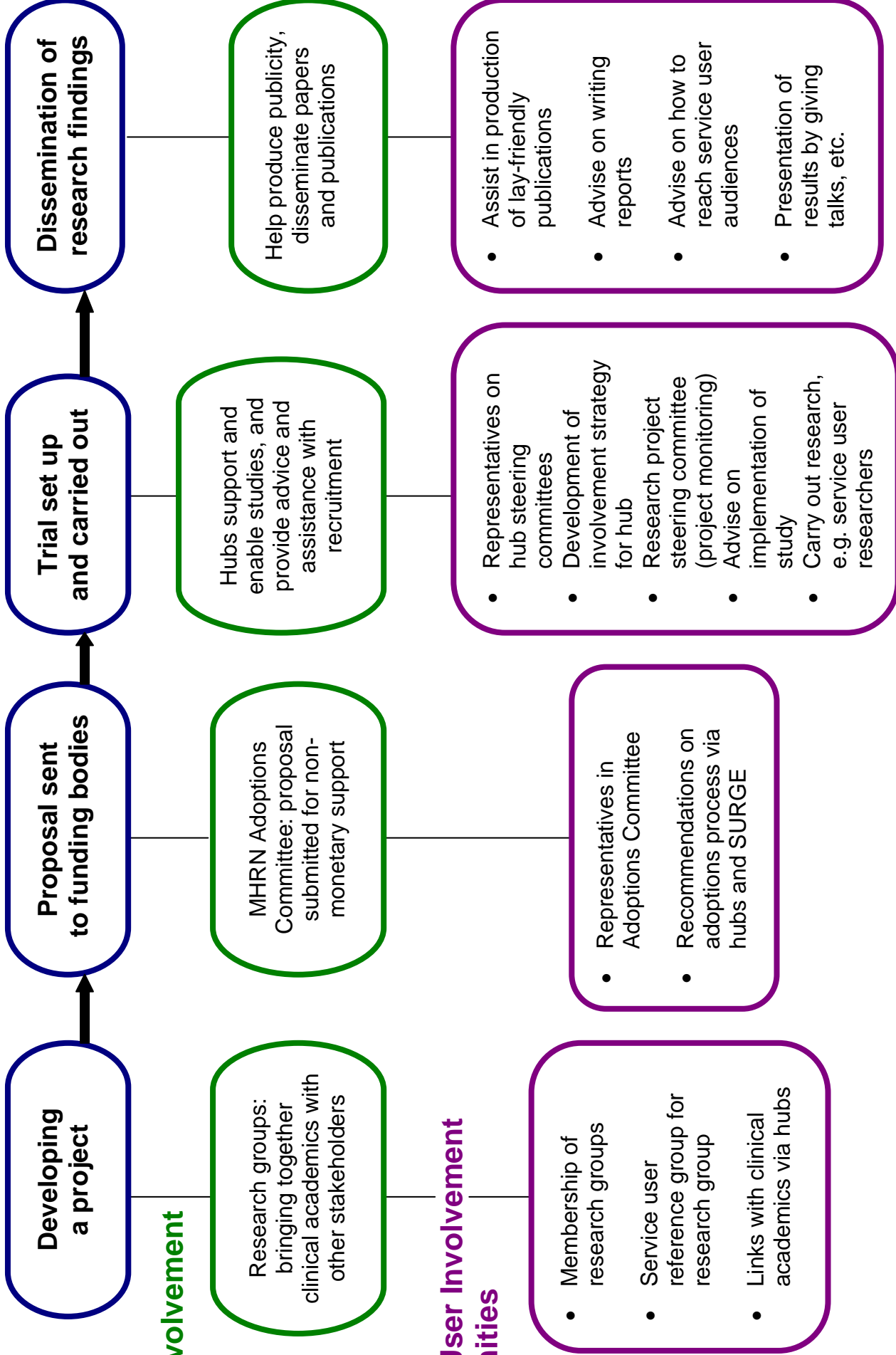
How SURGE and the MHRN will Help

❖ SURGE, in conjunction with hubs, is able to signpost research groups to key national service user organisations, local user groups and individuals with an interest and willingness to be involved in specific topic areas.

❖ We can help facilitate communication between research groups and service user stakeholders, including the dissemination of results to service user organisations.

❖ We will provide advice, support and guidance on best practice in user involvement.

❖ SURGE is available to support networking opportunities to encourage building collaborative relationships.

❖ SURGE provides direct support and opportunities for peer support for service users involved in MHRN activity.

❖ We report on the degree of user involvement in network activity and would be keen to work in partnership in evaluating effectiveness.

Research Groups' Responsibilities for User Involvement in UK MHRN Activity

❖ To ensure meaningful involvement of service users at all levels of group activity

❖ To ensure ideas generated reflect the priorities of service users

❖ To ensure that all protocols include plans and appropriate budgeting for comprehensive service user involvement

❖ To contact SURGE for advice where needed and keep SURGE informed of service user involvement in group activity to enable joint learning and sharing of good practice across the network

Opportunities for Involvement in the MHRN

Research Process

```
Developing a project  →  Proposal sent to funding bodies  →  Trial set up and carried out  →  Dissemination of research findings
```

MHRN Involvement

- **Developing a project:** Research groups: bringing together clinical academics with other stakeholders

- **Proposal sent to funding bodies:** MHRN Adoptions Committee: proposal submitted for non-monetary support

- **Trial set up and carried out:** Hubs support and enable studies, and provide advice and assistance with recruitment

- **Dissemination of research findings:** Help produce publicity, disseminate papers and publications

Service User Involvement Opportunities

Developing a project:
- Membership of research groups
- Service user reference group for research group
- Links with clinical academics via hubs

Proposal sent to funding bodies:
- Representatives in Adoptions Committee
- Recommendations on adoptions process via hubs and SURGE

Trial set up and carried out:
- Representatives on hub steering committees
- Development of involvement strategy for hub
- Research project steering committee (project monitoring)
- Advise on implementation of study
- Carry out research, e.g. service user researchers

Dissemination of research findings:
- Assist in production of lay-friendly publications
- Advise on writing reports
- Advise on how to reach service user audiences
- Presentation of results by giving talks, etc.

Acknowledgements

SURGE exists to encourage and support people throughout the UK MHRN to involve service users in research. For more information, contact us at info@surge.scmh.org.uk or telephone 020 7716 6778.